Voicing Caregiver Experiences:

Wellbeing and Recovery Narratives for Caregivers

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A collaboration between Sussex Partnership NHS Foundation Trust and the Scottish Recovery Network

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Contents

Acknowledgements v

Terminology v

About this project 1

Chapter summaries 15

Chapter 1 What does recovery mean to me? 19
Ruth Chandler, Simon Bradstreet and Mark Hayward

Chapter 2 Recovery... a strange word for me 25
In Sussex, Anon

Chapter 3 The silver lining 27
In Sussex, Mr and Mrs P

Chapter 4 So you love someone with a mental illness? 39
In Scotland, Cathy Hamilton

Chapter 5 My story... so far 45
In Sussex, Anon

Chapter 6 Love is the first ingredient (transcript) 51
In Scotland, Anon

Chapter 7 Pause for thought 63
Between Sussex and Scotland, Ruth Chandler, Simon Bradstreet and Mark Hayward

Chapter 8 Every pebble counts 77
In Sussex, Anon

Chapter 9 Recovery – or simply acceptance? 93
In Scotland, Jennifer Robertson

Chapter 10 I wish I could go back and give myself a hug 105
In Scotland, Patricia Mullen

Chapter 11 Hearing the music and remembering to dance 121
In Scotland, Elinor Dowson

Chapter 12 Recovery together 137
In Sussex, Anon

Chapter 13 Making sense of it all 145
Ruth Chandler, Simon Bradstreet and Mark Hayward

References 161

Useful resources 163

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Terminology

The term ‘carer’ is most frequently used to describe the role of a family member or friend who provides unpaid, ongoing support to people with mental health difficulties. We have chosen to use the term ‘caregiver’ throughout to acknowledge this gift.

About this Project

Recovery – understood as living a meaningful and satisfying life in the presence or absence of symptoms – has taken centre stage in Scottish mental health settings, and is fast doing so in England. This project, jointly run by Sussex Partnership NHS Foundation Trust and the Scottish Recovery Network, responds to a gap in caregivers' understanding of recovery by building on work already undertaken by both partners to find out what recovery means for caregivers of people with longer-term mental health issues. The Scottish Recovery Network previously ran a small project on the experience of recovery for caregivers. This involved speaking with groups of caregivers in different parts of Scotland and sharing the findings in a report called *Carers and Supporting Recovery* (Parr, 2009). In Sussex, Life Story Work that actively named and reframed experience was key to *Voicing Psychotic Experiences* (VPE), an earlier collaboration with people who experience psychosis to name what both recovery and psychosis meant to them and to offer practice points to front line workers and other people experiencing psychosis (Chandler & Hayward, 2009). The method used in VPE was supported storytelling in which the editors took a hands-off approach to narrative content and format but offered support for each author's preferred storytelling style, as well as flexibility when authors were not well enough to write. Follow-up interviews with VPE authors suggested that the process itself was as helpful as the output in supporting their recovery, and this was an experience shared in Scotland within similar projects founded on people's recovery narratives.

This project combined both of the above approaches to work realistically with the unpredictability of caregivers' lives and the time constraints imposed by the activity of caring. Because caregivers are as diverse as the general population, we have not tried to represent their diversity here. One of the principles behind VPE was a commitment to **radical collaboration** informed by respectful curiosity and active listening to experiences different from your own (Chadwick, 2006). Radical collaboration does not start from a position of already knowing or by imposing an end point or top-down agenda on dialogue between partners, as this stops new learning from taking place; rather the commitment is to a *process* of supported discovery in which new insights are made sense of in a person-centred way. This process can be uncomfortable, as it involves listening to world views that can challenge your assumptions and beliefs and make you think more deeply about why you hold on to them. But the rewards outweigh the discomfort when, for example, it enables someone to make sense of a difficult situation or discover new possibilities within it.

The editors took the principle of radical collaboration as a way of organising this book without forcing a consensus. They went into the collaboration with a range of personal and professional perspectives on recovery and wellbeing. Lead editor Ruth Chandler has been a caregiver herself, and has also experienced psychosis within her recovery journey. For her, recovery is about having the power to name and reframe personal and social experience and to act on the lessons learned in this process. She is a researcher with an interest in Life Story Work as a support for person-centred recovery and as a way of improving relationships between 'experts by lived experience' and professional experts. The key word for her when thinking about these relationships is *authenticity* – that is, being honest about the enablers and disablers to genuine partnership working. Her role in this project was to facilitate Life Story Work in a Sussex context, put the accounts into an initial conceptual framework for thinking about recovery and wellbeing for caregivers and develop an appropriate methodology for thinking through the collective learning in the project.

Simon Bradstreet is the Director of the Scottish Recovery Network and has an organisational and personal commitment to supporting recovery and wellbeing for all parties in the triangle of care. His role in the writing of this project was to facilitate Life Story Work in a Scottish context, offer a national perspective on key debates and keep the conceptual framework and methodology grounded and accessible for caregivers in both locations.

Mark Hayward's work combines organisational and personal outlooks on recovery. He is a clinical psychologist who knows about the pain and struggles of caregiving from his attempts to support the recovery journeys of people experiencing psychosis. The lessons he's learned have been taken into research studies that attempt to find ways of directly addressing the needs of caregivers through brief, accessible writing interventions. His role in the writing of this book was to bring this wider research context into the development of interactive learning materials, facilitate Life Story Work in Sussex and analyse key themes.

These different perspectives were sometimes mutually exclusive in terms of process and outcome but were mutually aligned when it came to viewing recovery and wellbeing for caregivers as a meaning-making process that everyone has a right to access, with organisational resources to support it. Contested meanings are par for the course in debates around recovery since,

as we explain below, there is no single story, model or point of view that could hope to explain recovery and wellbeing for everyone. Rather, the range of meanings in play is part of a widespread shift away from top-down definitions of wellbeing and recovery and towards a more democratic process of listening to and learning from the different meanings caregivers and service users attach to their experiences.

There were also the related questions of power and empowerment to consider. Empowerment is not something you do to someone else. The last thing the editors wanted to do was reduce the narratives to the status of examples or case studies in a project *about* caregivers instead of creating a shared learning journey. One of the lessons of recovery ways of working is to give up the idea that language and power are somehow separate or that power (formal and informal) is somehow a bad thing. All three editors are paid to write about recovery, which involves dealing with organisational pressures and opportunities (e.g. performance targets, securing and making good use of time and resources), and this shaped the way they put the book together. It would look very different (and indeed be much shorter!) had there not been sufficient organisational power and support to produce it. But this kind of power carries responsibilities and limits: the editors are not free to say whatever they like (or rather they are, but they would not keep their jobs for very long!).

The caregiver authors contributed on a voluntary basis and were free to say exactly what they liked, but their timescales and priorities were driven by the same unpredictable factors associated with caregiving that shaped each narrative; sometimes they couldn't find the time and/or emotional strength to write at all. The challenge for the editors was how best to roll with the uncertainty of caregivers' lives and make enough room for the **interpretative agency** of each author (and editor) to come to the fore. This approach facilitated the self-empowerment of contributors to **name** and **frame** their own experiences in a narrative that made sense to them. To this end we asked each caregiver to put their recovery first – as a journey distinct from, but also bound up with, the recovery of the person they cared for – while recognising that some people might find this difficult.

How we worked together

One of the practical aims of our collaboration was to find ways of acknowledging our differences respectfully for the purpose of modelling this more democratic approach to recovery and wellbeing (made up as it is of multiple perspectives and values), and to draw out new learning about what these terms might mean for the caregivers in this book more specifically. We collected five narratives from each location over a period of two years, and worked with the authors to set the direction of the project and its editing process.

Two meetings with caregivers – one in Scotland and one in Sussex – were held at the start of the collaboration to establish the aims and outcomes of the project, provide information/support and clarify how the narratives would be used.

The agreed aims at the start of this project were:

1. To support the recovery and wellbeing of our authors, both within and beyond the activity of caregiving.

2. To share learning that supports the recovery and wellbeing of other caregivers, both within and beyond the activity of caregiving.

3. To share learning about caregivers' skills and knowledge with mental health providers.

4. To share learning about recovery and wellbeing for caregivers with policy makers and other key decision makers.

We did not initially ask about wellbeing, but because it was such a strong theme from very early on in the collection process we revised our aims to include it. It was agreed from the outset that some authors might identify with some aims more than others, and that the resource should aim to reach out to caregivers who may not have thought about recovery or wellbeing for themselves and to service providers and key healthcare decision makers who do not yet routinely consider recovery and wellbeing for caregivers in their plans. Presenting such a complex topic to such a broad and disparate readership proved a real stylistic challenge for the editors. On one hand, we

aimed for clarity and accessibility – but on the other we wanted to talk about things that can be quite hard to think about, because they're important in terms of helping us understand the range of relationships and mixed feelings reported by caregivers throughout this collection.

Due to the sensitive nature of the topic, an informed consent process was used, which also obtained consent from the person cared for if they were identified. Authors were also offered the options to anonymise, change names and details and/or take back their narratives before publication. To make space for people to **name** their own experiences of recovery, the editors took a 'stepped-back' approach to collecting the narratives and offered appropriate support to remove barriers to participation. Support around structuring a narrative was also offered but editors limited their content alterations to correcting grammar and removing anything that identified people who had not consented to take part. The resulting differences in style between the narratives are a consequence of this facilitated process.

As the project unfolded it became increasingly clear that recovery and wellbeing for caregivers was not at all straightforward, and the editors had to name and reframe some of their own professional understandings about recovery and wellbeing – most notably their ideas about the role of hope and hopelessness. In our middle section, *Pause for thought*, we offer an interactive framework for readers who want to explore these concepts with us.

Towards the end of the project, a second authors' meeting was held in Scotland to ask authors to identify key learning points and to provide an opportunity for them to take their narratives back or amend them if the disclosure felt too exposing (to edit the editors, as it were). In Sussex most authors chose to be anonymous, and a second group meeting would have compromised this, so authors were instead approached individually about key learning points and offered the opportunity to amend or take their narratives back. The key points generated in the final meetings and individual feedback were then used to frame our concluding discussion about the wider learning in the collection. In this way, we hope to have produced a resource that is collectively owned and has, as far as is practical, core recovery principles embedded in its production process.

What do we mean by recovery?

Before reading the narratives, it is worth taking a little time to think about the word 'recovery'. We will then go on to consider how recovery relates to being a caregiver. Recovery can be a confusing term in mental health because it means lots of different things to different people, and its meaning for any one person can change according to where they are in their individual journey. Up until quite recently, the most common understanding of recovery was a **medical** one that placed the most weight on curing or reducing symptoms. This understanding is still very important and meaningful to caregivers and people who experience mental health difficulties – a diagnosis of mental illness, for example, can reduce feelings of self-blame by offering an explanation and treatment options aimed at reducing or managing symptoms. As with a faulty engine, specialised knowledge is required to diagnose and fix the fault and provide ongoing maintenance to keep the engine ticking over.

Critics of the traditional medical interpretation of recovery say that the dominance of the medical model can make it more difficult to see anything else about a person beyond a diagnosis that's often loaded with hope*less* or low expectations about what that person can do. Within **medical recovery** some diagnoses have historically had a greater weight of negative expectation attached to them, but this isn't always backed up by the research evidence. In a ground-breaking report, the British Psychological Society points to studies that looked at the long-term health outcomes for people diagnosed with schizophrenia and found that full recovery rates (understood as symptom reduction alone) were as high as a third. These figures should be a source of real optimism about treatment at a time when predictions for people with a diagnosis of schizophrenia seem to be getting ever gloomier. The report describes this kind of mismatch between evidence and attitude as 'the clinician's illusion': if a worker only sees people when they are very unwell – on an acute ward, for example – they can start to become hopeless for *them* and believe that no change is possible (British Psychological Society, 2000).

More recently, a more holistic and person-centred understanding of recovery has taken centre stage. What we in this book call **person-centred recovery** has historically defined itself *against* the hopelessness of medical recovery and placed the emphasis firmly on living a meaningful life. People in receipt of mental health services have suggested that low expectations about their capacity to live a meaningful life have, in themselves, stunted their capacity

to do more. This profound and far-reaching shift has been achieved by enabling people with experience of mental health problems to reclaim the word 'recovery' through the sharing of their experiences and an improved understanding of the holistic nature of the recovery process. Associated with this has been the drive to learn from these experiences and apply that learning in mental health policy and practice – what has become known as the **recovery approach**.

Person-centred recovery can also be characterised as a process of growing beyond the experience of mental health issues and recovering some of the losses that living with mental distress often incurs. For some it's about *discovering* new opportunities and experiential gains; in these cases great weight is placed on the social and/or personal aspects of life, depending on what holds most value for the person. For example, a person who finds most meaning in social relationships (e.g. having friends or an occupation) may value developing a sense of belonging or connectedness with other people in the community. Practically, person-centred recovery could be about developing the confidence to join a club or gym or take up voluntary work as a step to paid employment, or it could be about campaigning for social justice.

Many people have described recovery as a deeply spiritual journey. There may be no way back to the days before the often-devastating consequences of mental distress took hold, so the task is to find new meaning when past meanings no longer hold good. Individual development also features strongly in these accounts; people have described developing a new understanding of mental health as part of a bigger process of emotional growth and awareness.

Although medical and person-centred recovery may appear opposed, this should not overshadow the fact that many people who use mental health services continue to attach a great deal of importance to **medical recovery**. For some people, one of the editors included, enough symptom reduction needs to be in place for them to get out of bed in the morning before the social and personal aspects of recovery can become meaningful options. The caregiver authors in this collection also differ in terms of how much meaning they ascribe to medical and person-centred understandings of recovery. This collection contains both views, and most of the narratives combine them.

Key recovery themes

Accounts of resilience and the overcoming of adversity from all walks of life have sent a resounding message to mental health services to change the ways they support the strengths, identities and human rights of people within their care. Although there has been much talk of a 'recovery model', it has become increasingly clear that person-centred recovery journeys are unique to the individual and as diverse as the general population. Within this diversity, however, the life stories of people with experience of mental health problems have been found to have a lot in common. Though not without their critics, the three key themes have been identified as:

Hope – means seeing the future as somewhere better than the current reality, and aiming to reach it through the realisation of social and personal goals.
Agency – is about feeling empowered to change the current situation by acting to realise social and personal goals (often in very small steps).
Opportunity – is the practical window in which the realisation of goals takes place (for example, an opportunity for positive risk-taking or respite).

In person-centred recovery, hope, agency and opportunity are all part of the human condition whatever the medical symptoms may be (Repper and Perkins, 2003), and they're core components of most recovery ways of working. The aim of person-centred recovery working is to support people to define steps towards self-determined goals and to optimise opportunities for resourcing these – for example, by supporting someone to take control of their unique recovery pathway through the facilitation of goal-setting and the creation of self-management plans that belong to the person and refer to life domains that are meaningful to them. In this framework, a person might set working in a charity shop as an opportunity to achieve social goals, such as making friends and having a valued role that could be a further platform for paid employment. Another might set working in the same charity shop with personal or spiritual development as the main recovery goal.

Person-centred recovery is very different from the medical understanding of recovery in that setbacks are understood as part of an overall process of growth rather than relapses within an illness model. In practice, working hopefully is closely linked to **positive risk-taking,** where opportunities to fail and learn from setbacks are actively encouraged.

Why is recovery for caregivers important?

Readers might rightly point out at this stage that for a group of editors whose stated aim is to put the recovery and wellbeing of caregivers first, we have spent quite a lot of time talking about recovery for people who use mental health services. We came to this project with an awareness that the concept of recovery for caregivers had been given little attention and that, for some caregivers, recovery could be a challenging idea. We agreed that there was an increasing awareness of the needs of caregivers and of the importance of focusing on recovery for people with experience of mental health problems, but that much less effort had been made to consider what recovery actually *meant* for caregivers. Additionally, we were aware that it can be incredibly hard for caregivers to separate their own stories and experiences from those of the person they care for – and, if anything, this entwining of life experiences was re-emphasised as we gathered and reviewed the narratives. Despite these concerns, however, we were convinced from our respective experiences to date that the principles and methods of a recovery approach – in particular the giving of voice through narrative approaches – had enormous potential for caregivers. We based this view on a number of elements.

Firstly, on an individual level, it is known that sharing stories of recovery can be a source of much-needed hope for people who are struggling with their mental health, as well as providing learning for service providers seeking to implement organisational recovery. In Sussex, themes from focus groups on the usefulness of recovery narrative work for caregivers suggested that their journeys involve the redevelopment of both social and personal identity, and that affirming narratives that speak to both the pain and the hope should be actively supported. Narrative approaches could be a facilitator for hopeful dialogue between caregivers and professionals, but caregivers also reported feeling that they were perceived solely in terms of the needs of the person using the services – leaving their own needs, hopes and aspirations unrecognised and disrespected. Two caregivers in the group reported a sense of 'merged narrative', in which their life stories had been collapsed into the stories of the people they cared for. All of the participants struggled to keep the focus on themselves, as they were much more used to putting themselves second on a routine basis.

Secondly, exploratory research undertaken by the Scottish Recovery Network has shown that the presence of caregivers can be supportive of the recovery

of the person cared for. Although we're deliberately not looking at service user experiences here, it's important to emphasise that there's no reason to think of recovery for caregivers as being detrimental to the recovery of the people they care for. Rather, the suggestion is of an 'and/both' synthesis in which seeing caregivers as people whose own hopes and aspirations need support is good for wellbeing all round. Findings from *Carers and Supporting Recovery* (Parr, 2009) stress this need to recognise caregivers' own recovery as part of a *holistic* process that takes the following areas into account:

- The different levels of understanding of recovery among caregivers.
- Recognition of caregivers' own recovery process.
- The importance of understanding time and *pace*.
- The reality of what caregivers actually *do* (e.g. intensive support and care) as opposed to what they *could* do (e.g. helping to engender more positive relations with support services).
- Caregivers' understanding of the key role of social activity/interaction in recovery.
- The complex mixture of managing risk while 'letting go'.
- Caregivers' understanding and recognition of recovery barriers like stigma.
- The benefits and strengths that can come from having a caring role.

The narratives in this collection bear witness to all these points while offering extra levels of insight. Each contributor has a different understanding of recovery and, as the project unfolded, it became clear that we could not organise these into any kind of hierarchy. In Scotland, where recovery and wellbeing for caregivers appears to some extent more organisationally developed, accounts point to more collective and social initiatives for caregivers in which personal recovery plays a part. Examples include offering access to WRAP (Wellness Recovery Action Plans) and other learning opportunities as well as caregiver support groups. But less weight is given to what caregivers could do to improve relations with services than in the Sussex narratives, where the accounts also tend to describe more individual journeys. These different emphases may be due to the different political and social contexts in which the stories and experiences exist but, in most of the accounts, a commonality of core themes outweighs any differences related to location. Recognition of recovery barriers like stigma cuts across all the narratives and each one testifies, in its own way, to the complexity of managing risk and letting go.

Our third driver for taking a narrative and recovery approach was that the need to support people to sustain caregiving roles, and the right to a life beyond caregiving, have been recognised in UK policy for over a decade. Although this is not always called recovery, the basic point that caregivers are also entitled to hold hope for themselves while feeling empowered and having opportunities to realise personal and social goals is at the heart of this policy context. Sadly, however, the implementation of this policy is patchy at best, and often results in unsustainable levels of long-term burden and considerable amounts of cynicism from caregivers as each new raft of policy appears before anyone's had a chance to make good on the last one.

Worthington and Rooney point to an optimal relational triangle of care between caregiver, service user and professionals (Worthington and Rooney, 2010). Based on respectful partnership working between people and groups with different kinds of expertise, this is perhaps no more than anyone should expect of 21st century mental health services and as such it is held as an ideal by the editors. But the optimal triangle is not representative of the current reality for many caregivers, which may involve greater risk of hopelessness (Chandler and Repper, 2010) and poorer long term psychological and physical health outcomes (Kuipers, 2010). Caregivers in England and Scotland continue to report the problems they have when interacting with services as significant stressors in their lives (Carers UK, 2009; Support in Mind, 2010). Without recognition of the journey that caregivers negotiate themselves, there is an obvious danger that new cycles of mental health problems will be created within the triangle of care.

The points made here are backed up by *Recovery: a Carer's Perspective* (Machin & Repper, 2013). Part of the ongoing ImROC (Implementing Recovery through Organisational Change) project, this sets out a basic framework for organisations to consider caregivers as 'fellow travellers' with the people who actually use mental health services, and provides tools that support recovery for caregivers. Machin and Repper build on research that shows most people do not automatically identify themselves as caregivers when someone they love becomes unwell. Rather, they often go through a process that can be compared to bereavement in order to come to terms with their altered situation and find new hope and meaning in life. Further, the meaning caregivers assign to their experience often changes over time (Repper *et al*, 2008). The theme of bereavement is a recurrent one throughout this collection, but research also shows that caregiving that is well supported can

be a positive and rewarding experience for both the caregiver and the person cared for, bringing families closer together (Grice *et al*, 2009).

Recovery from what?

This leads us to the question of what caregivers might be recovering from. Person-centred recovery places a lot of weight on hope for the future and challenging the way hopeless expectations from the past can stack up to limit present action. Machin and Repper thus present recovery as the discovery of new opportunities. Critics of this understanding of recovery say that it paints an unrealistic view of the world and does not connect with the current reality of human suffering. We were keen to avoid this criticism so our middle section, *Pause for thought*, spends some time relating hopeful (and hopeless) world-views to real-world actions. While we have given reasons to include caregivers in the core recovery themes of hope, agency and opportunity, part of our learning throughout was that there is no good reason to suppose that caregivers have the same orientation to these themes as the people they care for (although there may be similarities). Further, there is every reason to suppose that the hopes and expectations of caregivers – for both themselves and those they care for – are significantly changed (for better or worse) by the activity of caregiving and the supports that are available. Many of the narratives speak about recovering losses in terms of a previously anticipated life and regaining a sense of balance or wellbeing following the disruption of previous hopes and expectations. But these journeys are by no means straightforward and there is tremendous variation between the narratives over the possibility of hope, especially where the setbacks have consistently outweighed the gains and the losses are not seen as recoverable.

Given the contested and deeply personal nature of these themes, we encouraged authors to tell it like it is, 'warts and all', and this resulted in the airing of some strong views both for and against person-centred recovery as a meaningful category of experience for caregivers. Both views are given equal weight throughout as they can both give us valuable insights into how recovery for caregivers can or should be supported, as well as strong messages about what else needs to be done. We hope that this combination of views opens a sustained discussion and call to action around practical support for all caregivers as equal partners within the triangle of care. As a first step in this direction, the range of voices in this collection presents a real challenge to any overly rosy or simplistic view of recovery while attesting to the healing power of hope and love, sometimes against all odds.

Using this resource

To remain as true as possible to the collaborative aims of this project, we have reflected the contested nature of recovery by organising the accounts as a debate about what recovery means for caregivers. This also allowed us to stay as close to what our authors actually said as was practical without imposing a top-down recovery model. However, the very act of writing a book with a beginning, middle and end makes it impossible to avoid imposing meaning altogether. Caregivers in the Sussex focus groups identified a preference for narratives similar to their own experiences early in their recovery journeys and a preference for different or more challenging ones later on. We have tried to respect this preference by putting narratives that may speak to a wider range of experiences earlier in the collection while leaving the more unusual or challenging experiences for the later chapters.

To support readers who want to think through what recovery means to them, we have included some questions to act as prompts during this process in the next chapter. At the second authors' meeting in Scotland it was suggested that the collection could be used by caregiver support workers as a recovery tool that supplements other awareness-raising work or training for caregivers. Authors in Scotland also thought it was important to work with services, and stressed the importance of group support to anyone working through these processes; authors in Sussex, on the other hand, stressed the importance of the choice to work alone or with others. We certainly recommend group support for caregivers where it is available but recognise that not everyone likes, or has access to, such groups. Because of the sense of 'merged narrative' reported by some caregivers, it might also be helpful in some cases for caregivers to work on these exercises with the person cared for.

In Sussex, individual feedback put more emphasis on supporting the wellbeing and recovery of mental health workers in the triangle of care. It also suggested that if workers are feeling hopeless it is wrong to expect them to have any hope for others. We hope that this collection will provide a training resource for mental health teams and individual workers that can be used as a stand-alone tool or as a supplement to existing tools (those provided by ImROC, for example). To help with this we have also included a slightly different questionnaire for mental health workers, to get them thinking about the relevance of recovery for themselves and how they support, or could support, caregivers within their practice. We recommend that mental health

decision makers, service managers, commissioners and policy makers should also participate in this process of hopeful dialogue and perhaps even invite caregivers to facilitate it.

Finally, much thought was also given to the inclusion of sad and/or distressing accounts alongside the more uplifting ones. Positive stories can inspire hope in other caregivers, but sad stories can also be helpful in terms of reducing feelings of isolation and increasing a sense of connectedness and empathy. A potential downside of sad stories is that connecting with difficult or alienating experiences can actually increase caregivers' feelings of hopelessness or isolation. Accounts that show shortfalls in the triangle of care can also be difficult for mental health workers to hear, particularly at a time when caseloads are increasing and everybody is expected to do more for less. None of our caregiver authors was interested in 'service bashing', however, and all were keen to offer their experiences as a platform for working more hopefully and constructively together, while taking a sober approach to sources of hopelessness for everyone in the triangle of care.

Chapter Summaries

1. What does recovery mean to me?

This section contains questions and prompts for readers around what recovery means to them.

2. Recovery... a strange word for me

In Sussex, Anon

This narrative is a mother's account of caregiving with and without support from services. The author invites us to think about whether recovery is a meaningful category or not. She describes an emotionally exhausting battle – fought without support from services – for the right diagnosis of her daughter's psychotic illness, and a dismissive attitude from those in authority towards the opinions of caregivers. There was no recovery for her as a caregiver in this situation. She also describes receiving a supportive service in which her wellbeing was seen as key, and in which she was kept informed and made to feel valued. Because her daughter's condition is ongoing, there can be no complete recovery for this caregiver; she does, however, discuss how, with the right support, it is possible for a personal process of 'recovering' to begin.

3. The silver lining

In Sussex, Mr and Mrs P

This narrative is an uplifting account of how a husband and wife overcame confusion and distress together after their son became unwell. The couple frame their account within a medical understanding of recovery, and speak of their journey to seek out information and understand their son's condition. Armed with good information, they describe the process of establishing a good working relationship with the professionals involved in their son's care. Assertive and united, they explain how they achieved this goal before begging the contentious question of whether providing good support at the outset would head off the need to consider recovery for caregivers at all.

4. So you love someone with a mental illness?

In Scotland, Cathy Hamilton

Cathy offers an empowering account of being a caregiver for a husband whom she loved and continues to love, and explains why she's decided that recovery is a meaningful category for caregivers. She describes her negative feelings

about the lack of support and information she received when her husband was first diagnosed with bipolar disorder, and the deterioration in her own mental health caused by his using alcohol to cope. Both social and personal recovery started for Cathy when she joined the sister group of Alcoholics Anonymous, which gave her the tools to start managing her personal recovery and successfully support her husband to sobriety. She talks about how taking her skills and experience into the social domain of employment as a Carer Support Worker enabled her to see recovery as something that should be for all, but is by no means there yet.

5. My story so far

In Sussex, Anon

This often-painful narrative is the journey of a nurse whose athletic son first became physically disabled and then suffered psychotic symptoms. Her son's recovery was understood in purely medical terms, rather than as a personal or social journey for her. Now living with the devastating consequences of this journey, the author also writes about managing the current reality and finding new opportunities to do things with her son as she takes up voluntary work and a new career as a magistrate.

6. Love is the first ingredient (transcript)

In Scotland, Anon

This inspiring interview explores the recovery of an Asian mother whose daughter has mental health problems, but whose family finds it difficult to talk about or acknowledge such problems. The author speaks of her initial shock, her feelings of bereavement and the impact on her career, before moving on to talk about how she has rebuilt her life with carers' groups and training opportunities while maintaining a close bond with her daughter and supporting her recovery. The transcript offers a hopeful view of recovery that embraces medical, personal and social understandings and describes a largely positive experience of services.

7. Pause for thought

Between Sussex and Scotland, Ruth Chandler, Simon Bradstreet and Mark Hayward

In this stand-alone chapter we talk about the difference between hope and expectation as supports for recovery and wellbeing. Negative expectation occurs in situations that feel hopeless or where no change is believed possible, and can lead to discrimination when mental health services do not expect

service users to have positive outcomes. Hope is a powerful antidote to this view for caregivers, as it engenders the belief that things can be different and that wellbeing is a possibility. The relationship between hope, hopelessness and expectation is not at all straightforward in this sense, but it remains central to understandings of recovery as a meaningful or meaningless category of experience for caregivers. Interactive exercises are offered throughout for readers who want to explore these issues in a more personal way.

8. Every pebble counts

In Sussex, Anon

This reflective narrative from a husband caring for a wife with depression talks about personal pain and hope as the author questions whether recovery for himself can be a meaningful category when it is so bound up with the wellbeing of the person cared for. Writing in a 'stream of consciousness' style, he concludes that understanding recovery as regaining what has been lost is impossible for him but adds that, by working together, he has managed to develop day-to-day strategies that enable him to maintain wellbeing.

9. Recovery – or simply acceptance?

In Scotland, Jennifer Robertson

This bleak yet inspiring account talks about the meaninglessness of recovery for a mother while her daughter is not free of her psychotic illness, and her resilience in acceptance. In her 'diary of despair' the author writes of the pain of hope deferred as she watches her daughter lose everything – even her child – and become increasingly institutionalised. Only poetry and literature have the words for this writer to express her loss, and the only thing that can shelter her from it is acceptance that the loss has truly happened.

10. I wish I could go back and give myself a hug

In Scotland, Patricia Mullen

This remarkable account demonstrates how effective organisational support for social and personal recovery can be in empowering caregivers to take back control of their lives. The author begins by describing her distress at the poor provision for her son and then goes on to talk about a range of national and international training initiatives around recovery for caregivers that both support her wellbeing and enable her to better support the recovery of her son.

11. Hearing the music and remembering to dance

In Scotland, Elinor Dawson

This strong and heartfelt account brings the question of 'Recovery from what?' to the fore. On one hand, the author offers an uplifting narrative about the power a recovery base approach has to improve caregivers' lives and service delivery. On the other, she reflects on the life opportunities she's missed as a caregiver and calls for real choice in supporting wellbeing.

12. Recovery together

In Sussex, Anon

This is a moving and thoughtful account of personal and social recovery for caregivers and service providers against all the odds. The writer starts by talking about the lack of cultural awareness and good information in mental health services for her brother, from the perspective of a young girl who'd just fled war-torn Iran. She then talks about how lonely and isolated she and her mother felt without understanding of the culture they had come into or their cultural differences from it. She ends by describing how starting a carers' group and training as a psychotherapist enabled her to understand and forgive service providers on the basis that they are often poorly resourced and supported themselves.

13. Making sense of it all

Ruth Chandler, Simon Bradstreet and Mark Hayward

Chapter 1

What does recovery mean to me?

Ruth Chandler, Simon Bradstreet and Mark Hayward

One of the benefits of reading the recovery stories of others is that they can inspire you to write about your own journey or talk to someone about it. We have included some questions to help you get started with this. You may find it helpful to go through them with another caregiver or a family member. Involving the person cared for in a caregivers' Life Story Work can strengthen the relationship by helping each person to see the other's point of view, but it may not be so helpful if they have negative feelings towards each other and is perhaps best avoided where this is the case.

It is worth finding an example from your life for each question. This could be a written example but things like photos, newspaper clippings and favourite songs are just as effective, especially if you're working with another person. It's your life, so choose the things that hold the most meaning for you.

Exercise 1
Caregiver questions

1. How would you describe your wellbeing today?

2. Do you consider yourself to be on a recovery journey?
   If yes, how would you describe it (see below)?

   Recovery is relief from symptoms
   Recovery is living a meaningful life
   Recovery is holding hope for the person I care for
   Recovery is holding hope for myself
   Recovery is about services holding hope for the person I care for
   Recovery is about services holding hope for me and the person I care for
   Recovery is something else (please describe)

   Choose all the statements that apply to you. Don't worry if some seem

contradictory; it's not unusual for someone in a challenging situation to hold two opposing views simultaneously.

3. What are you recovering from (if relevant)?

4. Whose recovery is it? Look back at your answers above and decide which of the following is most relevant to you:

   Recovery is about the person I care for
   Recovery is about me alongside the person I care for
   Recovery is about me separate from the person I care for
   Recovery is all of the above
   Recovery is not relevant to me

5. What were your hopes for yourself before the person you care for became unwell?

6. What are your hopes for yourself today? Record an example of something you would like to do for yourself. What would help you to achieve this? What would make it difficult?

7. What (if anything) is making you feel most hopeless today? Record an example of something that's stopping you doing something for yourself. What makes this difficult to overcome? What would help you to overcome it?

8. What have you learned so far as a caregiver?

9. What could other people learn from you?

10. What has been the most helpful element of your recovery journey (if relevant)?

11. If you have time, put all your answers together and come back to them after reading the narratives. Has anything changed? (If yes, find some new examples that show this to add to your list.) Is the change supportive of your hopes and aspirations? (If yes, what would help to strengthen this? If no, what would help you to overcome it?)

If you are interested in exploring your responses further, please note that we revisit some of these themes in *Pause for thought.*

Questions for the person cared for

1. How would you describe your wellbeing today?

2. Do you consider yourself to be on a recovery journey?
   If yes, how would you describe it (see below)?

   Recovery is relief from symptoms
   Recovery is living a meaningful life
   Recovery is holding hope for myself
   Recovery is something else (please describe)

   Choose all the statements that apply to you. Don't worry if some seem contradictory; it's not unusual for someone in a challenging situation to hold two opposing views simultaneously.

3. What are you recovering from (if relevant)?

4. Whose recovery is it? Look back at your answers above and decide which of the following is most relevant to you:

   Recovery is about me
   Recovery is about me alongside the person who cares for me
   Recovery is about me separate from the person who cares for me
   Recovery is about services holding hope for me
   Recovery is about services holding hope for me and the person who cares for me
   Recovery is all of the above
   Recovery is not relevant to me

5. What were your hopes for yourself before you became unwell?

6. What are your hopes for yourself today? Record an example of something you would like to do for yourself. What would help you to achieve this? What would make it difficult?

7. What (if anything) is making you feel most hopeless today? Record an example of something that's stopping you doing something for yourself. What makes this difficult to overcome? What would help you to overcome it?

8. What have you learned so far in your personal journey?

9. What could others learn from you?

10. What has been the most helpful element of your personal journey?

11. If you have time, put all your answers together and come back to them later. Has anything changed? (If yes, find some new examples that show this to add to your list.) Is the change supportive of your hopes and aspirations? (If yes, what would help you to strengthen this? If no, what would help you to overcome it?)

    If you are interested in exploring your responses further, please note that we revisit some of these themes in *Pause for thought.*

Questions for mental health workers

1. How would you describe your wellbeing today?

2. Do you consider yourself to be on a recovery journey?
   If yes, how would you describe it (see below)?

   Recovery is relief from symptoms
   Recovery is living a meaningful life
   Recovery is holding hope for myself
   Recovery is holding hope for the people I provide care for
   Recovery is holding hope for caregivers and the people I provide care for
   Recovery is all of the above
   Recovery is something else (please describe)

3. What are you recovering from?

4. Whose recovery is it? Look back at your answers above and decide which of the following is most relevant to you:

Recovery is about the people I provide care for
Recovery is about the people I provide care for and their caregivers
Recovery is about me alongside the people I provide care for and their caregivers
Recovery is about me separate from the people I provide care for and their caregivers
Recovery is all of the above
Recovery is not relevant to me

5. What were your hopes for the people you provided care for when you first became a mental health worker? Did you come into your service holding hope for caregivers too?

6. What are your hopes for the people you provide care for today? Are caregivers already included in this? Record an example of something you have done or could do to support caregivers. What would help you to achieve this? What would make it difficult?

7. What (if anything) is making you feel most hopeless today? Where could you go for support with this?

8. Record an example of something that stops you offering support to caregivers. What makes this difficult to overcome? What would help you to overcome it?

9. What have you learned so far from working with caregivers?

10. What could caregivers learn from you?

11. What has been the most helpful element of your recovery journey (if relevant)?

12. If you have time, put all your answers together and come back to them after reading the narratives. Has anything changed? (If yes, find some new examples that show this to add to your list.)

    Is the change supportive of your hopes and aspirations? (If yes, what would help to strengthen this? If no, what would help you to overcome this?)

If you are interested in exploring your responses further, please note that we revisit some of these themes in *Pause for thought.*

Chapter 2

Recovery... a strange word for me

In Sussex, Anon

I was advised some twelve years ago that my daughter's most likely diagnosis would be schizophrenia. I read, delved deeply into the internet and asked for information about expected future outcomes for her and how I, as a parent, could or would cope. A year later the consultant confirmed my fears. He informed me, explained the possible future and, with his help, I began my journey towards accepting and therefore starting on my own road of recovery from the shock, disbelief and the mourning of my lovely daughter's future.

In 2004 a new consultant joined our local Trust, took over and turned the diagnosis on its head. Not a psychotic illness but one of a psychological nature, was his opinion... nurture not nature. He implied that my daughter had suffered abuse, had had a bad upbringing and was now suffering from one or all of a number of labels associated with psychological issues: dissociative identity disorder, borderline personality disorder and/or post-traumatic stress disorder. She was hospitalised again and again and filled with test doses of various drugs, but only seemed to become more and more psychotic. He insisted that I should not visit her. She was then admitted by this consultant to a private hospital for the treatment of post-traumatic stress disorder. They diagnosed schizophrenia. She was readmitted to our local Trust, where the consultants refused to acknowledge the diagnosis and refused treatment. I fought to have a second opinion from outside the Trust, away from the very opinionated, arrogant, biased consultant whose dictatorial and wholly wrong diagnosis had caused my daughter and our family so much unnecessary suffering. Not only was my daughter completely 'mad' following two years in his 'care' but I felt beaten, betrayed, unheard and unable to protect my daughter from his and his colleagues' distrust of a parent/carer's care and opinion.

I fought and won; a consultant was sent from a London Trust. He immediately diagnosed my daughter with a psychotic illness and she was admitted to the Bethlem Royal Hospital at the beginning of 2007.

In my opinion, much of recovery – or 'regain', as one dictionary defines the word – depends on the wellbeing of the person to whom you are giving care and all the others involved in their care. I had left our local Trust feeling like a beaten dog; I was exhausted, had lost weight and generally felt that no recovery of any sort for either my daughter or myself would ever be possible.

On my first visit to the Bethlem, I was introduced to all the members of staff. I was also invited to discuss any issues with and ask questions of and with the Staff Nurse and Primary Care Nurse, invited to ward rounds once a week at a time to suit me and asked to collaborate in my daughter's care from day one. Her consultant questioned me, listened to me and expected me to be part of the team. The staff were endlessly supportive and kept me informed as to any changes in my daughter's wellbeing, kept in touch with me and offered advice – and, above all, we all trusted each other. The consultant's attitude was that if I was not strong, healthy, informed and trusted, how could I care for my daughter when she returned home? The entire turnaround of my former experiences enabled a leap in my recovery.

Recovery, if that's the right word, is, for me, support with the role of caring. Knowing that someone is in the background relieves some of the fear and anxiety. Trust and willingness by the services not only to listen but to hear, exchange ideas, be 'there' for you and be willing to jump if the need arises are crucial. Unfortunately, with a diagnosis of schizophrenia, the journey of recovery is similar to that of a roller coaster ride. It is dependent on my daughter's mental state. Currently she is stable but, if she missed her medication for more than 72 hours, we could be thrown back to around square one, which from my point of view means that recovery is relative. I was warned early on that this diagnosis could be likened to all the stages of bereavement but without the death; in other words, there is no closure. My 'recovery' is not complete, and of course it never will be, but with my care of my daughter and her subsequent blossoming, my ability to 'read' her mental state and the knowledge that I have back-up, I can remain in a state of what I would like to call 'recovering'.

Chapter 3

The silver lining

In Sussex, Mr & Mrs P

It was summer 2005. Life was buoyant and fun. The weather was fine and sunny, but storm clouds were gathering. Not in a meteorological sense – these storm clouds were of a different genre. They carried an obnoxious potion of fear, uncertainty and panic, all brought about by the onset of mental illness.

Prelude

Up to this point in my life I'd been blessed with a relatively trouble-free existence. I was happily married for a second time, incorporating my son, who was born in 1983 from my first marriage. The three of us lived a comfortable life. I held a position as a company director and my husband worked as an accountant. In conjunction with my first husband, we were able to provide my son with a private education. We continued sponsoring him into tertiary studies after he was awarded a scholarship to attend a top university, where he followed a degree course related to environmental sciences. He flourished in this setting, being dedicated to 'saving the planet' on the one hand and pursuing an energetic social life on the other. He was a bright, capable, academic young man with excellent prospects for the future. Once out of university in 2003 he quickly acquired employment as an environmental technician. He was still living at home with us and all was going well.

During the early part of 2005, coexistence with my son became a little more difficult. We had upsets over his dogmatic views on life values. There were opinions being foisted upon us relating to religion and criticisms of our apparent disregard for the environment, and we fell out over his sudden acquisition of some rather strange tattoos that were very much out of character. In short it seemed he was intent on continuing a student-type lifestyle with the associated rebel factor very prevalent. As a result, my son decided to leave our house and live at his father's house with his father's partner and her family.

His father prepared for his son's arrival by providing him with accommodation and bespoke furnishings. Despite these efforts the liaison was troubled and my son soon left to take up lodgings nearer his work south of London.
In an instant, my son was introduced to some people in his new home town by an old school friend and duly invited to a party by them. We know now that he encountered the dubious world of illicit drug-taking through these people and it is almost certain that these events caused my son to become psychotic.

Our first brush with psychosis came a few days later, when we received a call from my son's workplace at the close of a working day informing us that he was behaving strangely and that they would be bringing him home to his father's house.

Lesson 1 taking drugs should be avoided at all times by people predisposed to psychotic tendencies

That evening, we all wrestled with his deteriorating condition as he lurched from one nonsensical notion to another. His behaviour was so alien to us that we were in a position of not knowing exactly what to do. We did manage to see a locum GP late in the evening who advised us that he was showing psychotic symptoms. He prescribed sedatives for my son and advised us to take him to our own GP in the morning. My son was up early the next morning and very agitated but we did manage to get him to our GP.

Episode 1 of 5

Our GP diagnosed psychosis, and in the middle of the discussion my son stood up, thanked everybody, announced that he was fine and quickly left the surgery. He started running through the streets, calling into pubs on the way; he was advising them to stop selling alcohol and grow organic food produce instead. He ignored our pleas for him to return home. I was extremely worried that some harm might come to him, as he had no notion of how irregular his behaviour was becoming. His fitness level being very high made him difficult to keep up with – he was flying on the wind, and the only way to catch him was to involve the police. He was caught and taken to a mental health hospital. After a few days he was detained in the hospital under a section 2 but within a month he had been stabilised with medication and was released. My son came to live at my home but, being heavily medicated, he was a shell of his former self, although the psychosis had abated and he was able to return to work.

After six months the psychiatrist stopped my son's medication, implying that he had had a one-off drug-induced psychotic event and would probably not encounter the condition again.

Lesson 2 ensure a carer's assessment is completed by hospital staff during your first encounter with hospitalisation (this will get you into the 'system')

Two devastating elements had been introduced into my life: my son had experienced a psychotic episode without any insight into his condition and I had been into a mental hospital for the first time and entered an alien world. Little did I know at the time that this first involvement with mental health would be just the start of a long, stressful, and dark journey that at one stage seemed totally hopeless with no resolution in view.

Lesson 3 seek solace and understanding from carers who have had very similar experiences to your own

Episode 2 of 5

It had been so saddening to see my only child in such turmoil after a lifetime of normality. All the same, I began to convince myself that this was just a glitch and we would all get back to normal, and for a while that was exactly what happened. My son had gone back to work but decided to change career and move to the West Country to work on 'nature' projects. I can remember feeling so relieved that all was normal again, but I was soon to be devastated as I watched the onset of psychosis take over my son once more.

In total my son was in the West Country for about 18 months, and during that time his condition got steadily worse as I and my family and friends increasingly received strange letters and bizarre telephone messages from him. I visited him on numerous occasions during this period and tried to persuade him to come home but he was set on staying where he was. Eventually, with no work and finding it increasingly difficult to manage (at one point he was living in a log cabin in an open field on a farm), he finally came home. His condition was now causing me great concern and I had to take steps to get him medical attention. This proved once again easier said than done as we attempted to line up the required key personnel to address the problem of a poor soul unaware of his own condition and requiring medical attention. The trauma and anxiety levels were sky high during May 2008.

An assessment was arranged that involved two psychiatrists and a social worker. They deemed he was to be admitted to hospital as a section 2 patient – detained for up to 28 days. If he went voluntarily that was good, but if he didn't then the police would be called. In the event he went voluntarily but the entire process was incredibly intense and emotional as he struggled to understand what all the fuss was about and I struggled with his abject irrationality. I was beside myself with grief, in mourning for a lost son and at the same time buffeted by a brutal hospital induction ritual.

Lesson 4 have an action plan in place that can be executed should hospitalisation be required

Visiting my son in hospital already had a mild familiarity about it. He was heavily medicated yet still managed to maintain some fairly paranoid opinions that he would suddenly lay on me. The combination of confused thought processes and the stress of hospitalisation resulted in him making some strange decisions. At this stage in his illness he decided that I would no longer be his next of kin and that it should be his birth father – my first husband – instead; this despite the fact that I had brought him up without his father for the last seventeen years. Paranoia had replaced normality, causing my son to give away his possessions, adopt rigid eating patterns and hold religious views to a delusional level. Driving such attitudes was a belief that he had been wronged by his immediate family and that it was their fault he had been 'swallowed up' by a mental health system he was unable to rid himself of. He was then released from hospital but this time on prescribed medication that had hefty side effects, again for a condition he did not believe he had.

Lesson 5 poor insight may have a psychiatric cause but will probably require a psychological solution

By now my personal life was so ravaged by the necessity to constantly focus on mental health issues that it had become unrecognisable from just two years ago. Strains were put upon previously unassailable relationships and an underlying feeling of oppression prevailed, not helped by the dismissive attitude adopted by my son's father, who became a very noticeable absentee from the entire scenario. From a family perspective I felt very isolated, and I was always mindful that my husband was not directly related to my son and conscious of the burden being placed upon him.

Lesson 6 demonstrate a strong parental relationship providing strong, unwavering support

There followed a period of 'splendid tranquillity' during which my son became 'normal' for many months. Initially he was lethargic and suffered weight gain from the medication, but after a while he became fit, lithe and energetic. His strong intellect appeared unblemished by psychosis either during or outside episodes, and nine months out of hospital he successfully applied for a course on the teaching of chemistry, physics and biology that was to start in September 2009. This direction was fully sanctioned by his consultant. Things were looking positive for a change.

Episode 3 of 5

Then, in October 2009, the world came crashing down around our ears. Unbeknown to us, my son had stopped taking his medication back in March.

Lesson 7 constantly check that medication is being taken regularly

This tied in with the renewal of vitality and energy we had been witnessing since March and made him vulnerable to relapse. There had been a problem with the university's medical form processing that led to significant delays. By the time they made the decision that he was medically unsuitable – despite achieving best student status and being elected student representative for the course – my son was already well into the course. After raising his expectations and involving him in a solid life skill he was suddenly dumped and abandoned. The stress created by this action buckled my son and he became very psychotic again almost immediately.

Lesson 8 stress is a major factor with regard to triggering psychotic episodes

Once again we were confronted with the daunting prospect of hospitalisation; the level of emotional trauma now rose exponentially with every occurrence.

Lesson 9 social services and associated organisations (except the police) are very poor when it comes to the act of hospitalising mental health patients

The pattern was now beginning to follow a very predictable cycle: 1) no medication; 2) psychotic episode; 3) stressful journey to hospitalisation; 4) erratic hospital treatment towards stabilisation; 5) hospital discharge on medication; and 6) the wait for it to start all over again. My husband and I were beginning to tire of this roller coaster process.
Recovery in hospital this time involved my son spending time on the acute ward as there were no beds available elsewhere. This was not helpful. He seemed to take much longer to respond to the medication and remained in a confused state for what seemed forever. But a recovery did take place and he was able to leave within a month.

His overall condition had worsened since the first episode, although the psychotic symptoms had not changed. He was still in denial over his condition and keeping him on medication was not going to be easy.

Episode 4 of 5

Once again my son stopped his medication and was hospitalised with the assistance of the police. This time it had only been 196 days since he'd last left hospital and he was back in again during April 2009. We had been subjected to the hospital entry façade once more and felt wiped out by it.

I succumbed to illness on this occasion, the stress of it all being too much to take. I could no longer go on being an ineffective bystander amid this whirlwind of unpredictability. I had to fight back somehow, so I decided to find out if there was anybody else suffering in the same way as myself. All this time we had been isolated and I was truly surprised to find so many people suffering identical crises. A new word became symbolic of our plight: carer! I was a carer for someone with a mental illness. I was not alone any more.

Lesson 10 wholeheartedly step into the world of carers

I met with a local support body and was introduced to some fellow carers, who all seemed to have the same issues as me. Although there were groups established in nearby towns there was not a carer group for our town. So I started one and set up monthly coffee mornings that were immediately well attended and have remained so to this day. It was an excellent forum for sharing, and much advice and learning resulted. I experienced a renewed energy and a sense of purpose and community from this development, and a

newfound strength from feeling I was at last doing something positive to help my son. However, there was to be more upset.

Episode 5 of 5

My son was still in denial over his condition with extremely poor insight, and he stopped his medication yet again. But this episode was to be different in a number of ways where his treatment was concerned.

In January 2011 he became very unwell – the worst, in fact, he had been since the onset of his condition. He was more distracted than ever with confusion, thought blocking, unsolicited laughter, distraction and poor mental processing. We went through the most awful experience to get him into hospital that ended with him being arrested in a public place after a particularly harrowing period where he went missing. The relief when he was taken to hospital was palpable, yet somehow, despite the awfulness of the experience, I was able to gather myself into a pragmatic package that was determined to get a much better result for my son on this occasion.

Lesson 11 don't be subservient: assume a position of leadership

Notification that my son was to be held under a section 3 this time signified the seriousness of his condition. He was to spend up to six months in hospital, where, initially, his paranoid behaviours were extreme and his response to medication very poor. So poor, in fact, that at times we doubted he was taking medication at all.

Final recovery actions

This time it was going to be so different. I was determined to have a much better outcome following hospitalisation.

Because the internment period was so protracted this time it gave us more of a chance to analyse the processes used by the hospital. Firstly, there was the ludicrous position that patient confidentiality applies to mental health patients. It is unbelievable that someone with severe mental processing difficulties is given the responsibility to make decisions on their treatment and overall life direction while the 'normal' carer is excluded from these

discussions, particularly as the carer has responsibility for post-hospital welfare. It was a situation we were determined to overcome.

Lesson 12 establish a very close relationship with your patient's consultant

We started by developing a close relationship with my son's consultant. Although he had to strongly adhere to the confidentiality nonsense we eventually made an agreement that we could put our thoughts and desires into a letter to him. He would then respond to us by answering the letter verbally, thereby creating the desired communication path. We were only able to discuss my son's treatment at a fairly superficial level but it was better than nothing and did yield some good joined-up actions. We wrote the letter to the consultant every week, timed to reach him the day before he visited my son for his weekly assessment. The letter also had the effect of addressing another issue.

We had noticed that staff input to the consultant prior to the weekly consultant's assessment was not sufficiently comprehensive. Staff continuity was poor due to holidays and frequent training days on top of stretched staffing levels in general. As we visited my son regularly we were able to offer some solid feedback about his thoughts, his mental and physical states and when he was responding and not responding to treatments. All this went into the weekly letter.

At the same time my husband and I went on a crusade to learn about mental illness. I bought numerous books from Amazon, visited libraries and attended lectures by psychiatrists. We even learnt about the causes of and treatments for patients' poor insight into their own mental health conditions. We armed ourselves with the correct information and understanding of what we were dealing with and we had a strong dialogue with key medical personnel. We were no longer on the outside peering into the mental health abyss with bush-baby eyes. We were an integral part of the system and it felt good.

During the research we came across an American doctor who had some interesting views on the psychological approach to use on psychosis sufferers. It is important to understand the most suitable language to use on patients to aid communication and understanding on both sides and we found his book *I Am Not Sick – I Don't Need Help!* most inspirational and helpful. It's by Xavier Amador (with Anna-Lisa Johanson).

Lesson 13 research the subject of mental health that relates to your patient. Doctors do not know everything!

The result of this 'involvement' type of approach has been remarkable. We pinch ourselves regularly to make sure we are not dreaming the life we now have. My son still has the condition but it is much better controlled. We are aware that relapse is possible at any time, but in that event we are much better prepared to deal with it. Life is fun once more!

Epilogue

I am in no doubt that the information we provided to the consultant enabled him to arrive at the best and most suitable medication for my son. He has the medication administered by monthly depot injection and experiences the mildest side effects we have witnessed since the onset of his condition. He has a Community Psychiatric Nurse (CPN) appointed whom he trusts, and we even had a say in the selection of that CPN.

We have a better understanding of the entire approach to treating psychosis – including the psychological aspects – and that helps when we communicate with my son. We are also able to assist other carers with our newfound vigour and, in many cases, offer some guidance on the best way to approach the mental health system and its pitfalls.

As for my son, he has the best life that could be hoped for as a sufferer of psychosis diagnosed with paranoid schizophrenia. He has a job and works 20 hours a week. He has a girlfriend he met in hospital at the end of his last treatment and they are planning their wedding day for 2012. This is a position I never even dreamt I would be in and both families are giving total support to this couple.

One thing I am extremely grateful for is that drugs and alcohol do not feature in either of their lives, for if they did it would surely ruin everything. There is, however, a factor other than drugs that should be scrutinised: the genetic trail created by the 'family tree'. Important clues can be obtained by examining family history and traits, for example evidence of depression, social integration, etc. This history can provide important pointers about treating the condition you now face.

Below is one of the letters we compiled during our information-sharing with the consultant, and I hope it serves well as a model for anyone wishing to follow our approach (in the interests of confidentiality, all personal details have been removed). Writing letters can be a tedious chore but in this case the advantages are numerous. Written matter is a one-way communication. You can put down your views without interruption in the manner you wish. Letters serve as a solid reference for past events. It's too easy to forget undocumented information after verbal communication as data tends to get confused or, even worse, overlooked after a short period. And there is the chronological aspect: in a letter, events are recorded and time stamped so there is no doubt about what happened when. It is an irrefutable record.

This whole experience has been one of trauma, so it may sound strange for me to say that I am pleased in some way to have lived through it. We have found out that my son has a predisposition to this condition and we have to deal with this. Along the way I have met some amazing people; I have a high regard for my son's consultant, who has made this recovery possible along with my husband and I. My husband has been my solid rock throughout, and considering he is not the father of my son I regard him as a very special person to have shared this experience with me. I feel that because he is not the father of my son he's been able to adopt a pragmatic view on the whole thing, with an emotional detachment that is not easy to accomplish as the parent. My son, whom I admire greatly for his positive attitude and the special, thoughtful, caring ways he displays to people, has recently published a book containing his deep thoughts on life and the behaviours he feels one should adopt for it. He has great faith, and this has carried him forward through the struggles of his illness. I am delighted he has met a very loving young lady whom he adores and can share his life with. They are two very special people indeed.

In the future we will continue to monitor the situation by constantly reviewing his wellbeing, looking for signs of regression. We will be ready to put our remedial plans in place the minute we detect a diversion from the norm.

Lastly, I would like to say to all carers, 'Never give up hope'. Be positive and strive for the outcome you want for your loved one. Don't be afraid of the medical profession – work alongside them to achieve the best possible outcome. It can be done, so I hope this story will enlighten others and inspire them to achieve the best possible result for themselves and those they care for.

MOST PRIVATE AND CONFIDENTIAL

Your Address

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****

****

Consultant's Address

****

****

****

****

Monday 7th March 2013

Dear Dr *********,

Re: Patient's Name

I am keeping you informed of my/our observations regarding **Patient's Name** to give you further insight into his/her condition, particularly conversations, visits and letters.

We feel Quitapine works so well for him/her and has the fewest side effects. However, we are convinced from experience and from comments made by **Patient's Name** that he/she is again not taking his/her medication. **Patient's Name** spoke to my mother on the telephone yesterday. He/she appeared confused and unable to string a sentence together. He/she said, 'I am upholding the law'. This is the type of thing he/she says when not taking medication. From experience all the signs are there, and I would suggest that he/she stopped taking medication over a week ago.

His/her current condition points to him/her not actually swallowing the medication. I understand the staff are being so helpful and are trying their best for **Patient's Name**. I don't want for one minute to tell the nurses how to do their job, but would respectfully ask that **Patient's Name** be requested to poke his/her tongue out when he/she has taken medication. **Patient's Name** is a bright, clever young person who will try everything he/she can to deceive them as he/she is so against taking medication. I called the staff nurse yesterday to discuss this point.

Patient's Name knows how switched on my husband and I are regarding his/her condition, and this also goes for his/her grandfather. We are the ones he/she does not want to visit him/her in hospital as we are the closest to him/her and can see when he/she is meddling with his/her medication, having been a part of this journey from day one.

Patient's Name wrote to me last week saying a dear friend had had a heart attack and this must have been caused by the medication he was on. He said he left a message for him on his telephone wishing him well and 'God bless him'. The letter was dated 28 March. This situation would have worried **Patient's Name**.

Yours sincerely,

.cc Nurse (hospital)
.cc Community Psychiatric Nurse
.cc GP
(COPYING THESE PEOPLE IN KEEPS EVERYONE AT THE SAME INFORMATION LEVEL)

Chapter 4

So you love someone with a mental illness?

In Scotland, Cathy Hamilton

First experience

Many years ago I was introduced to mental illness when my husband was diagnosed with bipolar disorder (then called manic depression), although at the time I was very naïve about how this would affect me and my family.

There was very little going on to explain things or support us, and through my own lack of knowledge I reacted to this in a very negative way.

In the beginning my husband was hospitalised for a long time. This was on and off for many years, and at no time did anyone offer to explain what was happening.

I was once called into the consultant psychiatrist's office and felt I was being held to blame for my husband's mental illness. You can imagine how distraught I was, and never forgave that person. Thank goodness things have moved on since then and the individual has long since retired.

Because I found that mental illness was so unpredictable, I had to go on my own journey to educate myself and, in turn, try to explain to my family about mental illness.

I loved my husband very much (and still do), but I kept on reacting very badly to his illness. I so wanted him to be well, and just wished that someone would say a magic word or give us a magic pill and all would be well. I really struggled through this time in my life. I felt alone, stigmatised, unsupported and left very much to my own thoughts, which were at times not healthy. I was fast beginning to feel very unwell myself, and full of despair.

Problem drinking

My husband used alcohol to deal with his illness. This was obviously not good, and it caused major problems in our relationship.
Eventually, however, he decided to do something about his drinking and joined Alcoholics Anonymous (AA). I in turn joined the sister fellowship of Al-Anon, and was able, through the 12-step recovery programme, to start to understand myself and gain the tools I'd use in my own recovery.

I learned about detaching with love, and how to listen without always wanting to jump in and fix him. When he had relapses of his mental illness (my husband has never used alcohol again to this day), instead of watching, waiting and offering loads of advice, I stood back and respected his decisions.

I learned the difference between bad behaviour and mental illness. I was able to set boundaries without thinking that this was going to cause a relapse.

To say my husband was pleased with all these changes in me would be an overstatement, but eventually we started getting to a place where we respected each other.

Carers and experience

There is still learning to be done, but being part of Support In Mind Scotland for the past 14 years and managing the Tayside Carers Support Project has given me the opportunity to work with carers all the time.

This has also been a great learning curve. I am aware, as the years have gone by, of the difference in the services and how they have improved with their support for carers.

This has been a slow process, and there is still a long way to go, but the general consensus among carers is that the quality and shape of the education, support and information you receive depends on what doctor, nurse, social worker and support worker you get.

Most of the time carers like me are looking for ways to cope with their loved one's mental illness. So looking at coping skills is high on the agenda as they help to improve the relationships.

The Tayside Carers Support Project

Our service offers one-to-one support, emotional/telephone support, practical advice on coping and access to support groups. There are also social activities and we have involvement workers, making sure that carers have a voice.

We have a Tayside remit covering Dundee, Perth & Kinross and Angus. Fortunately I don't do all this by myself any more, as there are now part-time carer support workers in Perth & Kinross and Angus, plus full-time and part-time involvement workers.

Carers who want to become more involved and 'have a voice' are able to attend meetings with healthcare and social work professionals, and be considered experts themselves by virtue of their own experiences.

We run a preparation course for the carers who want to be more involved, which has proved very positive in terms of making our carers feel informed and supported.

This is a long way from my own early days in my caring role. These days I prefer to be called a 'supporter', and I have discovered that a lot of other carers prefer this term as well.

Recognising and supporting

Unfortunately, not everyone recognises themselves as a carer. They are just a mum, dad, husband or wife, sister, brother or friend – and feel it is simply part of their function to look after the people they love.

That is why it is so important to look at our own wellbeing as carers/supporters, as far too often lives are put on hold and people's own mental wellbeing becomes an issue.

We run training courses and wellbeing days, to emphasise how to try to reclaim our lives while still supporting and loving the person we care about in a more emotionally healthy way.

This is important because we cannot support someone if we become unwell ourselves.

Many carers feel guilty about taking time out. I know I did – I thought that because my husband was depressed I should not be having any fun or having a life.

This always led to conflict, because I would then become resentful towards him for not letting me having a life, but in fact it was me who was putting my own life on hold. He never once asked me to do this and I effectively became my own prisoner.

Intense situations

Because of the nature of the caring role and because we carers love the people we are caring for, it all becomes very intense, worrying and difficult to understand.

I know that the professionals who look after our loved ones do not always recognise that there is a family out there who have become emotionally involved in the illness. Carers are hurting and very often grieving for the person they knew, and in many cases will never be the same again.

Recovery for all

I am a great advocate for recovery and always feel that no matter what degree of recovery the person achieves, it is theirs, and very often hard-earned.

I also believe there is a recovery process for the carer, because they have been affected by their loved one's illness.

It is very hard sometimes for a carer to separate their life from the life of the other person (the person they care about). I have heard many carers say that if their son, daughter, husband, wife, friend is feeling okay then that makes them feel okay.

What we try and achieve through our one-to-one support, support groups and training courses is to try to get the carer to concentrate on their own life.

This hurts, because it always feels like you are leaving the person behind, but I have to say it is also very rewarding, in that it keeps us emotionally well.

Using different techniques and language in particularly difficult situations can certainly help to calm down situations and make the other person aware of changes in you.

I have personally proved this time and again with my husband. He used to say to me, 'I may be mentally ill, but I am not stupid', and he felt I always treated him as someone who could not think or feel for himself. I had to change this in order for our relationship to flourish.

I became more aware of these things as time went by, and started to feel better within myself. What was happening was that I was beginning to reclaim my life, and that could only be a good thing.

Moving on

I am so glad that I do the job I do. It has given me an opportunity to feel, see, and understand others in a similar situation.

For me, things have moved on. It is good to have a voice and be able to speak out when I feel unhappy about services, as this is the only way we can move forward.

But what about the carers who do not feel they have a voice and are feeling 'out there' and alone?

It would be great to think that they could find help within our project or other projects, so that we can pass on our experience, strength and hope with each other.

Editor's note

Cathy has since retired from her position with Support in Mind Scotland and Tayside Carers Support Project. She has assumed a new position within NHS Tayside but continues to be involved in a range of recovery initiatives including Wellness Recovery Action Planning (WRAP) Facilitation.

Key learning points

- The carer bears the brunt of the illness, yet has to educate themselves and their family and friends about the illness. This must change. Information should be offered right at the start in ways that are easy to assimilate.

- Mental illness affects all family relationships. Close family members (siblings, children, parents) will have different needs and responses but they all need help.

- It is important to try to detach the manifestations of the illness from the person.

- Carers need to be helped to learn coping skills.

- Carers and close family are all hurting and grieving. Recovery should be for all.

Chapter 5

My Story... so far

In Sussex, Anon

I trained as a nurse in London, wearing lovely uniforms and being at the forefront of medicine. During my second year I opted for a placement in a large psychiatric hospital in Surrey. It was huge, with its own farm and church, and set in beautiful surroundings. As a student I was sent to various units including locked wards, an ECT[1] suite and psycho-geriatric wards. Patients were just people who got in the way of the running of the place and I can remember the space, light and air, but the care was minimal. Patients were given clothes to wear: women had a clean apron weekly and clean dress every fortnight; the bread was buttered, the tea sugared and institutional living was the norm. I hated this type of control of people, and the lack of personal care. Everything was suited to the running of the hospital and nothing to the individual patient; it all seemed terribly wrong.

When my second child was born, I remember thinking something was wrong. He cried a great deal and hardly slept. A visit to the local paediatrician resulted in him being quickly prescribed Largactil and me being told I stimulated him too much. All I could think of was a night's sleep so I gave him the medicine, but for a short time only as I thought his liver would suffer. I remember waking up when he was about four or five years old, listening to him talking to his farm animals and soldiers and wondering how he could not be tired, but somehow he just kept awake for days and days. For me this was an overwhelming time as I also had a little girl; those levels of exhaustion have stayed with me until now.

James had excellent gross motor skills, so he could ride a bicycle, swim, run and jump at a very young age. He required a lot of input and I became adept at throwing and catching cricket balls, usually with the supper cooking wildly on the stove and me rescuing the meal just in time. I was aware that his concentration was not good, except for sports, so as a family we became loyal supporters of his sporting interests. He will say he had a happy childhood, but always at the back of my mind I knew something was wrong. However, without knowledge or any idea of where to get it, I felt helpless. To the outside

[1] Electroconvulsive Therapy

world he was a blonde, attractive little boy with the ability to read the flight of a ball; so what was the matter with me, and who could I discuss it with?

First concerns

My first real concern was when I was told by his prep school teacher that he could not be found. A search was made and he was eventually found gazing out on the cricket field by himself, having left a lesson. So, an 8-year-old stands and stares; I started seriously thinking something was not right.

As his teenage years approached I felt very uneasy and successfully persuaded James to visit his GP to discuss mood swings and anxiety levels, but all in vain: the kindly GP called me to placate and smooth the path and said how well-adjusted and charming he was and what a good cricketer. Needless to say, this did not help and left me feeling very bewildered.

Back pain was a problem, together with unexplained behaviours and isolation from the family. I felt compelled to keep him busy and involved with activities; he ate, drank and slept cricket but, on a move to Sussex, became more isolated. Two trips were undertaken to Barbados to play cricket, and I was worried that if he got into trouble he would be incarcerated, but on his return he decided to visit his GP about the increase in back pain. The orthopaedic consultant decided that unless James had a piece of bone taken from his hip and grafted onto his spine he would be in a wheelchair very soon as the nick in his vertebrae would pierce his spinal cord, leaving him unable to walk. The surgery was brutal and he was in a full body plaster for weeks, unable to move or shower and living on painkillers; for some reason I was so involved with the physical aspect, I actually forgot about his mental health. After a long time James was sent back to the orthopaedic consultant to find that everything had broken down and there was an urgent need for another spinal fusion operation.

He was admitted and his spine was hooked up with wires and fused together. I remember thinking that this time he was psychologically scarred and that his sporting days were over. The days and weeks that followed were traumatic, learning to walk on a huge amount of analgesia and accepting that this was how it would be now. For months I was worried about what he would do – sport had been his life, and now it had been taken away. I hit on the idea of applying to a local drama group with the thought that perhaps he could give

out programmes. To placate me he agreed to go, and returned from the first meeting full of enthusiasm for acting. He auditioned and was given a lead part. I remember thinking how happy and untroubled he looked. For weeks he attended rehearsals, and I was booked every day to hear lines. We saw the play and were amazed by how he carried a ladder on stage and pretended to get into the girlfriend's bedroom. As it was a farce, he made a meal of it and was terribly funny. On stage, James seemed in control, and became the person he was acting.

Mental health crises

One fateful Saturday, as the Nat West cricket final was on the TV, James was found curled up in the foetal position. I was not his mother, his sister was not his sister and his level of confused thinking was alarming. Our GP arrived and James was persuaded to go to hospital as a voluntary patient. He took medication and, after a very long time, was discharged. He had strange beliefs and sometimes talked about them. This followed numerous admissions and a degree of aggressive behaviour with thoughts of persecution and being tortured. He believed that I had been a prostitute and was in collusion with mental health staff.

He eventually took himself off to drama school. After a while he went to a drama college, and although he enjoyed the experience at first, after a couple of terms he came home for good. He went through a revolving door period of taking the medications, long relapse, detained under the Mental Health Act, treated for months and then discharged; each time the fear and dread of the unknown increased.

He wanted to get back to the theatre. He was making nuisance phone calls to the older lady whom he believed he'd had an affair with – re-occurring thoughts from his very first admission. The police were involved and I knew he was just on the edge of normality. He continued to have admissions – sometimes in Psychiatric Intensive Units, where he was completely locked up. His beliefs returned so powerfully that he thought I was involved in prostitution or had been abused, and also strongly believed I was responsible for his incarceration. He was convinced he had been a prisoner and could describe being tortured. The list could go on and on. He thought he was linked to the Pentagon and still the lady, whom he had only spoken two words to, was his long-time lover.

On one occasion when James was an inpatient, I was contacted by the ward to say he had been attacked and taken to theatre at the local hospital as his arm was broken. On his return from surgery he was left alone on a trolley and the attacker hit him around the head. After a long time and many meetings I sued the hospital for negligence, and James was awarded some compensation. I felt relief that no one else should ever have to witness or suffer what he had, and hoped that the Trust would make psychiatric intensive care a priority and offer local provision.

A terrible day

In 1999, the day after Boxing Day, I went shopping in London with my daughter while my husband and James went to play golf. It was a terrible, wet day. James met us off the train in the evening looking ashen; we were laughing about our bargains and swinging our shopping bags. We were told that my husband had collapsed on the golf course. Apparently the helicopter had been unable to land, so James had had to run to a nearby house to call the ambulance and try to resuscitate him. For all of us this was a terrible time; although the psychiatric team gave us support, I knew it was just a matter of time before James had another relapse.

When I remember my husband it is for his great kindness, sense of humour and complete love for me and his children. He supported James with all his enthusiasm and encouragement, but found the lack of logic and the behaviour patterns difficult to grasp. He was very protective of me, and tried to shield me from the awfulness of relapse. We had a very busy life and, at times, planning for the future was overwhelming. When he died so suddenly my world changed overnight: I was now the head of the family, with the knowledge that I had the burden of James.

My daughter was seriously thinking about not having children. Although, as far as we know, James is the first person in the family to have a mental illness, she was acutely aware of the devastating effects it can have on a family. Elisabeth became very protective of me, and although she worked in London she came home every weekend to be with me. We just got on with it the best we could, with the sure knowledge that Dennis would never have chosen to leave us. The mental health team were prompt to visit James, but within a year he was readmitted and the revolving door started again. I managed situations knowing that I was my own tap root now and had to make decisions on my own; chatting over a cup of tea or coffee was over and I was finally

fully grown-up. I still feel that James was dealt a dreadful blow to have had to witness the sudden death of his father – which to this day I know he has not recovered from. I have been sustained by my faith, and have often felt looked after. During that horrible year of 2000, I was very ill with a perforated colon and peritonitis. I remember lying in the hospital, miles away from home, and feeling that someone was watching over me.

Moving forward

I have always been acutely aware of when James is showing relapse signs. In the early days no one ever paid any attention or listened to me, so every time I spoke to a professional with the explanations, the signs and changes in presentation were ignored. It was as if I counted for nothing and had nothing to contribute to his care or treatment pIan. Staff would get very worked up about confidentiality, with little understanding of what I was doing in the background. One of the most frequent signs of relapse was paranoia against me, and even though I was dealing with his financial affairs, paying bills etc., I would not be allowed to be told simple things like decisions made at a ward round. I must say, though, that this attitude has improved; also, the blame culture is much less in evidence and the respect for dignity has improved. More space on the wards with privacy and routines that are less rigid yet have boundaries have made for a calmer, cleaner and healthier environment, and an understanding of spiritual needs has made inpatient care more caring.

James has been an usher at his sister's wedding, travelled to Egypt twice to see her and enjoyed riding a camel around the pyramids. He has helped me enormously with lots of things when well, but I am acutely aware of what he has experienced, seen and heard as a user of mental health services. The consultant psychiatrists have always worked tirelessly to find the right medication (no easy task as he is drug resistant), but in recent years the attitude towards carers and relatives has been so much more enlightened. The assertive outreach team have surpassed themselves, and their positive and persistent attitude has been likened to a 'dog with a bone' approach. I can only be grateful – in fact words cannot convey my admiration and respect for all the team members.

Reflections

Writing a potted history of James has been difficult. However, while I would

never wish this terrible illness on anyone or their family, it has enabled me to meet extraordinary people and have a better understanding and respect for mental health workers. I hope and pray that medicines improve and the media help with stigma, and that we as a nation will continue to support people and carers who experience serious mental illness.

On reflection, my thoughts keep returning to the early concerns and possible neglect of my daughter – not intentional, of course, but I am sure it was the case. My husband's inability to solve the problem or in fact understand illogical thinking and behaviour was also a burden. Relationships with staff members who seemed unable to understand my anxiety and offered throwaway comments did not help, together with other people all being experts' with their strong opinions. My life is about always sorting things out and being aware that a 40-year-old is not a little boy, about how much to discuss with him and not giving him any further anxiety, about holidays and always hoping he would be all right.

The worst things are often coping with the bereavement over what might have been: a job with respect, family and grandchildren, a nice home and independence, friends and neighbours. I am now resolved that this is how it will be – surely we have both been through enough – and that we have to learn to live with this. Many people have it worse, and I tell myself we have our arms and legs and our heads are on, but it has been a struggle.

Finally, I guess that as a small family unit we have been lucky, because we have supported each other. I am not the same person who became a youngish widow. I have done various jobs and a lot of travelling on my own. I have opened my garden with the National Garden Scheme and raised a large amount of money for charity by selling tea and cakes with my children on hand (James washed up all afternoon – for almost 250 people!). I have trained to become a magistrate, started and run a successful business and explored parts of the world that I would never have thought possible to see. It is not all bad. I would say that although James has been seriously ill in ITU (Intensive Treatment Unit) with respiratory failure and then renal failure, and we knew he was near to death, nothing has been as bad as the mental illness. I take comfort from the fact that he knows I will always support him, and in his own way he definitely supports me. When well he is the kindest and most thoughtful person who battles daily, and I admire his tenacity. I suspect he will not make old bones but for the moment he's managing – and, I guess, so am I.

Chapter 6

Love is the first ingredient (transcript)

In Scotland, Anon

Could you start by telling me what recovery means to you?

It's quite a funny word, recovery, because it is an ongoing process of getting better – that is what is really the thing. Recovery as a carer, or recovery looking at the person in my family? At first I did not think I needed any recovery of any sort. My perspective has changed a little bit on that. Some kind of help is needed on the way for the carer, you know. I notice, I mean I needed recovery as a carer. But recovery for the person who is ill is not totally finished, ever – at least to me, because always as a carer you or the person are always on guard and thinking is there going to be another illness, you know, a relapse. So it's not finished but it is good to see the person recover slowly with help – with my help, for example, and with the help of doctors and nurses. It's an ongoing, long process and you have to learn a lot on the way to help that person recover.

Is recovery a helpful word to use?

Recovery is a helpful word to use – it's not as if there is another word you could replace it with. It's a good word. It is a positive. But in the beginning I wasn't thinking about myself in terms of recovery. As a parent, you know, it's automatic that you help your family, you know, your child. It comes automatically – but there is something to learn about it too, you know. If I did not come across services and things like that I would not have known what other way to approach it and to help. It's my daughter I am talking about, my daughter.

So do you consider yourself to be on a journey of recovery as well?

Yes, myself, yes I do. Because when I first found out that my daughter was ill it was like a bereavement – it's like totally, totally, I mean, it's like somebody died. So you don't know what, you are like a headless chicken running around and, you know... I mean all your emotions and everything is all over the place, so... and you don't understand mental illness – at that point I did not know

much about it. When I saw somebody ill, for example, in the buses or acting funny or talking away, I never thought, 'That's an illness' like, you know, it's *medical* – you never think about it. I wasn't aware and I thought I would change place and be scared of that person. But once you found out it was not like that, you have compassion as a result of that and better understanding.

You said you felt like it was a bereavement – that you had lost the daughter you had?

No, no, the shock of it was like a bereavement. It's the shock you get, such a shock finding out because at that stage – you know, the psychosis stage – it's not like I could see any sign because I did not know. But I see now that if I see somebody else with even a little sign or that combination of signs I am able to recognise it and to catch it. I don't have another daughter, but if somebody I know is in that situation I would know to take them to the doctor. In my daughter's case, I did not know what to do. I did not understand, I did not think about it before we had it – you know, it hit home as we did not know anything.

So you had a steep learning curve?

Totally, yes. But I was very lucky that it happened in 2002 and straight away from the intensive care where I took her in emergencies, they took us to Stobhill[2] where we met the ESTEEM Group[3], and that was a lifesaver because the way they approached it was new – that was the very first year. When I heard later that this was very new, I realised we were lucky to have something that included me in the process a little bit. Not as much as I would have liked but, you know, it was really helpful so I was lucky that we stayed. Unfortunately, it was only for three years because of first episode and the age and everything. But we were very lucky to have ESTEEM because that was the first and it was a very, very good system that includes the family. They gave us an explanation and we had a few seminars for the parents. The parents met, so it was really, really good to know that there were other people there. If not I don't know what the situation would have been today.

So your first experience of working with mental health services was quite positive?

Very positive. Even in the hospital later on I had a very positive experience.

[2] A psychiatric hospital in Glasgow.
[3] An early 'intervention in psychosis' service run by NHS Greater Glasgow & Clyde.

When we met at ESTEEM, other parents had their children – not their first episode but they were there as well. But they said, 'This happened to us in the hospital' and this and that. I did not have any bad experiences in hospital. I mean, the nurse in the hospital, the head nurse, sat with me, talked to me, the doctors came, talked to me. That was very, very important to me and people did not experience that before. I mean they had worse experiences. I didn't, and when I say that to people they say, 'We really had this problem and that problem', but I never had that problem.

Did meeting with other carers in ESTEEM and being informed help further down the line?

Yes it did but, you know, we did not have ESTEEM on the first night we entered the hospital. I only had one little bad experience but then it was rectified – I was not allowed to accompany my daughter, just at her bed. The nurse was a bit abrupt with me – only that. Apart from that, the rest were good because I asked them questions – I asked what medications, what time, what was she fed and all these things because she wasn't eating and everything. So in that experience they were really, really helpful and they were really good people. Absolutely, they were doing their best and they informed me every time – they said you can call any time and I did call and they were really good. Every time I came I asked for a lot to be explained and they told me, and when they could not they even asked the doctor we met and everything.

So how long ago did your daughter first become unwell?

Ten years, I think – 2002.

What was helpful during that time?

The first thing that helped was for me to get the information, obviously. Second, I think, because I have been through the process and I have been with the carer group at GAMH (Glasgow Association for Mental Health). Not that it really was any different – I went to GAMH in the carer group because a friend I have known for a long time asked me to come. But at that point it was not a major need for me because I already had the information I needed, really, for helping my daughter at that time. But even before having any information I was sure I was part of my daughter's recovery – you know, obviously my responsibility, absolutely it was my responsibility to make her better. I was thinking I knew the doctor could help give her medication but the rest of it, in all steps, is my responsibility. So I had to be there for her. Do everything – not the physical, like helping her dress or anything and shoes, but all the things

she went through with the mood like making sure I made jokes and we went out and did other things.

The only bad experience I had as a carer was when you don't have financial help. I had to stop working because we are only two of us so I wanted to be there all the time, and if she was on her own she was not in that state to be on her own. Nobody else offered to be there with her or when she was at home. Anyway, it's not in the system that you can be there twenty-four hours with that person, and if that person doesn't have anybody else you have to be there. So I stopped my business. I was a beautician and then I looked after her. I have given up quite a lot because you have to – because it's important. To take back, I worked between relapses but it wasn't that easy. I changed career many times. In those ten years I have done a lot myself. But in the beginning, when she really was ill and getting better, I was there twenty-four hours at that time. All the time, with her.

So you play a very active role in your daughter's recovery?

Totally, yes. I think everybody has to do that because that person needs somebody. I know people have to work but being a couple of hours on your own when you're anxious in the house must be terrible for that person. It's impossible – even if it is not your child, when you think about other people they should have somebody, in mental illness. In other illness, your mind is okay so you know what you are doing, you can wait, you can do, but this is different. So you really, really, really need somebody there. I played a role in that sense, in that I distracted her a lot from her thoughts and things like that, you know, making sure that she didn't think too much about the illness. All this, I knew how serious it was.

I had to learn quickly. She had nobody else, and I had nobody else here because my family is in France. And the thing is – maybe it is one of your questions, about the stigma and things – that there is a lot of stigma attached to the way Asian families think about mental health. Although we are very modern and we were not brought up in Pakistan or India, we are still Indian and my family still has this difference. Maybe other people have stigma with mental health in this country, but when I was talking about when my daughter had depression, I started like that. I never talked about psychosis as she wasn't even there. So she got mental health – the family said, 'Depression! Take her this and do this'... They do not understand, and maybe I was the same before I knew what happened with my daughter. To this day, even now,

when I say 'mental illness' nobody likes the term. They say, 'No, she's not – she's not mad! Why are you talking about mental illness? She's not mad'. I say she still takes medication, she needs care. 'Oh, you are cocooning her – I'm sure if you let her do what she wants...'. She does whatever she wants, my daughter, she does – and I'm aware that I should not be doing too much for her. When she is well she does a lot and she knows very well, she is very intelligent and everything. When she is well she is fine but she's had a couple of relapses.

So, you mentioned earlier about being aware of the need to not do everything for your daughter and to let her do her own thing. We've done some work before and a lot of people have talked about how difficult it can be to get that balancing act right – when to hold someone and when to give them a gentle push. And particularly difficult for a parent – it must be quite hard?

I am always pushing her – it *is* hard but I am always pushing her to do her own things and participate in the house, and she does, she does a bit of shopping and when she is well she does a little bit. But like everybody else living with their mum or their family when they are children, I think they just get lazy – it's mum's duty to do the dishes. This and that is my duty, to cook and everything. I do ask her, I'm a little bit bossy as well so I like things done properly and maybe she does not care too much. I mean, she does not feel it. We discuss it with the CPN (Community Psychiatric Nurse) and people and I've said she is free to move but, in an Asian context, all my family, even now... Nobody thinks of moving out until they are married. Staying on their own – that's ridiculous. We think, 'What will you do on your own? That's sad!'. So it's not – I will be on my own, she will be on her own, two expenses, she can't work at the moment, we don't see that way. Our way of seeing things, Asian people, is we don't leave the home unless we are married – even boys. Even if they are forty and not married, fifty, they will be staying with their parents and that's normal and that's home. There's no problem really, it's not like we're not independent – nobody's keeping you back or anything but it is just a way of being.

My daughter takes medication really on time, she set up an alarm and everything that way – she manages her illness herself. At the moment, I don't even know what dosage of medication she is on because it has been so long. When she goes to see the doctor, I mean her psychiatric doctor, he says, 'Oh, your mum is not with you because you are better now, you know'. He knows only when she is not and she can't go out on her own and I am with her – if she is anxious, I am with her.

So he uses you almost as a barometer?

Yes, absolutely.

So in terms of your own wellbeing during those ten years, what's been good about that experience and what have been some of the challenges that have come out of it?

I'll start with the challenges: first, when my daughter became ill and I had to leave my job – because that's the very first day I said no and closed the shop. It was a hairdressers but I just stopped. I could not deal with all this and I could not deal with all the paperwork I had to do and I could not deal with my rent and they were sending me red letters and 'Yes, I will pay my electricity'. It's not like I could not manage – I talked to them a couple of times but she was so unwell and I, because I had the shop, did not realise. I could not function, actually – I was doing things for her a lot in the house and then I did not have time to do other things. That wasn't important to me – the important thing was just what I was doing, and I was functioning that way. I did not know that I was in, sort of, a shock state. And I was, I knew I was, for a long time, but I did not know I was, you know – everything went that way. Until everybody was after me and I asked the social for help.

They should tell you because I never asked for any social help before, because I don't know the system in this country and in France I never asked. So I worked and I never knew how to ask for housing benefit or anything, although I knew they were there. In the process they said, 'Why don't you do this and that'. I think, at that time, somebody needs to sit down with you and make sure your financial things are okay. I was struggling. Although I got the financial help like I was unemployed, I had to still finish the business part and show them this and show them that. I did not have time for all this. That's where I needed somebody, some kind of help. I did not know what kind but that's when I needed somebody there to do that bit. You know, the social bit, social worker bit.

So looking back, it would have been good to have someone right at the beginning to say, 'This is what you are entitled to, this is the information you need'.

Yes, now I think they do, they do. Like, 'You're okay?'. They didn't ask me, 'What are you going to do? Did you stop working?' – I just stopped working. Actually, I did not even apply for benefit until maybe two or three months later. I don't

know if I got any backdated or anything – some problem there as well – and sometimes I got something and sometimes I had to pay. I ended up paying a whole year's rent because I neglected to answer the question and nobody could take it out for me. So that was three thousand or six thousand housing benefit, for all the years I had to pay it – it's not a good experience that way. I think having someone explain at the beginning is what we should experience.

The positive things I have learned with recovery is there is always hope, obviously, to see in the person. But knowledge is also very, very important. From the beginning you learn about the illness, about the medication, about how to handle the person, and along the way I met people who helped me. Which is good, you know. That was my positive experience – that you need to learn about it with others. Sometimes this is not there – for example, I went out to a carers' group which I did not like, in a church in Partick or something. I found the crowd was too old and had no interest for me. Although they had sometimes... some speakers sometimes, it was a bit, kind of, very slow. I left it after a few months and was looking for something else, and my Asian friend came and she wanted me to do some more sessions. Although it was not really for me, I think being there supported her and the group. I stayed because the group did not really gel together. It's not a huge group so I felt like, okay, I'll just be here, but I learned plenty because we had the recovery, you know, the WRAP (Wellness Recovery Action Planning) training, and we did a lot over the time. Sometimes I felt like I was wasting my time but I still learned plenty.

Where I learned the most is in the voluntary work I do – that's where I really, really learned. When my daughter was well I looked for something for myself, so to start again I went for some training. I volunteered my skill as a beautician in the Partick Health Centre. We had an annexe open where I used to give the service and learn other things there. I am still with them, still involved with GAMH and all this, and in between I worked with the NHS. Through work in The Annexe[4] I got training in smoking cessation. I did that and got a job with the NHS for a project – ethnic minorities and smoking. So I did that for about a year. Then it was drug and alcohol, so I did work, and I did work other times as well in those ten years but I've learned all the time.

4 A community enterprise in Glasgow, delivering health and wellbeing initiatives.

We've touched on this earlier, but do you consider yourself to have had a recovery journey, in the same way that your daughter is in recovery? Do you think that's appropriate?

Yes, I think it is totally appropriate because – I think I said in the beginning – it's like a bereavement. It's a shock and it's not only physical. Each relapse, each time you are helping and everything, you're not there – it's not like I have an illness but it's like part, like totally part of that thing, that illness. And you have to manage it and you have to do all this because that person has a mental illness. In other illnesses it's okay, that person can manage their illness, but if that person's mind is not there and it is not working the way it should then you have to be there for that person. When she is better I still have to carry on, even now – jokes, and making her laugh and after, it never stops. And your recovery, my recovery is meeting people outside her and doing my own things. And letting her go and do her own things. She goes out a lot with her friends and they go dancing, eating, going to cinema. My daughter also did a good thing after leaving ESTEEM. She met a couple of people there and they got together one day in our place after she invited them, and from there they all went out together. They were all recovering. We weren't using the word 'recovery' at that time but they were all getting better, and in ten years they are still meeting. They still have that group. When my daughter was well she also studied to be teacher – she is a teacher of English as a second language. So she does voluntary work at the moment but she can teach later on now she has got her certificate. She had a relapse after that due to a bereavement in my family – my dad passed away. I don't know if that triggered it or anything but that's what she thinks triggered it and that's what the doctor and everybody thinks. Her mind did not accept his death. For me, recovery is about recovering from the shock of relapses. We have had at least three relapses in ten years: two major relapses and one minor that was caught in time because we got a bit more expert about it.

That's what I was going to ask: would you say that your expertise and your ability to respond to those circumstances have changed as you have become more knowledgeable and aware?

And the system helped in that – like I said, in GAMH we did the WRAP training. My daughter came as well, because it was there and there were other people who were not well there. I think the whole group had experience of some kind of mental health issue except a couple of parents who were there. I think if somebody is not well and if, yourself, you recover from emotion like we went

through, I think we need that as well. And what also helped was when the CPN comes and they do the relapse programme, although she did that with just my daughter. I also asked her to involve me and she did so we talked about it a lot, and also I have to work with my daughter on some things.

So you had to ask to be involved with that?

In the beginning, yes – but after it was a second relapse it was kind of automatic to be involved. In the beginning, I think in 2002, it wasn't really said, except for ESTEEM. I think they started the movement of including the carer. It's good for the carer. I don't know how much the doctors and the CPN need to know about us because it will work, the treatment will still work, but we are 50% involved and then are necessary for the betterment of that person. I know that for sure.

In the very beginning I just assumed that if I needed something I would ask them to involve me. I just asked the doctor, 'I need time with you, I need to assess, I want to talk to you'. I used to ask one doctor here and we talk quite well. I can talk to the new doctor here, although this one is not as approachable.

Do you have a message for people who work in mental health services about the role of family and carers in recovery?

I think they already know nowadays that it is important to include the family in care, because without the family they cannot achieve the result quickly – you know, accelerating the healing process. Families are a necessary part but maybe there are families that are not so close to each other and they have problems, and maybe that is why. But even those families who have never taken interest in their family should speak with somebody in the health service – they should have a bit of counselling themselves and be given all the information they are looking for, even if they are not looking. I was not looking for information about the brain, about medication, and I got it from ESTEEM in the beginning. And I am very grateful about that – that was really good luck for us to be in that. So, they need all this information and they are very, very important in this and need to be taught how to help if they cannot and they are willing to help their children or their family member who is not well. I have no problem – I have positive kind of experience in the help I got. I cannot say, 'I feel bad about this service' except for that social thing – I needed help and didn't know how it could be. I think, the first time, people should think about

the carer and what they are going to do – are they going to manage? What help do they need themselves to help the person? If you take my worries or guide me to do my social thing, applications and things like that, I am a bit more available and less distressed myself. That understanding from the doctor and health service is very important, because the parents could also be in trouble as all of a sudden they have this and they have other problems.

Do you have any messages you would like to convey to other carers or family members about your experiences, your recovery?

Yes – I think, for a start, be there 100% for that person because they need you. To understand and learn. Especially learn about what is happening, all about their illness, about their medication... Go out there and look for help. For example, get involved in anything like I got involved in GAMH. In an Asian context it is actually really needed to understand the need to go out. The person who is treated is not allowed to go out, really. I have a friend who is treated and I know her mother, who talks to me. I ask her, 'How is your daughter?' – 'Uh, she is lazy!', 'She is not doing any effort', 'Oh, she is just, now she is better, she does not think she is better, she is not working, I don't know what to do with her', 'She is not married'... I say, 'My daughter is not married', but they have lost that big chunk of their life and they are not able to function so you can't really blame them. For me it was difficult as well to understand that my daughter wasn't lazy, she was recovering. I still think she is a bit lazy – I tell her, 'You are not participating in the house – you can physically do it'. She does now but I think the parent role is, especially Asian people, the parents' role is to do everything – you are always a child. She is 36 and I still sometimes treat her like a child... Not like a child, but sometimes when I am not on guard, I'll talk to her like 'Do this and not do that'. Then I rectify: 'Well, do what you want'. I am just saying that is not very easy. Because you are a parent and you are looking after that person when they are at that stage, when they are ill, they are like a baby for you and for themselves when they need you so much.

So you think that while being conscious of the extra love and care somebody needs when they are at their most ill, you should be careful to change that for a time to help them?

Yes, and that is difficult sometimes, but she is kind of independent so she is making sure she knows her place as well – she has pushed me away, so I remember to do it, so she helps me not to mother her too much either. But you said just there a very important word: love. Without that there is no

recovery. Absolutely not. That's the first ingredient for me. I had some friends and I still have them, but even last week I was at a carers' meeting with a friend from GAMH. I went there because a person from Stobhill came to talk about the triangle of care and the help and things like that, so I went to listen. I don't always go but I will go once in a while, and this lady was talking about her son and in the past I had also a similar problem. They cannot express love and affection to their children and I say you have to – they need to know, they *so* need to know that and they will recover faster.

My daughter's friend, the one who moved into her place, understood because she saw me all the way. I'm not ashamed of cuddling, kissing and things, and maybe because of my French background I'm a bit more so than here. In Scotland I notice that people don't show affection, not always, but they have to show affection, here and back home. We talk about men sometimes and we say there, if a person passes, going down the street, and men are looking at them and they like them they will turn their head and whistle. Here people will curse you if you do that – it's not done, it is a different culture. And Asian people don't like that, but for me here it is a compliment – for example, if I am in France I feel quite fine about it. 'Oh, yeah, it must be something it looks like – I am this or that, some little bit thing.' So I say you need to show affection to the children – that's what they need the most, you know, especially at that age from twenty-five when they are trying to do their own thing. They feel rejected from the family and wonder, 'What will I do? I have too much responsibility, I am a burden' and all of this. You show them it's not, because you are there for them, that's what I think. That's the way I feel and have always felt, and it's quite natural. It's not a big deal at all. Any other questions?

No, not really; I think you have covered an enormous range of issues and are really inspiring. You're obviously an incredibly supportive, encouraging and empowering person for your daughter.

But I think it is natural. I always think it is very natural or extraordinary, but through all this I have learned a lot. I made so many good friends, I think my life changed in a good way. I don't say if I did not have this I would have been... I would have been a different person but I really met so many beautiful people, nice people. I mean, I have made so many friends – the people I met not only in the hospitals but the parents of people I kept in touch with, four or five of them, all the voluntary sector like The Annexe. By meeting so many people it is so good. I like it and it is good for me.

Chapter 7

Pause for thought

Between Sussex and Scotland, Ruth Chandler, Simon Bradstreet and Mark Hayward

In our introductory section we highlighted two approaches to recovery: medical and person-centred. In medical recovery, we pointed to the importance of symptom reduction and/or containment. In person-centred recovery we pointed to the idea that hope, agency and opportunity are fundamentally important to wellbeing. In this chapter we want to pause for thought about key relationships between hope and hopelessness and positive and negative expectation, and explore how these relate to person-centred recovery and wellbeing for caregivers. In particular, we will look at the way interactions between hopeful and hopeless relationships are influenced by **positive and negative expectations** from the past and how we think about the future for all people in the triangle of care.

These concepts and their relationships to each other are perhaps more complex than we can describe here, and will be different for every person. We are all human beings, subject to a vast range of combinations of emotions: joyful and bleak, mixed and resolved. But we want to suggest that hope has a special *future active* quality when it comes to transforming difficult or hopeless situations in the present. This is particularly relevant for people experiencing mental health difficulties and for services seeking to combat the organisational discrimination associated with negative expectations for people who need support for mental health difficulties. A hopeful orientation towards the journey ahead may also help restore wellbeing for caregivers when negative expectations *from the past* have stacked up. But – and this is crucial – we conclude with the suggestion that, in principle at least, caregivers already bring a level of wellbeing to the activity of caring within the triangle of care. Although the pragmatic case on the ground is often very different, we want to suggest that positive expectations that wellbeing will be maintained within and alongside the activity of caregiving are subtly different in kind from hope for wellbeing in the future. This subtle difference, we suggest, may offer a different orientation towards the question of recovery for caregivers within the triangle of care.

Why is hope important to recovery?

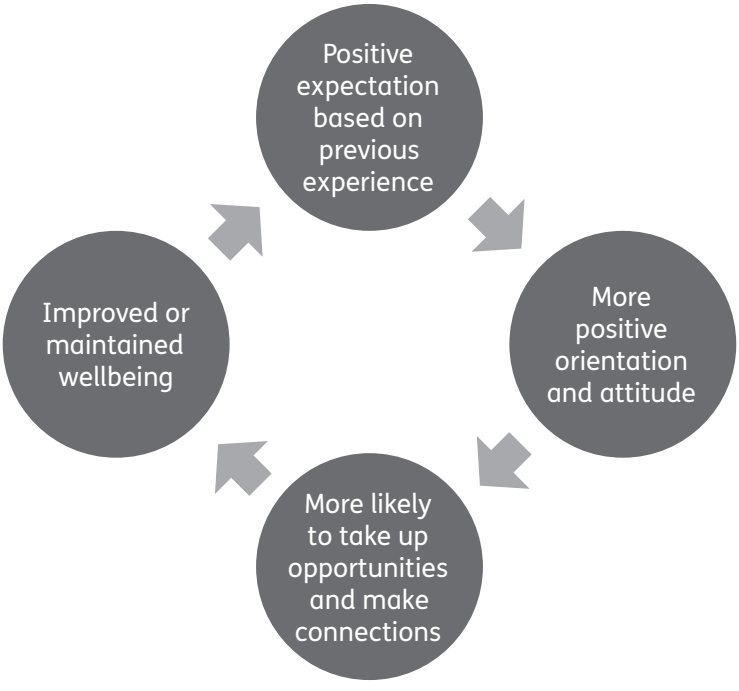
Hope has taken centre stage in personal and social understandings of recovery because, without hope, it is difficult to feel that one can change the current situation or make use of any opportunities to support goals and aspirations. Despite its importance, hope, like recovery, is a difficult concept to pin down. Hope can be for a particular event or occurrence, like winning the lottery. It can also be more general – perhaps a hope for things to improve or be different. Hope is **future-oriented** – you don't hope for something to be different if it is already happening or expected to happen.

Hope is also linked to positive expectation – the belief that a positive outcome is possible. What distinguishes hope from positive expectation is the role of past experience in predicting how likely it is that something positive is going to happen. Ironically, hope is also closely linked to negative expectations from the past. Although this sounds like a contradiction in terms, hope is perhaps most powerful when negative experiences have stacked up, and is closely linked to positive risk-taking. To think about this another way, most people do not expect to win the lottery as the odds look very slim, and most people who play the lottery have more negative experiences of losing their money than positive ones of seeing a return! But the hope of winning structures the everyday actions of millions of people, and may open the door to new possibilities – for example, bumping into a friend on the way to buy a ticket.

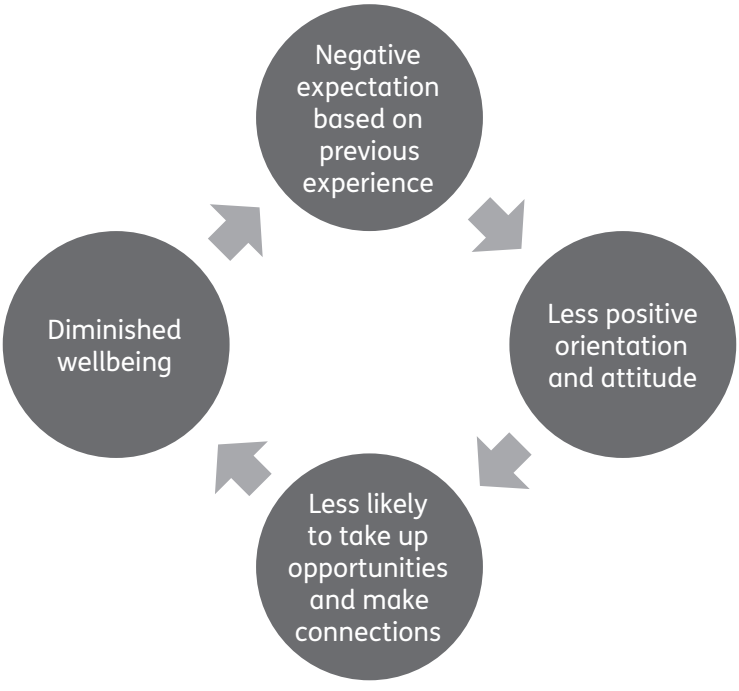
Expectation and wellbeing

How can something as positive as hope be linked to negative expectations? Before we answer that question, let's take a look at how positive expectation supports wellbeing and how negative expectation can undermine it. We base our expectations on how likely we think something is to happen, and this is influenced by past experience. We don't have to hope the sun will rise tomorrow, as past experience suggests that it most probably will – so we *expect* that the sun will rise tomorrow. People whose past experience contains lots of positive experiences are likely to have positive expectations for the future, and these positive expectations are very important for **wellbeing.** Although most positive expectations are not as certain as the sun coming up, they still influence our attitudes towards present actions and decisions. For example, if, from the evidence of past experience, you expect to enjoy spending time with your friends, you are more likely to make an effort to see

them and to feel confident in their company. Having a strong social network is known to support wellbeing, so these positive expectations of meeting with friends create what might be described as a 'virtuous cycle'. People with lots of positive expectations have very little need to hope for things to be different, as life is likely to be quite good as it is.



Negative expectation works in exactly the same way: if a person has had negative past experiences, they are more likely to hold negative expectations about the future. For example, if, on the evidence of past meetings, you expect your attempts at friendship to be rebuffed, you are less likely to make an effort to meet new people or to try and maintain existing networks. In this way, your negative expectations undermine your self-confidence and potentially lead to isolation, with knock-on negative effects on wellbeing. So rather than a 'virtuous cycle' we get a 'vicious cycle', where negative expectations appear to increase the likelihood of negative outcomes. People with lots of negative expectations may feel more hopeless and think it is inevitable that bad things are going to happen or that nothing will change. They are much more in need of hope because life is not fine as it is.



Hope against negative expectation

It is easy to see how a virtuous circle of positive expectation can support wellbeing and how a vicious circle of negative expectation might undermine it. So how is hope different from positive expectation, and how does it relate to negative past experience? It is important to remember that both positive and negative expectations are merely best guesses about how things will be – they are not facts. So it is not inevitable that negative expectations will result in negative outcomes or feelings. However, the build-up of negative expectation can lead to **false certainty** that things can never change or that negative outcomes are inevitable, and this can be very powerful in influencing day-to-day interactions. The belief that a negative outcome is certain is the foundation for feeling hopeless and powerless to change a situation or too frightened to take any risks. Yet expectations are also not fixed. When you have a positive and perhaps unexpected experience that runs counter to previous experiences, this can offer a small window of **hope** that things will be different and that wellbeing is possible. With hope, you are more likely to interpret past events in a better light and look forward more positively as a

result. And the more hope you are able to hold against the vicious cycle of negative expectation, the more likely it is that you will begin to form positive expectations that support the virtuous cycle of wellbeing.

Read the two scenarios below and try the exercise that follows to get a more concrete sense of the power of hope to work against negative expectation.

Scenario 1

Imagine you are in a desert without any water. All you can see are sand dunes in all directions and you've been exposed to the heat for days. All you can hang on to is the hope of rain or reaching an oasis that keeps appearing miraculously on the horizon. Everything you already know about deserts tells you that rain is very unlikely and the oasis is a mirage. What do you do?

Based on the evidence of past experience (what you already know about deserts), your expectations of survival are most likely to be pretty bleak. If, as would seem quite realistic at this point, your negative expectations pass into hopelessness, the range of action and possibility is limited to waiting for the inevitable, which makes it almost certain you will die. If, alternatively, you hope (quite unrealistically at this point) that there really is an oasis beyond the sand dunes, the range of action broadens to include going in search of it. This search may, in turn open wholly unexpected possibilities and opportunities on the way – for example, by going in search of the oasis, you stumble on a nomadic tribe who give you water and lend you a camel to help you find your way out of the desert. Although the oasis never became a reality, a hopeful orientation towards it widened the real possibilities of action, making a positive expectation of life beyond the desert more realistic on the way. While this example is fictional and somewhat far-fetched, a hopeful orientation in everyday life is often about expanding very narrow possibilities into a present window of opportunity. **Hope has the power to break the hold of hopelessness because it looks beyond the false certainties generated by negative expectation.**

Holding hope for the person cared for

Like positive and negative expectation, hope has important knock-on effects on everyday actions. For these kinds of reasons, mental health services are being encouraged to be more conscious of their role in promoting hope and

their potential to remove hope. In support of this, they are encouraged to work alongside people and, if necessary, 'carry' or 'hold' hope at times of greatest distress while setting personal goals and planning achievable ways to realise them. Retaining and conveying hope can be particularly hard for practitioners who work with people who are at their most unwell. If you constantly see people when they are at their lowest ebb, it's not hard to see how an expectation of poor outcomes and unremitting illness might be set. Perhaps this means there is all the more reason for professionals to rotate between different service settings, so they can see people in different stages of recovery.

Scenario 2

Imagine you are a doctor working in an acute ward. All you see on a daily basis are people who are very unwell. Everything you already know about mental health tells you that medical recovery for these people is very unlikely and holding hope is unrealistic. Jane, one of the clients on the ward, tells you she wants to be a doctor. She has reported hearing voices and acting on their guidance. She left school with no qualifications, but her caregiver tells you she was studying to go to university before she became unwell. What do you say to Jane?

A hopeless response

Based on the evidence of your past experience (what you already know about mental health and your own experience, if relevant, of training to be a doctor), you are quite likely to hold a negative expectation about Jane's chances of achieving her goal. You might assume her voice-hearing experiences are negative and think it would be unkind to hold out false hope, so you tell Jane and her caregiver that her aspirations are unrealistic and should not be encouraged. As a result, Jane refuses to get out of bed and is unreceptive to further efforts to talk to her. Jane's caregiver feels discouraged and does not offer you any more information about how to support Jane back to wellbeing.

A more hopeful response

You ask Jane what she needs to do to achieve her goal, and find out from her caregiver what she does at home that might support this and what stands in the way – not getting out of bed, for a start! You ask the caregiver to find

out what community resources are available to support Jane's dream – extra support at the local college, for example. You ask Jane whether her voices are sympathetic to her ambition or whether they get in the way. Jane tells you that the voices tell her to read books, and get cross when she's slacking. You might still think the chances of success are slim, but by holding hope for Jane it is possible to work on small steps towards her goal, like getting up and dressed and aiming to go back to college when she is discharged. As a result, Jane makes an effort to get out of bed and is keen to talk to you. She brings some notes to your next meeting from her recent studies. Jane's caregiver is encouraged and brings in more information to help you and Jane plan her discharge.

Whether Jane eventually becomes a doctor is not really important in this scenario. What matters is that her opportunities are not reduced by negative expectations of her and that unhelpful assumptions are not made about the positive or negative influence of her symptoms on her future wellbeing. Holding hope in the triangle of care means that opportunities to work towards Jane's wellbeing *in partnership with caregivers* can be acted on as real possibilities, whether the dream is realised or not. Returning to the earlier example of the lottery, most people do not expect to win as the odds look very slim but the *hope* of winning opens the door to new possibilities. Although Jane may never become a doctor, supporting her dream in small steps may enable other supports for wellbeing to come into play, e.g. improving social networks by going back to college. Sharing your hope for Jane with her caregiver and valuing her perspective also supports her to hold hope and take the extra step of accessing resources in the community that could help. If there is hope in the triangle of care, people may put in a bit of extra effort and achieve more than they expected. Future expectations may then be less negative, and the likelihood of future success increases as the vicious cycle loses some of its momentum.

Sources of hopelessness for caregivers

Of course, life is rarely as black and white as the situations we have described above. It is hard for all parties to hold hope when negative expectations have stacked up. The challenge of retaining hope for mental health professionals and the people who come into contact with them is further compounded by the language used in mental health services. It's not hard to see how descriptions of 'severe and enduring' illnesses, 'chronic' conditions and

'disordered' personalities can inhibit positive expectations and hope. Because of their intimate knowledge of the negative experiences and fragilities of the people they care for, caregivers can also hold negative expectations and find it difficult to be hopeful or facilitate activities relating to recovery, particularly if they are fearful of the result.

What you don't want is for them to go back to work and then fail...

Caregivers often question themselves about when to push their loved ones to engage in activities and social life and when to draw back. This can be particularly difficult for parents, who have a lifelong responsibility to maintain the safety of their child. In this respect, hope can be linked to positive risk-taking. In the complex business of 'letting go' and supporting loved ones to take risks (in relation to work, social life, medication use, behaviours, independence), caregivers can experience a range of emotions from fear to guilt to pride.

I'm frightened, I'm almost frightened to do anything apart from, you know, go in and try and chat to him – you know, take some soup in.

It is important not to be judgemental when caregivers identify emotions and behaviours that might inhibit positive risk-taking, as these often need to be owned and worked through in order for alternatives to come into play. Caregivers have testified to the difficulty of positive risk-taking, but also discuss how being hopeful and taking the risk to 'let go' can help loved ones respond differently to the world around them. If one holds hope, it can transform a risk that seems to have only negative consequences into an opportunity that has the potential for positive outcomes. The presence of hope in a situation thus plays a pivotal role in creating positive outcomes for people who experience mental health difficulties, even where this is against a backdrop of negative experiences and expectations.

Exercise 2

To understand these issues in a more personal way, please try the following exercise.

Think of a situation that felt hopeless for the person you care for. .....
.....
.....
.....

Why did the situation feel hopeless? Was past negative experience playing an influential role?.....
.....
.....
.....

Were you expecting a negative outcome?.....
.....
.....
.....

What would have been an alternative and more hopeful attitude to take into this situation? .....
.....
.....
.....

Who/what could have helped the situation to feel more hopeful? .....
.....
.....
.....

What outcomes might have resulted from holding a more hopeful attitude?
.....
.....
.....
.....

If you are a mental health worker, please consider these questions in relation to the people you provide care for. Can you think of any examples where working with caregivers might have helped a situation to feel more hopeful?

Supporting hope for caregivers

Where does hope come from? For people using services it frequently comes from other people, as it is difficult to hold hope for yourself if your experience is very negative. However, it is not so clear how caregivers' hope for themselves and the people they care for can be maintained. Holding hope and allowing positive risk-taking to happen can make for a fraught emotional time, and caregivers often need support in order to manage the process of balancing hope and risk for the person they care for. Where the triangle of care is working well, service providers can be a source of much-needed support in holding hope. Where it is not working so well, however, caregivers are especially vulnerable to feelings of hopelessness for themselves as well as the person cared for, as in the non-fictional situation below.

Scenario 3

> *It is still really difficult to express how we were affected by this turn of events. We were, or so we thought, a perfectly normal professional family with four happy, healthy, grown-up youngsters all progressing towards or already into adulthood with stable, secure futures ahead. Then suddenly, like a bolt out of the blue, a severe mental illness struck a member of the family...*
>
> *With my wife approaching retirement I also arranged to retire early. These plans were well advanced when we began to ask what the purpose of this was, as our quality of life at home at this time was really poor.*

In a few short lines, this caregiver describes a life in which his positive expectations of health and happiness are turned upside down, involving a complex interplay between the loss of an anticipated future and an increasingly difficult home life. It seems pointless to retire because the family has started to believe the situation will never change. Nevertheless, despite the initial sense of shock and loss of quality of life, the author describes how, with the arrival of effective support, he finds

> *...some recovery in sharing our experiences with others, and helping those in similar situations to ourselves to realise that there is hope.*

Looking back, the author also reports that this period of hopelessness reflected both the received stigma about mental health and a lack of support

and information in the early days. Although family wellbeing and quality of life were temporarily undermined by hopeless expectations at this time, the author reports that they were subsequently regained and maintained through better information and support, despite ongoing fluctuations in the mental health of their son.

At a personal level, feelings of hopelessness are part of the human condition and it's not unreasonable for caregivers to hold them when negative experience has stacked up. Organisationally, however, this understanding of hope and hopelessness has far-reaching implications for changing the current position of caregivers in the triangle of care. It is easy to see how hopeless expectations could lead to less resource allocation, less support for people who use services and/or less inclusion of caregivers. In *Travelling Hopefully,* Basset takes this line of enquiry further by suggesting that hopeless services are more likely to lead to socially exclusive and unwittingly discriminatory services, as illustrated here:

Organisational hopelessness can be said to have become explicitly discriminatory when negative expectations are overtly attached to more stigmatised diagnoses, often against the evidence. For example, people who experience psychosis or have a diagnosis of personality disorder are perhaps

more likely to experience discrimination by way of hopeless or negative expectations than people who experience anxiety or depression.

Basset also shows that hopeful services lead to more social inclusion and outreach for everyone in the community, caregivers included.

In other words, hopeful services have the power to combat discrimination based on negative expectation, and have every part to play in making the optimal triangle of care a reality for everybody.

Exercise 3

To understand these issues in a more personal way, please repeat the exercise that was used previously – but this time, think about yourself and your wellbeing.

Think of a situation where you felt hopeless for yourself (e.g. 'I can't go on like this', 'Things will never get any better', 'I will never get a break', 'I am never recognised', 'I will never have a life of my own').....
.....
.....

Why did you feel hopeless? Was past negative experience playing an influential role? .....
.....
.....

What did you expect would happen if you put your wellbeing first? .....
.....
.....
.....

If your expectation was negative, what would have been an alternative and more hopeful attitude? .....
.....
.....

Who/what could have helped you to be more hopeful in this situation (e.g. a friend, relative, fellow caregiver, mental health practitioner)?.....
.....
.....
.....

What outcomes might have resulted from holding this more hopeful attitude?
.....
.....
.....

How did you get on with this exercise? It is often difficult for caregivers to put their own wellbeing first, and mental health workers can struggle with it too. If this applies to you, maybe you could ask someone you trust to help you consider the exercise.

Recovery from what?

The approach we have outlined above is a relational one in which hope and hopelessness are part of a spectrum of wellbeing and closely linked to expectation. Like expectation, this understanding of hope is a *belief* about the future that influences the actions taken in the present. It is crucial that what is hoped for is believed to be possible, but hope can still emerge even when the possibility seems very slight. Unlike expectation, hope is oriented beyond

what is believed to be likely, towards imagined possibilities that, like dreams, may not be counted on or even predicted. Everyone has a right to dream and to attempt to realise their imagined futures, no matter how improbable they might seem at the time. For people whose negative expectations have stacked up into hopelessness, hope implies committed action towards possibilities that may present as very unlikely at first but, through small steps, may become positive expectations (or begin to seem more likely) as successive good outcomes stack up.

This returns us to the caregivers' 'Recovery from what?' question. It is entirely appropriate to advocate hope for people who use services, as – bluntly put – there would be no need to use services if levels of wellbeing were already good. However, we also want to suggest that caregivers may start in a different place in relation to wellbeing, which should ideally be something they already have a right to maintain in the triangle of care. As we have shown above, hope is at its most powerful when negative expectations are high. So hope is grounded in adversity – there's no need for hope when things are fine as they are. At an individual level, then, holding hope can be both empowering and difficult for caregivers to do. Yet, as David Harper has recently suggested, it is highly problematic to locate concepts like wellbeing exclusively in individual strength and resilience, as this can implicitly blame those whose wellbeing has been undermined for not being 'tough enough' and deflect focus from social contributors to distress (2012).

The same can be said of hope in person-centred recovery. Without wider social consideration, advocating hope for caregivers can be an insulting suggestion if the weight of their personal experience has been so overwhelmingly negative as to compromise wellbeing. As is evident from the caregivers in this collection, person-centred recovery is frequently a tale of *getting over* interactions that have been based on low or hopeless expectations for the person cared for and/or have not been initially responsive to the hopes and wellbeing of caregivers on their own terms. Should we then be aiming for more than hope as a *corrective* to this legacy of hopelessness and negative expectation? What about supporting caregivers' positive expectations for their own wellbeing early, before they have a chance to be undermined?

We'll revisit these thorny questions in our concluding discussion.

Chapter 8

Every pebble counts

In Sussex, Anon

Recovery is not the word I recognise when it is used in mental health practice, and it stretches the point even further when considered from a carer's perspective. To me, recovery is to get something back again after a temporary loss. It is also linked with the wellbeing of the person you support. Relationships are built on desires and needs, common goals and working together to achieve them, giving freely and sharing. What happens when one person loses their way through ill health? We become individuals performing a dance with each other, trying to find some form of balance. Sometimes we can participate as equals but usually the carer is the one giving, working within a process that does not always recognise us as people or support us in times of need.

Sometimes others around you do not see the tears behind the smile or the pain in your life; this leads to further isolation and, potentially, a downward spiral. Questions about how you are will often be posed while you are in the presence of the one you support. How can you give an honest answer about your feelings without destroying them? Can you bear the pain, or should you be so brave as to say 'I can't cope'? Watch them physically shrink before your eyes as another person says they have given up on them and can freely give no more. Why, if professionals really care, do they ask the question at that time – is it more a signal of *not* caring or understanding than an offer of support?

From a personal perspective, I give support 168 hours a week or 8,760 a year. What about the professional support? At best, when the service user is in the community, it comes out at maybe an hour or two a week. We do not have an evening or weekend off. Respite is dangled in front of you in words but it fails to become a reality. On the rare occasions it is available, it usually has a prohibitive cost.

To start to get some understanding of life it has to be redesigned, considered from a fresh perspective and fought for. It requires a lot of hard work and inner

strength to achieve this. It often means foregoing parts of your life that may once have been very special to you, which can cause an inner conflict as you struggle to come to terms with the loss of the person you once knew while seeking a new ideal. To seek out something that offers you a remote glimpse of hope for the future is a struggle and a long process.

The beginning

As it is not something that stands alone for me as an individual I do need to start at the beginning and work my way through our joint journey of discovery, what happened and how I survived the process to the present day. It has been a journey of much pain, hardship, anger, frustration and guilt but also laughter and enlightenment.

My life as a carer has been a period of over 11 years. It's not a title I asked for or one I believe to be appropriate but it is one the system usually recognises and even occasionally does something about. Once you have this piece of information you can start to learn what it means to you and others around you. As an individual, it's something I found I liked and then hated; like so many parts of the journey, it takes a long time to get things understood. I now know it's a badge I must wear sometimes to get a response to a need or recognition that I am either part of the problem or a potential part of the cure. There it is again, 'cure' – another word, but something that is needed for a true recovery in my eyes. Even if the person I support regains what they lost (true recovery in my eyes) and then decides they no longer want it and moves on to something else.

Digression – always one of my failings (note to self: don't see it as a failing, there are enough of those anyway – and so we're back to guilt again). My mind rambles sometimes, which gives a sense of freedom but also one of a lack of control. Is this a good or a bad thing?

My journey started with a wife, Bluebird, becoming unwell. Not an illness I understood, and that in itself was a learning curve. Much frustration with her for not helping herself, anger because everything depended on me and nobody helped, fear because there was no control over what was happening and desolation because the important parts of life were being torn violently away. The loss was something I could see for my own part but it was harder to understand what it meant for her as she seemed not to care. Time has taught me that her loss was as great as mine, although at the start of the depression

she was so withdrawn that days would pass without any acknowledgement from her that life existed.

The first grasp for some control

The doorbell rang and I opened the door. The stranger asked, 'Does Bluebird live here?'
'Yes,' I replied.
'Is there anyone else at home at the moment?'
'No,' I replied.
'I'm going to have to ask you to go out because I need to talk to her,' said the stranger.

I shut the door firmly and leant against the inside of it. Anger and fear boiled up inside me and tears welled up in my eyes. Anger because I felt battered and bruised and above all useless, fear because the action I had just taken could remove what little help there was and leave me totally alone to deal with the situation. I felt my hands tremble and took a deep breath. The bastards were not going to beat me into submission. Bluebird deserved better than this.

I opened the door again. He stood there looking bewildered; I sensed a spark of pleasure inside me, a small feeling of warmth. There was also a small bit of guilt because I had possibly hurt another human being, but overall it was good to feel that I had some control again.

I said, 'I'm Morris. And you are...?'
He still looked bewildered, lost – like a little boy who'd done something wrong and didn't know how to get out of trouble. Then he suddenly recovered and sprung to life. 'I'm Dr. _____.'

I invited him in and offered him a drink, which he declined. I asked if we could have a few moments when he'd finished as I had some questions to ask, then led him through to Bluebird. I left him to talk to her while I continued with my work.

I was lucky in one sense that my work meant periods of time at home, where I could try and support Bluebird while also maintaining employment. The downside was that it also involved travel throughout the UK and parts of

Europe, and this often meant being away from home for a week or more at a time. The need to balance being at work and being at home often led to extended days: it was common practice for me to leave her and the children behind early in the morning, drive to a customer site, spend the day there and return in the evening. Glasgow could even become a day trip.

Hearing the door close with a quiet click, I got up and walked quickly from the study to the hallway. There was silence in the lounge, so I gently opened the door; only Bluebird was there. Turning and opening the front door, I saw the doctor disappearing at a rate of knots along the pavement and getting into his car. So much for gaining a bit of control! What about that chance to talk to him I'd asked for? What was going to happen, how was she going to get better, what could I do to help! A glimmer of hope had gone in an instant, and now it was back to the isolation and loneliness. Life was once more this strange existence, my new so-called normality. All I had found so far was some information on the internet, which seemed to be full of contradictions.

I walked into the lounge and sat down. Experience had taught me that if I came in and asked a question straight away it was likely to result in a very pained expression from Bluebird, and that she would not hear the question but appear to struggle to find out why I was there – almost as though she didn't know who I was. We sat in silence for a bit. I asked how she felt and how she had got on with the doctor. It was a slow response: he seemed nice, we chatted, I can't remember what about but I think I have to call him or someone to get another appointment.

This was one of the early situations where I tried to bring some control to a process that did not seem to see me as an individual with my own rights. I have learned a lot since those early days and can now see why this situation ended the way it did, as well as the part I played in allowing it to happen. Time has taught me to understand that it would have worked better if I had seen the doctor first. The fact that he needed to see Bluebird would have given me a bit of leverage, as without me showing him where she was he wouldn't have got the access he needed. I also understand now that, for the most part, it is the care coordinator, CPN or other support worker who's more able to give up-to-date information on how the patient is and the general plans, if any, for helping them move forward. Building a relationship with these people will take time, and it is unlikely to happen if you (rightly or wrongly) have a go at them for what has happened or is happening. In my experience they generally have far too big a caseload to work as effectively as they'd like and are usually

fighting the system just as you are. Give them time to decide whether you are part of the cure or part of the problem. Remember that they are human beings too.

Being linked to the expectations of the person you are supporting means that there is a constant process of readjusting your own. Flexibility is something you'll need to learn. Just because something worked out one way a month or even a day ago doesn't mean you should expect the same result tomorrow. Bluebird can quite often get a fixation about something – a diet, a garden design course or all the books by a particular author, for example. This will give you a momentary glimmer of light at the end of the tunnel, only for you to find it's the express train coming at you. It takes a lot of skill to be able to support an interest with enthusiasm while at the same time getting ready for it to potentially crumble and become of no significance to the cared for at all. Quite often the support team (if you have the luxury of one) will be behind this wholeheartedly, also looking at the potentially short-lived enthusiasm and seeing, as you do, someone you love looking closer to happiness than you may have seen them for a long time. Unfortunately they're not the ones who have to pick up the pieces financially (it's usually something costly that catches Bluebird's eye) but, like everything else on the journey, it's about learning on the job by your own mistakes. If you can build a relationship with the team, you may have a bit more influence on how things go and it might save a bit of the expense and heartache.

Mental wellbeing

A crossword or Sudoku puzzle can become a huge thing. Succeeding and solving the puzzle makes you feel good – you've won, you are a winner – and the challenge gives you something to focus on. It takes your mind to a place of freedom and respite. You can get there easily; no walking out of the house, no questions over where you are going or when you'll be back. A part of the survival toolkit, like a book taken in with you to A&E to fill out the long wait with a semi-comatose cared for. On a good day, not solving the puzzle is usually okay. On a bad day it can plunge you further into the black hole. Can't even do a simple puzzle! What use are you?

I nearly deleted this piece just now. I read through what I'd done and decided it was a rant. What use is a rant in a piece of work designed to help others to either understand or recover themselves? But I must have learned something

during this process, because I didn't go with the snap decision; I saved it and waited before coming back to it on a better day. Make a much more reasoned judgement. I'm lucky it's still here. It's still the default for me to jump to a decision quicker than I should. Bluebird is not the only one to have changed; my life was always about measured decisions, what's the best angle and how to get to the end goal in the best way. That was back when I had a degree of control over my world and some confidence. When I had a partner at my side, supporting me as I supported her. When life was about some degree of freedom and choice over what happened.

Back to the Sudoku, let's look at this again. Can't do a puzzle so you're a failure? It's something of an overstatement but in the cold light of day, with emotions running around the racetrack of your brain, you can't see the stupidity in it. Learning that this is one of the symptoms of your own illness means you can try and do something about it. Depression hits a lot of people who are carers – not just those who look after people with mental health problems but people from the whole spectrum of caring. Don't forget that there's a lot of it about, and it doesn't take long to find another carer who is also on antidepressants or getting (if they're lucky) some talking therapy support to help them with it. It's not a sign of failure, in fact it's the opposite: you're starting to put together the toolkit that will help you stay as well as you can. It's only when you are in a good place that you can help your cared for. That shouldn't be your ONLY reason for looking after yourself, though – you are, after all, a person in your own right, and are entitled to as much good in your life as you can get as long as it's not at someone else's expense. A good maxim is 'self first with due consideration for others'. Don't expect your cared for to understand this, but it's not that they don't care. It's that their illness doesn't.

A sample of life

Today has been about cooking and misunderstandings; how do we end up like this? A simple discussion about who was going to cook and it's blown up out of all proportion. I was going to do it but then there was a phone call and I was off to my mother's. She's in her eighties now and has been a widow for over ten years. She's had issues with pain for a long time, going back to the days of being a teenager and having an accident. Recently, though, it's been getting worse, and after a lot of doctor's appointments a stage has been reached where a medication without too many side effects may have been

found. She does have trouble swallowing tablets but seems to be coping. Now I've found out she's going to run out earlier than I thought, but I can borrow a couple from Bluebird (for once, a bit of luck that they both have the same medication but for different reasons). I can put the repeat prescription request into the doctor's on the way. It should just about get the prescription into the pharmacy in time for me to pick it up before they close tomorrow and get the tablets to her for tomorrow night's dose. I'm sure having only two instead of three for one evening won't cause a problem.

Anyway, job done but I upset my mother by not stopping for tea and a chat because I needed to get back to cook dinner. When I got home I found Bluebird part-way through two different meals; she had started on one but then found she didn't have everything she needed for it, so started on something else. As soon as I came in the door I knew it was going to be a volatile situation. 'Why didn't you tell me what we were going to have tonight before you left?' 'It's on the white board, like I said.' What an idiot! She'd forgotten that we'd written up the menu for the week as a prompt for her, but I shouldn't have mentioned it – now she was blaming herself for not remembering. I'd been thinking about my mother and how little time I get with her. How much longer with her do I have? Another guilt trip, and as a result I'd taken my eye off the ball. It took the rest of the evening to settle things down a bit, and even then I knew that, under the surface, Bluebird was still upset.

Material support – retail therapy

Books, books and yet more books but no getting on and doing. Dragging heels, lost, lost, lost! (Just a friendly rant to myself – a few thoughts running about the way life can go...) Books were indeed a fixation for a while, being bought faster than they could be read. I'm sure many were never even opened and just went directly to the bookcases, shelves and cupboards, and they piled up on the floor in many other places. To make life easier I had moved a lot of my books off the shelves and packed them away to make some space for a while. I didn't think this phase would last for long and I wasn't wrong, but it made sense to stand back and let it run its course. Somewhere in the fug of depression the message hadn't been taken in correctly and she'd decided I was going get rid of my books because I didn't want them, so there was space for more books. What I had done had exacerbated the problem – with good intent, but I had made the situation worse for myself. In charity shops,

at car boot sales and various other places, books kept appearing. A few times a duplicate copy would arrive – if this was questioned it caused upset ('One might get spoiled, so I have a spare now just in case').

I was beginning to learn how the game needed to be played. Let it run its course. Standing back and trying to look at it as an outsider, I could see the books being almost stroked as they were moved from one place to another. There seemed to be a peace and serenity about it all. I never did understand it and still don't today but it did something for her. Many of these must-have books are gone and forgotten now ('Where did this come from?'). This is now something Bluebird won't even remember, and to be told of it would only cause her pain as it's not how she would act normally. When well, she is a very considerate, kind and caring person. It's the illness that makes the changes. The book-collecting is still there, though now with much more control and meaning. It's a part of her life that has grown in importance, but there is much more of a selection process and a good number of books are read and passed on to the charity shops.

Cutting this short as I'm about to be pestered again. I know it's not meant as pestering but that's how it feels – it's like a lost lamb checking all the mothers in the field, looking for its own.

Free time to do something at home without a figure appearing and asking questions, always looking for reassurance, that's one of the things I miss. I usually find it by working with the problem rather than fighting it as I used to. She sleeps more than me so it's either stay up late or get up early and do whatever needs my full concentration. Easy to say but not always so easy to do, as if she wakes up and finds I'm away from her side it sparks an anxiety session that means I get watched and followed more closely for the next few days.

Knowledge

Gaining knowledge of the illness helps, but finding a reliable, trustworthy source is difficult. Other carers are a good source of information but beware: they may be in a worse place than you, and you may come away feeling worse for the experience rather than better.

After nearly three years I became aware of a local carers' support group. This met once a month, very close to where I live. Sharing my thoughts and feelings with people in a similar situation helped me a lot. It took a few sessions for me to find my feet, open up and talk. I still remember the first time I said I hated the person I cared for but loved them at the same time, and how I was confused by this and felt guilty because of my thoughts. The person next to me asked how long I'd felt like this. To my response of 'Most of this year' he said, 'You lasted a lot longer than me before you got there – it only took me the first six months of it before I felt like that'. The meeting helped me come to terms with how I felt, and I soon saw that my feelings were seen as 'normal'. Other people talked of the behaviour of their cared for in a way that made it seem like normal, reasonable behaviour. A few years ago I would have thought this very odd but it gave me the space I needed to talk to people who could understand the life I was living; my turmoil was their normality. Just being able to sound off and release a bit of tension was helpful, and there was so much free advice on how to make my life better.

This is an important message – when you're caring, everyone's focus is on the person who's ill, so you as an individual can get lost and cease to be a person with the right to a life of your own. You are so busy keeping the world on an even keel that you forget to look after yourself. Do you ever have the time? It's a difficult concept to get your head around at the start, but unless you look after yourself you won't be in a fit state to help anyone else.

Balance in the relationship is important. It may be that there is a need for change, but there must always be a balance of needs. The carer cannot become secondary to all that is going on. For some, the only way to cope with that is to leave.

Leaving is something I've thought about many times, and it's not always been clear in my head whether it's guilt about going or my feelings for Bluebird that have kept me here. At times, all that has kept me here has been the thought that I cannot pass on my caring role to the children. That just wouldn't be fair – they never asked to be brought into this world so I would not pass the burden on to them. As time has progressed, the appeal of walking out has lessened, but the idea has never left me. I can now honestly say that my staying *is* more about my feelings for Bluebird than what my family, friends and society at large would think of me for going or the impact on my children if I did.

It's a question of stability, but how do you achieve this magical state when both you and your cared for are bouncing about between extreme highs and lows? Add to this the effect of people around you and the pressure of working, paying the mortgage and all the other bills and keeping up with the rest of life and it's bloody hard.

Experience has taught me to try and live in the long-term rather than the instant of now, but once again that's easier said than done. When you've worked hard to resolve a situation but all the cared for does is point out the flaw in your solution or bring up another problem, it's not easy to step back and build up some positive feeling about your achievement. Banking good stuff is helpful for me. I try to remember the good bits that have happened, writing them down in case I forget – things like the 'Thank you' I got five days ago for putting up some metal stakes to hold up the side of a raised bed for a potential fruit cage that may never happen because Bluebird forgets about it, or finds another project that is more interesting. All the hard-earned money spent on things that suddenly ceased to be important – money that could have been used for things *I* saw as important, or foregone altogether so I wouldn't have had to spend so much time working for it – just disappears. She'll say, 'Well, you spend some money on what *you* would like'; the comprehension that that would means working even harder to get even more money never even comes close to sinking in. This is a good example of how the good bits get lost. I did get a thank you, there was some short-lived temporary recognition that I'd done something for her and I did get a hand-squeeze and a hug. A bit more learning: if you do something for someone it is reasonable to expect them to respond in a positive way and give something in return, but carers can't always afford to think like this. It's nice to receive thanks but I needed to learn that anything I do for Bluebird has to be because it's what I want to do. If I do things looking for something back in return then I am expecting too much.

Doing something for yourself

Tomorrow I'm going out to meet a friend, a fellow carer. We're meeting as friends, not carers, and although part of our time will be spent talking about our caring roles and how our lives have been it will be much more about us as people, enjoying the garden we're visiting and a shared lunch. The caring bit will soon disappear as we both enjoy the companionship. I won't feel guilty about not attending another review of medication and what progress

has or hasn't been happening. I've done my bit and made a few notes for the professionals to consider. I've made it clear what I feel is needed and it's up to Bluebird (if she agrees with my thoughts) to fight for what she wants today, not me. I can't do it all and it's not right for me to try to. It's good for her to do what she can for herself and take as much control of her own life as possible. This is as important for me as it is for her.

Finding a way that works for us

This is a real jumble of thoughts, ideas and suggestions, which in many ways reflects the life I live. Trying to force what is happening into a tightly controlled style of life doesn't work. I get tired and worn down very quickly if I try to make life work in an ordered and controlled manner. Mental health doesn't fit into patterns, at least not for us. I mustn't lose sight of the 'us' because we can only move forward by working together.

The sometimes-erratic behaviour of one of us means that the other has had to fit in with what is happening. Sometimes life is like pushing a huge rock uphill: once you get the momentum going it's easier. Every now and then the rock gets harder to push and your instinct is to try and keep the motion going, but it's not always the best thing to do. Sometimes you have to stop, walk around the rock and look to see if something is stopping you from moving it forward. To do this, you need something to stop the rock from rolling backwards; a small pebble is often all you need. It might only be a small pebble, but it's enough to stop the rock from moving. Walk around the rock, study what is blocking it and then move it, but only when you understand what it is that you're moving. Why? Because it might be there for a reason, or it might only be another small pebble, or it might be that you are going in the wrong direction altogether. It could be that the small pebble is the one thing that will be there to stop the rock rolling backwards when you next need a rest. It might be better to push the rock around the pebble and leave it there.

What does all this mean? For me it's a picture in my mind of what I'm doing (yes, I have a strange mind). To manage life you need a strategy, and your strategy has to include the person you support. Sometimes the rock of life – i.e. responsibilities like work, cooking, cleaning and everything else – needs to be put on hold, and the small pebble behind the rock is there to help. It gives you a chance to walk around the rock and see what is in front of you. The small pebble might be a chat with a friend, a carers' group meeting, a walk along the

seafront or a bar of chocolate. All of us need to build up as much support as we can from what's available; sometimes it only needs to be a small pebble. The small pebble in front of the rock is what's holding up the person you are supporting, so removing it might not be the best thing to do. You might discard something that's important for them. Losing it might mean that the support you both need won't be there in the future.

Don't lose sight of the fact that your cared for is also pushing a big rock and that the small pebble might be there for them. When you stand in front of the rock, try to have the one you support there with you. Ask them what they see; their perspective as to what you should do next might be very different from yours. This is part of a business meeting (more on this later) and it gives you the chance to find out if you are pushing the rock in the right direction. Remember, it's hard pushing it uphill but to manage a reverse action and move it downhill is another matter. Planning where you need to go and keeping things flowing freely... well, I'll leave that for you to ponder. While on the subject of the rock, remember that you sometimes, maybe only on rare occasions, have the option to ask the cared for to hold the rock for a short time while you get your breath back; they might feel helpless, but don't make them feel useless.

Standing in front of the rock does give you a better view. Sometimes Bluebird and I do that individually, sometimes we do it together. Both approaches are important. It helps each of us to try and get some forward planning in place and think about where we might like to push the rock. Sometimes we both need to put a small pebble behind it and walk forward without the burden to get a better view of the future. Maybe, in this case, the small pebble is a day out with simple rules like no talk of work, health issues, money or any other problem. Just enjoy the moment, or at least try to.

Collect the pebbles and understand them. Use them like a bit of spare cash under the mattress and pull them out in times of need. Just don't hoard too many of them or the mattress will get lumpy and you won't sleep well.

A business meeting

I'm lucky in that although my cared for may not always have a good memory of what has happened in the short term there is a degree of understanding, so it's possible for us to try and make plans for what we might like, discuss how

things are going for each of us and try to resolve any challenges we might have. We try to approach this like a business meeting. We set aside some time to talk to each other; no blame is given, just free expression of how we feel. What might be a challenge for her and what might be a challenge for me. We have an agenda of sorts – easy things like what food we might have that week, who is going to cook it and on what days we might share the cooking, a review of what we have in the freezer for emergencies if I get home late and she doesn't feel like cooking and what jobs have what priority for each of us. I'm always the last one to think the bathroom needs cleaning and she's always the last to think of putting the wheelie bin out for collection; understanding something as basic as this helps us to understand that we are both doing things for each other, that it is two-way traffic. After our planning session we write up what we are doing and when on a whiteboard, including the menu for the week and our shopping needs. By the end of the week a lot will have changed but some of it will have happened, and although things never work out as we planned we are at least starting from the same point with a feeling of shared existence.

Bluebird says that having a plan for the week helps to remind her of what is happening and what she wanted out of the week. This doesn't always work, of course – it all depends on how well she is at the time. But it is a common start point. We both understand that we are both pushing rocks and need to respect each other for the work we are putting in. By planning, we can each learn about what the other needs and what they identify as a support. This goes back to not discarding the small pebble without understanding what it does; we can easily see the possibility of getting comfort from a teddy bear, but a picture of a cactus? Get real.

Some of my pebbles

I have built up a good reserve of special moments. Some are written down and some are in my mind. Pictures of good days out when we have both been able to put a pebble behind the rock. I allow myself to wallow in self-pity and tears if I want to –why not, it's my life – or to lose myself in distraction, laughter. I give myself permission to get things wrong and learn from them *and* to get things wrong, not remember and repeat the same mistakes. Why feel bad about feeling guilty? Try a bit of objectivity. If someone else made a mistake and got something wrong, how would I judge them? Most likely I wouldn't dwell on it for long.

Keeping well strategies are a great help. Keeping physically busy, keeping up what social life I can. All of these things help me keep well.

Every now and then, to add a bit more interest to life, the services that are there to support our loved ones lose their way and do some bizarre things. They all have policies about what they do and how they do it. But many of these policies are developed with the involvement of service users and carers, to try and achieve the utopia we are all looking for and make the process work well with good outcomes for all.

Getting involved

Occasionally a spanner gets thrown in the works and we're the ones who have to pick up the pieces. The resultant damage can vary from a slight bit of upset for the service user to complete devastation lasting many weeks or even months that takes us a long time to repair. Among the examples in our lives has been the loss of the local CMHC (Community Mental Health Centre) when it changed to an older people's service that excluded those of working age. A period of consultation was declared and promises were made ('We'll arrange for meetings to take place locally so you can avoid travel') and then promptly forgotten.

N.B. for the uninitiated to this sport: there is very rarely an option to say, 'No thank you, let's leave it as it is'. The options given come from the service provider and are usually derived from a national organisation such as the Mental Health Development Unit or the Royal College of Psychiatrists. Little thought is given to the application of these ideas in widely varying communities, or to the context in which they were first developed. Typically, what might happen is that an idea is conceived in a major city about the number of Community Mental Health Centres that are needed per head of population. This is then applied to a very rural community where a visit to a meeting is not a five minute bus ride away but a journey of 40 or 50 miles. Another scenario will be a comparison between the numbers of inpatient beds in two areas. From this, a conclusion is reached that area A has X beds and area B has Y beds, so area B has a surplus of capacity. Consideration to what area A may have in the provision of other services that enable this to work effectively is left out of the planning, thus distorting the result of any decision.

It is nonetheless important to get involved and follow the process, speak out at every opportunity and make sure you have a copy in writing of any promises made, especially those that affect you or your cared for directly. The direct benefit to me has been an understanding of how the jigsaw of service provision fits together, and who to call (and when) to get problems resolved quickly.

Bereavement

In amongst all the other emotions there is still a feeling of loss. This other person in my life is still basically the same but also very different at the same time. The values, intentions and desires we once shared have gone for one of us and been replaced with others (or, in some cases, nothing), creating extreme differences. This raises all sorts of doubts: were they ever really shared, or was it all just an attempt at appeasement by Bluebird? Was it the effort of maintaining this front that has caused all the problems? Should I cast aside what I've enjoyed and wanted for all of our lives together and look for something different? I have searched for a replacement life with new ideas and fresh challenges, but somehow it's doesn't quite hit the spot for me. It has left me with an empty hole inside. This hole is a vacuum which I sometimes feel is going to make me implode. I think this is the next stage of my learning, and I will try to use the knowledge I have picked up on the journey so far to guide and support me. I will try to be objective and realistic about what I do and how I do it. But it still scares me and often leaves me tearful if I think about it for too long.

The future

I still don't have the courage to even start to consider this, it's too much to even contemplate working on... But maybe, just maybe, life's like that for everyone: the unknown has always been the biggest part of it.

Writing this has been very hard, a strong and at times relentless reminder of the fragility of the whole situation and me in particular. I have tried to use it to focus on my wellbeing and keep myself well with the skills I have picked up on the journey. I am aware that with the passing of each day a bit of the future becomes a piece of the past, but it doesn't feel as good as it used to – quite often it's more like a day-by-day record of survival. I hope that, one day, 'recovery' will become a reality instead of a dream.

Chapter 9

Recovery – or simply acceptance?

In Scotland, Jennifer Robertson

Diary of Despair

When I first started writing about my daughter's – and our family's – experience of schizophrenia, I called my anguished outpourings *Diary of Despair.* This was 1991. Elaine (not her real name), whom a friend remembered as a child always 'wreathed in smiles', was now 20 but had spent the last 18 months in a state of withdrawal, opting out of studies and all her usual activities and spending long hours in bed. Another friend said, 'It will pass. She's too beautiful to be sad.'

But it didn't pass. We didn't understand what was happening. I felt I had to do something, and putting words onto a computer screen seemed the only way.

Don't think I didn't endlessly phone so-called experts, healthcare people, doctors, psychiatrists and consultants. I did. I phoned, was put on hold and waited, with minutes ticking away and phone bills mounting up, only to be told, 'Mrs Robertson, your daughter knows where to come for help' – or, to put this evasive answer more bluntly, 'Back off!'.

Here's an example of a letter I sent to the GP in January 1991.

'On Monday evening I was invited to a support group for a few parents whose children are causing heartache. However, the other children were all 14-16. My daughter is 20. I felt thankful that we haven't experienced the anti-social behaviour of these children but I also felt that Elaine appears more sick than these disturbed kids, in her second year of almost total inactivity. The other families were also receiving a large amount of social work and psychiatric help.

'Last winter (1989-90), when she first shut herself away, I sat with her for hours, brought her meals, listened to her hurts and tried to understand. I initiated things for her to do and tried, when she started to express violence

against me, to absorb this, thinking it would be better to encourage her in every outward-turning activity than to see her turn that anger inwards and hurt herself even more,. But I'm punch-drunk now and simply cannot see the way forward out of this total paralysis of bed, highly negative Bible reading and despair. There are nights when she weeps uncontrollably, howling until 3 am.'

The revolving door

Not long after this letter, a neighbour phoned our GP and said, 'This family is falling apart, you've got to do something'. An appointment was made for Elaine to see a psychiatrist with a view to being admitted for inpatient treatment – we'd already undergone weeks and months of so-called 'family therapy' on an outpatient basis, as the doctors had decided that Elaine was suffering from a maturation problem. Not mental illness, in other words; just a failure to move out of adolescence and a retreat to an earlier, angry childhood. Complete nonsense, as it turned out. So we wasted professional time as well as our own, Elaine got no better and life lurched into a downward spiral with anger, tears and wrist-cutting.

With every other illness we say speedy diagnosis + speedy treatment = better outcome. The same applies to mental illness but, tragically, nobody wanted to know.

So, inpatient treatment seemed the only thing.

I was in another hospital having a hysterectomy. My husband came to see me and told me, 'I'm taking her to the Royal Ed[5] this afternoon. She's to see a psychiatrist. They're going to admit her.'

So I lay there, just a few hours post-op and still strung up with drips and tubes, worrying but feeling thankful that something was being done at last.

Was it heck. At 4.30 that afternoon she appeared beside my bed. 'Hullo Mum!' 'Elaine! What are you doing here? Dad told me you had an appointment at the hospital.'

[5] Royal Edinburgh Psychiatric Hospital.

'Oh, yes,' she smiled. 'I went but they didn't admit me. The doctor said, "This is the loony bin. It's no place for someone like you".'

I stared at her, trying to take this in. Was that really what the doctor had said? Surely not... *She's done a bunk*, I thought. She didn't stay very long and I lay in that hospital bed sick with worry, imagining that she'd run away from the mental hospital and was sleeping rough somewhere.

Ten days later another appointment was made. Her dad took her once again and this time she saw a more experienced psychiatrist who used similar language but persuaded her to stay in. A few weeks later I went with my husband to see this man. We waited for him in a dingy room at the Royal Ed, some sort of classroom by the look of it. He appeared after what seemed a long, nail-biting wait, sat down and said a lot of things, none of which we were able to absorb apart from the terrible words 'Your daughter is very unwell, and may never live a normal life'.

Twenty-one years later I have not recovered from those words, or from that appalling interview (if it can be called that), for we were given no input, no information, no advice and certainly no offer of support. All I can remember is that I was nonplussed. *'Very unwell...'*

What did that mean? Yes, well, we know there's something wrong, but this is a hospital, after all – you're the doctor, you're supposed to be making her better, aren't you? If only! As for 'never live a normal life', that was too awful to even begin to take in – sadly prophetic though it has proved to be.

Although it is well known that bad news takes time to sink in and requires some sort of follow-up, we were offered nothing. Nothing at all. Not even a leaflet, let alone a follow-up appointment to talk through the implications of this illness. It is also well known that families are deeply involved in mental illness and have to learn to keep calm and unemotional, yet we were offered no advice about how to cope with our daughter's illness. And when she came out of hospital the only treatment given was tablets (Stelazine), which she refused to take. She got more and more ill, depressed, angry, isolated and withdrawn. I remember I once crushed these tablets and dissolved them in her drinking chocolate. I felt like some kind of Nazi, giving her medication without her consent, but when I took the half-drunk mug away I found the tablets at the bottom, undissolved and unabsorbed.

So much wasted energy. So much despair!

It took me six months before I could use the word 'schizophrenia' about my daughter. I looked up the phone number of the National Schizophrenia Fellowship and found their address in Shandwick Place (as it was at that time). My courage was evaporating by the time I got there, knowing full well that this visit would not bring a cure for my daughter. To my dismay I found that I had to speak through an intercom system in an alley between two shops., 'You don't know me,' I said to an unknown person upstairs, my voice breaking, 'but my daughter has schizophrenia'. 'Come on up, we're on the third floor.' So with a heavy heart I made my way up to the third floor, met people in an office and was given leaflets and a book called *Living with Schizophrenia*. I read the book from cover to cover, looking for light. Light?

For the next ten or twelve years we all went through the 'revolving door', with Elaine being admitted to hospital, pepped up with medication and then sent home, only to become ill and be sent back in again. For a good couple of years at the outset of this endless nightmare I was aware that there were people called Community Psychiatric Nurses who could administer medication to patients at home, but we were never offered one – and whenever we asked, we were told there were none in our area.

My husband and myself have a long-term commitment to Russia and had already made plans to uproot and go there. Everyone assured us that Elaine would progress better with us out of the way. So we went, but only for six weeks at first. We settled (or so we thought) our daughter in a flat with a very stable, kind female student but things were awful, and on our return I immediately went off to see the consultant – a different person this time. He said, 'We'll go for the jugular'. By which he meant, admit Elaine to hospital under a Section (i.e. compulsorily) for three months.

Elaine came to live with us in our temporary flat while we waited with dread and expectation to hear from the hospital. Christmas came and went. She was so withdrawn she literally didn't speak, just made little noises in her throat. She ate only with one hand, pushing the food around the plate and leaving most of it. If she ran a bath I had to check she'd put the plug in so the expensive hot water wasn't just running away. She would go out for long walks; her boots were worn down. And instead of cigarettes she smoked matches.

I phoned the consultant. 'What has happened? Why has she not been admitted yet?' 'Oh, I've been busy. I forgot.' There's obviously no hurry with this illness because there's no hope. Or so we felt, but we were due to return to Russia in the new year. How could we leave her like this?

On 31st December, at my sister's in Aberdeen, we went for a walk along the beach. Elaine is an artist. She is attuned to beauty and loves the sea. There was a dramatic scene: a red sun, round and glowing, shining through gathering mist in the still-frosty air. Elaine appeared not to notice, but years afterwards she referred to that walk and the scene we'd witnessed that December day when it had seemed she was in another world and had noticed nothing around her. 'The mind has mountains', as the poet says.

I had been given that poem to critique when I was eighteen. I had no idea that it was by Gerald Manley Hopkins but the words stayed with me:

> *O the mind, mind has mountains; cliffs of fall*
> *Frightful, sheer, no-man-fathomed. Hold them cheap*
> *May who ne'er hung there.*

We were hanging by our fingernails on a sheer precipice of the mountains of the mind. Then, in the new year, it happened. We had sheriff's men at the door with official documents stating that Elaine was to be admitted compulsorily to hospital. An ambulance came for her. She wouldn't go. In the end I called a taxi – but it sat outside for thirty minutes before she agreed to get in it with me.

So, she was admitted for three months and given injections at once. Guess what? They let her out for the weekend. And now, having become more aware of her surroundings and her fate, and realising that we were going away to Russia for good – although actually only for five months in my case, as I would return in May to be around for her – she cried and begged not to go back to hospital. I took her back by taxi once again and she immediately ran away. Her friend called to say that Elaine was at her house and she didn't know what to do. Our son picked her up on his motorbike and took her back to us, her long coat trailing in the spokes of the back wheel. She could have had a serious accident at the very time when she should have been safely inside the hospital. I phoned the ward. 'Don't you know that one of your patients is

missing?' They had no idea! 'Can you bring her back?' they asked.

This time the taxi stood for 45 minutes outside our flat before I could get her back to hospital. So what's the point of having sheriff's officers and all the paraphernalia of court procedure if the ward can't look after its own forcibly admitted patients?

Home the following summer, I struggled in vain to find the inner peace to deal with all this. Our flat faced north and my heart too seemed full of winter in spite of the summer outside. A poem written then reflects this bleak feeling:

'*Woman, be free!*'
Choosing the sunshine, I try to forget
she's in the shadows, sleeping at noon-time.
Try to find comfort in birdsong, waken each morning
to cadences carolled from branches and bushes
while she is shuttered in her summer of stupor,
a full-blown June rose, beautiful, blighted,
living with me in this house facing winter.
The sun doesn't brighten our windows, visit our garden.

I am still waiting for the sun to break through in our lives.

Once I went for a few days to a Christian fellowship where I truly tried to find inner sustenance. I turned to the Gospels and found the story of how Jesus healed a woman whose back had been bent for 18 years. 'Woman, be free!' he commanded. In a spasm of anguish I realised – and wrote – that I cannot be free because she is not free.

And that remains my situation. The years have gone by. Our daughter married and is still in the relationship, although she lives in a care home where she receives excellent support from Carr Gomm[6]. This has certainly taken the pressure off us as parents. She overnights with us once a week, her husband visits her once or twice a week in the home (though he has to leave by 9 pm each time), and she spends one night a week with him in his flat. Each bus journey, ten miles across the city, is a major achievement as she believes that passing cars can read her mind, the bus driver is out to get her and people on the bus know she is a mental health person and feel critical of her – or even

[6] A voluntary sector social care organisation.

think evil, harmful thoughts about her.

She is well monitored on oral medication that MUST be taken daily and receives support in all the 'activities of daily living'.

North Wing

Elaine has lived in all kinds of accommodation. She once lived in a care place where another 'inmate' committed suicide, jumping from an upper landing in this new town building with its high spiral staircase. She has also been homeless.

When she was 27 she was kept in the acute ward of a mental hospital for two years, awaiting a bed in a long stay ward because she had nowhere else to go (her husband having failed to pay the rent). Is that not traumatic enough for a well person, let alone one whose inner self is under constant assault? He owed the council £1,000. It cost them far more to house our daughter in hostels and places for the homeless, to say nothing of the stress this added to her already overloaded inner life.

I wrote to our MP and the heads of this, that and the next healthcare organisation to try to get things moving for her. After nine months they gave her a single room opening on to the ward. The door didn't fit and she could hear all the screams and swearing and abusive language as desperately ill patients were admitted from the street and medicated. There was no toothpaste on her washbasin, no soap, and when I complained to staff I was told, 'She knows she can ask us for toiletries'.

Eventually she was given a bed in a long stay ward called North Wing, a separate house within the precincts of the hospital. It's now the physiotherapy department and is no longer used for hands-on patient care. Here's an extract from another poem:

North Wing
North Wing is a hostel within a hospital, set among trees with its own front door like other old stone houses she has homed in.
Once-spacious dwellings for the well-to-do
now house those who can no longer do,
whose bodies function but whose minds are broken.

Paid carers point me to an open door,
a room chokingly smokeful, an uncarpeted floor.

I find my daughter there, among four dulled males.
Her eyes are closed, booted feet rest on a chair – she'll always break the rules.
'I'll be thirty soon.'
Half her life she has been:
in and out of hospital,
in and out of hostels,
in and out of council housing.
Evicted five times, made homeless twice;
eight addresses in as many years,
the hated hospital the only constant factor.
Brought in by car, taxi, ambulance, police car,
held down and forcibly injected.
She has had an army
of key workers, support workers, community workers, social workers, consultants, lawyers.
She has lost most of her friends.
She has lost the right to care for her child.
And she has no idea why all this has happened to her.
'I should never have come in here. That was the biggest mistake they ever made, putting me in here. It was the start of all my troubles. Why did they put me in here, Mum?'
She sucks her thumb, alone in a big, bad, adult world. Lost and stuck, reduced and overcome.

Losing a child to adoption

Yes, she has lost the right to care for her daughter. In January 1995, Elaine and I sat together in the absolutely horrible waiting room where Children's Panels were held. I was going through radiotherapy at the time for breast cancer, and struggled through the snow with her to the hearing. Our surroundings reminded me of remand homes I'd visited when I was a social worker in Glasgow, and I remember saying to her, 'You should never be in a place like this'.

Her baby was adopted, causing her immense pain. It is an open adoption so we all remain in contact, although for Elaine this ongoing contact is, as

a support worker said, 'a poisoned chalice'. Because she can never hear her daughter call her 'Mummy', never experience snuggling her on her knee, tucking her up in bed – and now that our granddaughter is a teenager, Elaine unwittingly makes it heavy by often treating her as the little curly-haired child she lost.

Do we not all recognise that losing a child is the most devastating thing that can happen to a parent? Yet my daughter and her husband, through no fault of their own, have to endure this heart-wrenching loss.

Our granddaughter is now living with my husband and myself, which is a huge joy for all of us and probably the thing that has brought me personally the most healing. It does mean, though, that I can't do quite as much with and for my daughter, who is so very needy. Elaine is like a sweet, charming, chain-smoking child who believes she is nine months' pregnant. There is little self-care and, sadly, she has recently had two teeth extracted near the front of her mouth. Anyone else would be fitted with a denture, but she would not be able to cope with it so is left with gaps.

Yet she remains the most generous-hearted and noble person I know, immensely intelligent, full of a lovely gentle humour and able to take a laugh against herself (a rare gift). A health visitor once asked me what was left of her from before her illness and I said, 'Her sense of humour'. Her ability at art, too, is with her still, impaired but flourishing. She goes to an art class weekly and derives a lot of satisfaction from this. She is also a good swimmer and I now take her swimming with me. She never stays long in the water, but looks so relaxed and contented. She loves the Jacuzzi too. It's lovely to see her doing normal things with normal people. She attends church faithfully and derives great comfort and help from that. Sadly she has lost almost all her friends, so depends on her family and support workers for social interaction.

Recovery, no! Acceptance, perhaps

Schizophrenia affects families. Our son has chosen not to have children because he knows that this cruel illness is genetic. Our granddaughter – who has already done some major fundraising for Support in Mind (previously the National Schizophrenia Fellowship) – is exposed in a big way to an illness that, as one friend put it, most adults find challenging if not downright impossible to deal with.

Recovery? No. A sort of acceptance, perhaps: this is the way things are and we have to work along with them. But the heartache never goes away. We just wish for a better life for her, that she should be freed from the dark delusions that persist and truly haunt her in spite of the medication, that she should be able to become more independent. 'Woman, be free!'

I once saw a film about people being given Clozapine, the medication Elaine now receives daily. I'd read about the big improvements this drug can make. One of the people in the film, explaining what a difference the drug had made, summed it up with 'Nothing much, you know. Just ordinary things'.

I once asked one of her nurses why she seems unable to keep herself clean. His reply frightened and depressed me: 'It's to do with the disintegration of the self, the separation of character from body'.

And I recalled the words of a writer, Doris Lessing, and thought, paraphrasing her: *Blessed are they who feel the earth beneath their feet. Who are aware of the experience of cold and heat – or even pain; who* know *that it is uncomfortable to be unclean...* These are the basic ingredients of normal life, and they have gone.

Just normal things – like feeling your child's breath upon your cheek or the mutual exchange of friends, with no effort made on either side. Gone, quite gone!

'This medication is giving her insight but not ability,' the psychiatric nurse had said. 'We're between a rock and a hard place.' Hope deferred makes the heart sick...

An elderly Anglican monk who fell and broke his hip while visiting us at our flat in Warsaw said quietly, 'It has happened, so we must just accept it'. What wisdom in those simple words! Am I wrong to refuse to accept her schizophrenia? It took me so many months before I could apply that word to her – it's like cancer, I guess, or how cancer used to be. I identified with Terry Pratchett when he said, 'We talk about "battling with cancer", about the "brave fight with cancer", but about mental illness (Alzheimer's in his case) we say only negative things.' I have come to learn that, unfortunately, out of mind most definitely means out of sight.

The good things in life have floated away, unattainable as butterflies, while I sink in clay. I read lines from a Lakota Sioux: 'Sometimes I go about pitying myself. And all the while I am being carried in great winds across the sky'.

But I'm not pitying myself; I am pitying her. It's the same with those wise words about acceptance. Yes, the way of wisdom and growth is to learn to accept the pain that happens to ourselves – but how can we accept the pain a loved one bears?

I have written down a quote from Toni Morrison: 'The function of freedom is to free someone else'. I recall those words from the Gospel – 'Woman, be free!' – and my heart-stopping realisation, 'I cannot be free, because she is not free'.

O come, great winds, and carry us across the sky to freedom, both her – and me!

Key learning points

- The slow, insidious onset of an illness is initially hard to diagnose but this early time, when the inner and outer worlds of the patient and the family are beginning to fall apart, is precisely when help, structures, relief and coping skills need to be given.

- Unhelpful, judgemental or coldly professional responses at this stage cause deep wounds that, added to the grief and horror of the illness, never heal.

- When a young child is involved, the whole thing goes even more awry. Too many professional bodies are involved: psychiatrist, mental health officer, social workers, the family... but there is no unified voice, no meeting together, and decisions that will forever affect the child's life – and the rest of the family's lives – are made in an ad hoc, mismanaged, unplanned way that causes irreparable damage and distress.

- In my case I am a carer of my daughter – even though she is married – and her child – even though she was adopted. My sister, as church elder and a member of a caring group, has recently had to help a 75-year-old grandmother with terminal cancer who is the sole carer of a five-year-old grandson whose mother, aged 40, is a lone parent

with schizophrenia. There are no care plans in this case either, and that grandmother will die grieving.

- Since the whole family is affected – in our case, my husband and myself, our other grown-up child, our daughter (the sufferer), her husband and his family and, above all, my daughter's child – the whole family needs counselling and help at different levels and different stages. Each member of our family has been torn apart by this illness, and each person's lifestyle has been radically and negatively affected.

- Tolstoy's novel *Anna Karenina* famously begins, 'Happy families are all alike; every unhappy family is unhappy in its own way'. But families with severe mental illness are alike in their suffering, as this book shows – living on a knife-edge of horror and grief, along with the total disruption of 'normal' life. For myself, to sum up, I am like another character in that novel who 'did not want to talk of her sorrow, but with that sorrow in her heart she could not talk of outside matters'. My sorrow, because of my daughter's tragic plight, has eaten me up, and I find no therapy for that wound.

Chapter 10

I wish I could go back and give myself a hug

In Scotland, Patricia Mullen

Introduction

It is really difficult to decide where to begin; what to include, and therefore what to leave out. In reality, I think it would be difficult to find enough words or the right words to describe the journey that myself, my son and my family have been on for the past 17 years.

However, I will try to give you a sense of the roller coaster ride, our emergence via the process from hopelessness and devastation and our hard-won journey of recovery, healing and hope, so that if you are reading this narrative from a very dark and hopeless place, you might begin to light your own candle of hope and thus begin your own journey through the process of recovery.

Entering the world of mental illness

My name is Patricia and I have two children. My daughter was born in 1974 and my son in 1978. When he was a few months old I left and later divorced his father, who was a violent alcoholic.

I am mentioning this because in later years, when I was going through my tick list of every cause or cumulative cause of schizophrenia (whether factual or not), this fact, and the circumstances surrounding his birth, were relevant factors. I would rage between anger, guilt and grief. I remarried in 1981 and my husband has been their dad ever since.

My son first became unwell in 1994, when it became apparent that something was drastically wrong. At first it looked like the usual teenager going off the rails, trying drink and drugs etc. but I had always seen and sensed a vulnerability in him, and knew his consultant was right when he diagnosed him a year later as having paranoid schizophrenia.

The effect on the whole family was devastating; the bottom literally fell out of my world, and in my mind it was equivalent to a nuclear bomb shattering everything beyond repair.

He was 16 at the time. For a long time I kept thinking and remembering what I'd told him when he was growing up: that he could do anything he wanted to do when he was older, the world would be his oyster... For many years I felt as though I had lied to him.

Instead he was admitted to an acute adult ward in the local psychiatric hospital within just a few months of leaving school. My daughter was at university at the time and later went on to achieve an Honours degree in Economics and Politics.

It is interesting, thinking back, that she was considering a professional career within the NHS at the time. This was not destined to be, however, and she ended up making a completely different career choice. Like myself, all her illusions and beliefs about what should happen in the provision of care, either in hospital or within the community, were completely shattered beyond belief after living through the first five years of her brother's illness and diagnosis.

The constant trauma and stigma of trying to get help and dealing with the services, along with living with the illness, was too much – and although much (but not all) has been forgiven, we have never regained the sense of trust we once had. Nothing in life had prepared us for the world of mental illness at that time.

How we were treated often had a sense of brutality and, more often than not, a basic lack of human compassion. Unfortunately this can still be the case all these years later: I've been working professionally with mental health carers for nearly ten years now, and I often hear carers, families and friends repeating the same experience. It is hard enough trying to cope with the illness, the fall-out for the rest of the family and your own personal feelings of fear, anger, grief and loss without having to deal with the services, no matter how well equipped and informed you may be.

But for every loss of trust or bad experience there are the good experiences; understanding and words of basic kindness that helped to sustain my hope against hope throughout the early years and beyond. My son proved to be

treatment resistant and had little or no response in the first four years. He was extremely impulsive, chaotic and out of control, had made numerous serious suicide attempts and was beginning to self-harm. I had already lost count of his admissions to hospital.

Most of the care assistants on the ward at that time had no training, particularly in mental illness; this is something I still feel very strongly about, and I hope that, in this present environment of cuts to funding, they do not even consider changing back to a system that would have been cheaper in the past but inferior, and costlier to the individual receiving the service. I have worked in the voluntary sector for many years now and still work with individuals who have mental illness, as well as their families, friends and supporters. It's very disheartening that the present funding issues within the community have left many voluntary organisations to bid against each other. Alternatively, the funding situation is so poor that poorly paid, untrained and inexperienced staff are now the way out for many organisations trying to provide support, care and services within the community.

Anyway, to say that the first five years were the worst would be an understatement, and I honestly don't feel it would be exaggerating to describe this period of our lives as a living hell. I did have information, was well informed and also had support from the Glasgow Association for Mental Health and The Charlie Reid Centre[7], which at that time was part of the national organisation known as NSF Scotland. I later went on to work for these two organisations after completing a series of SVQs[8] and an HNC[9] in Social Care, followed by ongoing training courses in anything I could get onto that was relevant to mental health. This was the darkest period for all of us, when the sense of hopelessness came in. I could fill books with examples of the stigma and isolation that come with this illness.

It's very difficult to think back on this time, and although years later we did emerge stronger, some of the scars are still there. There were very few glimmers of the real person, the son he was before this holocaust, and the roller coaster could turn on an hourly basis; the emotional trauma of watching him spiral out of control, suffering, scared and tormented, self-harming or desperately trying to kill himself, hiding and frightened or changing into a monster and smashing up the house, drinking and taking anything he could

[7] A drop-in support centre operated by the voluntary organisation Support in Mind Scotland.
[8] Scottish Vocational Qualifications.
[9] Higher National Certificate.

lay his hands on and threatening to harm himself or us – but all the time so ill and so vulnerable. He did take the medication, he did comply but it just wasn't working. This is the bit I will never understand and for which I will never forgive the services, who then began to talk about his behaviour, that maybe it was just his personality – after all, he was an out of control teenager and possibly the best place for him would be in homeless accommodation. 'Put him out' was their advice to me, mostly at times when I'd just nearly lost him. I just could not get my head around this and still can't. He was already diagnosed and it was obvious that he was treatment resistant. How on earth could they have hoped to improve things by putting a vulnerable and ill young adult out on the streets to make his way to the Hamish Allan Centre?

The police became frequent visitors for a time and were, on the whole, extremely supportive and helpful. They were frustrated at dropping my son off at the hospital only for him to be sent home again, usually within hours. My husband's physical health was deteriorating and my daughter struggled juggling part-time work, full-time university, staying up all night with her brother and supporting me. I very nearly gave in at that point – it seemed so hopeless and we were so desperate. I remember my daughter crying angrily as she told me that the cavalry (meaning help from the mental health services) was never going to come. To me, the thought of putting him in the homeless system was not even an option because he was so great a risk to himself, and I felt that it would be as if I was punishing him for being unwell and treatment resistant. In short, I was terrified for him.

The mental health system did not know my son before he was ill so how did they know what he was like when he was well? I did, but I felt that they were now introducing the scenario of 'mad or bad'. I lost all hope at times and clearly remember thinking that I had no choice but to consider killing myself and my son. This, in my opinion, is one of the biggest unspoken taboos for many carers and I was not sure whether or not to include it, but I think it is too important not to. I did not go down that path but was racked with guilt as to what kind of mother I was that I could even have thought that for a second.

Looking back, I wish I could go back in time and give myself a hug and forgive myself for these disturbing thoughts grown out of love and desperation. I have now worked with carers for many years and occasionally (usually only when the individual is aware I am or have been a carer myself) I am told the same story. A distraught family member will reveal that they have

had the same thoughts and tell me how ashamed they are. It's not rocket science: compassion, kindness and a strong dose of common sense and communication – just treating people as human beings – can stop this sense of hopelessness and desperation. Society still has a long way to go, particularly individuals working in the caring profession, when desperate and vulnerable people who are usually (on paper, at least) surrounded by support workers, CPNs, psychiatric nurses, consultants and GPs are left in situations where they think, even for a moment, that that is their only way out. I did not give up – it wasn't an option. But by this time, and for a number of years afterwards, I myself had been tagged and labelled by many within the mental health system. After all, they'd only seen me when I was overwrought, overtired, overemotional and looking desperately for help and answers.

One of the biggest factors that causes carers, myself included, to become caught up in the process of helplessness is being disempowered by the mental health system, particularly when they are at their most vulnerable. They weren't around the 95% of the time when we just got on with it, and sometimes it was worse and felt even more difficult when I questioned what was or was not happening. It is still very common for carers to be labelled as 'challenging' and it is still unacceptable. In most cases a skilled worker should be able to use communication and listening skills in a compassionate and understanding manner. In my son's case, it would have been easier for them if he'd moved on to live in a homeless unit and most likely fallen into the criminal justice system (although he has committed no crime), especially if there had been no strong family involvement to prevent it. Some CPNs told me bluntly that they thought I was deluding myself and that my son was out of control and spoiled. My self-esteem and confidence were hitting rock bottom but I'm really glad I didn't go down that path. I nearly did but common sense, love and an ability to rationalise the events up to that point left me in no doubt of his diagnosis and continued lack of insight.

Gaining insight

I would like to add a little context to this experience by telling you that I now have over 13 years' experience working with individuals who have mental illness at The Charlie Reid Centre in Glasgow, and many of our members have been through the homeless system. The centre was the first drop-in centre specific to mental illness to open in the Greater Glasgow area, and at present we are lucky enough to have a manager who at that time worked with the

homeless team managed by GAMH[10]. The work done by this particular team ten years ago made a huge difference in reducing the number of people caught up in the homeless system while diagnosed with and/or experiencing mental illness. This did not happen to my son, but it was very common at that time for young men to fall through the cracks in the system and end up homeless, on the streets or in prison.

Things eventually came to a head for my family and my son, but only after we'd all suffered irreparable emotional damage. My son was admitted to an IPCU[11] ward, which is known as a 'locked ward'. At that point I had to take a chance and refuse to take him home; it was one of the hardest things I have ever done. I knew I had not given up on him but I had to do something to stop the endless cycle of revolving door admissions and leave him in hospital long enough to be properly assessed. We were exhausted by trying to keep him safe and by services implying that we were exaggerating, or bringing up the behaviour scenario again. That this was considered necessary four and a half years after diagnosis I still find totally unacceptable, but I can only put it down to the short-sighted and judgemental attitudes of the staff in his usual admissions ward. We were terrified by the thought of him being held in a locked facility but it turned out to be the best thing that could have happened.

I remember myself and my daughter being pleasantly shocked because the staff at the IPCU were kind, communicative, civil, non-judgemental and, for the first time, hopeful. He was started on Clozapine, and that was the beginning of my son's and my own fight in the journey of recovery. One thing I firmly believe from experience in all my different 'hats' is that it's difficult enough to manage and support anyone through an acute phase of illness but even more difficult to manage a young teenager through such a phase. Clozapine was not a miracle but it was enough of a miracle for me, and it gave my son insight into the fact that he was ill. Without insight I had felt that there was nothing to work with, but now there was hope and I was determined to fight this illness with every fibre of my being. I made every mistake possible before I learned that my son had to learn to want to recover to the best of his ability and start his own fight. Although he was still very unwell and on huge amounts of Clozapine, part of him was back – that's the only way I can describe it. Also, after Clozapine gave him his insight it was as if all the other rubbish behaviours fell away. It was very much easier to diagnose and clearly identify symptoms.

[10] Glasgow Association for Mental Health (a voluntary sector social care provider).
[11] Intensive Psychiatric Care Unit.

Over the years he had many more admissions but was never put back in an IPCU ward. A few years later, while visiting on the ward, I remember the nurses saying to me what a nice lad he was and I thought, 'That's what I tried to tell you before he was finally tried on Clozapine!'. One day we were talking about some of his 'stunts' in a light-hearted way; he laughed but then said, 'Well, I didn't know what I was doing – but wasn't the hospital worried about me, didn't they try to do something about me or for me?'. He was no longer a teenager, and although very immature he had insight and a perspective. Over the next ten or so years came the hard work, when sometimes it felt like one step forward and twenty back. It was extremely difficult, and hopelessness and isolation would still come in waves along with the grief. At that time everyone was speaking about the benefits of creating a stress-free environment for my son.

So there I was, armed with the manual and determined that there would be no stress, but I soon learned that the high levels of medication he was on meant that we'd have to write our own manual of what was going to work and allow part of this to function between good days and bad days. I was creating more stress by trying to create a completely stress-free environment and nobody (especially not families) can live like that, walking on eggshells 24/7. I did realise that his best chance of recovery at that stage was to remain within the family, with the support of friends, until he was well enough to have his own place. As for my working life, I was very clear in my head that if I was to go any further in the mental health field it would have to be for a lot more reasons than just having been and still being a carer. Although I now realise that I had the benefit, knowledge and experience of working both with individuals who experience mental illness and with their carers, families and supporters, along with my own personal experience, having different hats has not always been easy. But at times this has given me a better perspective on the stigma that often comes from the mental health field itself. After many years, I now feel experienced and comfortable enough to use these skills to (hopefully) benefit others. I still experience examples of stigma and judgemental thinking but I now try to be more tolerant and understanding when challenging assumptions, stigma and discrimination.

Foundations of hope

In the late 90s I was lucky enough to get on a course run over eight residential weekends. The course was called 'Allies In Change', and for the first time it

brought together a variety of professionals, service users and carers (both the latter are terms I dislike). The people involved in all aspects of the course were all very highly motivated, and at that time it was a revelation to me to listen to and meet with professionals, many at the top of their field, who were caring, highly dedicated and determined to achieve positive change. I felt that I was now seeing the best and hearing what could be possible. The whole 'Allies' experience – the course itself and all the people I met – really came at the right time for me, and although I was not yet aware of the ethos around recovery, this course and the benefits of the whole experience definitely laid the foundation blocks of hope and the potential for positive change, together with good practice for me as both a worker and a mother. The benefits for me at that time (and to this day) were huge. We were told that it was not a 'movement' but, in retrospect, in some ways it was. Out of 'Allies' came Person-Centred Planning and Map and Path Route Planning, and in many areas across Scotland new and innovative projects came to life. For me there was no going back – the motivations, learning, debating and pulling together left me in no doubt that positive change *was* possible, and I was eager to do my bit and learn from the mix of expertise and experience offered by the individuals involved in the 'Allies' course. The building blocks were laid for many new projects such as Stepping Stones, Lanarkshire Links and the Glasgow Mental Health Network, to name but a few. It was also in the early days of this course that I had my first experience of the divisions between what was known as the 'user movement' and the carer and family organisations.

Historically this was nothing new but it was new to me, and I felt it was critical for me in all my 'hats' to understand it more fully.

Although we now know this is wrong, many families were blamed in the past for mental illness and caught in a cycle of stigma, fear and guilt. Some, like my own family, were encouraged to 'forget' or be less supportive of their ill relatives and concentrate on the rest of their family; more often than not they simply couldn't cope and were given little or no support. Personally, I believe that there's only a very small minority of families and circumstances in which it is not in the person's best interests to remain within that environment but historically, and in general terms, families were and can still be torn apart by stigma, ignorance and fear, losing essential and often critical support skills and the networks available for most other illnesses. I always tried to tell my son that he had an illness the same as any other illness, and I needed him to believe that. Much of the fear, ignorance and stigma that still exist lead on to

isolation and despair and can create one of the biggest barriers to recovery, leaving people to struggle alone and feel unable to seek help. When my son first became ill we were told that mental illness was very common, but for a long time I remember wondering where all the other people were. I had yet to learn that many families had become experts at concealing their situation, cutting themselves off from each other in what they think is a survival strategy. I wasn't for telling all and sundry but I was adamant that my son's illness was nothing to be ashamed of and determined he should believe that he had an illness the same as any other illness, which could improve with medication therapies, and that there would be good and bad times. That was part of my way of coping with the stigma, the services and the illness. We all need people we can turn to for support, talk to or have a cry with, and I was aware that my son had to learn in some way to cope with life, illness or not. We did have periods of isolation but at other times had continued support from friends, family and colleagues. Without this I think we would not have coped in the long term and the isolation and loneliness would have been too much.

A recovery pathway

My son enjoyed playing his guitar and joined various music groups, which I think also helped him to form and keep his own identity. I still worked (my husband was now medically retired), and although that was hard I think it helped me to cope and kept me sane, particularly through some of the most difficult times, as I was able to talk to others. It still felt like I was on call 24/7 and I probably was, but I am sure that we would not have been able to cope or move on with a positive outlook if I had been in the house all of the time.

Even after starting Clozapine he was still very unwell and on large doses of medication for many years. There were good times and bad, but the good times were crucial to the start of the recovery process for us both. Mental illness is a very lonely illness and it's easy for individuals or whole families to get caught up in the isolation and paranoia, sometimes doing the wrong things but for the right reasons. Many have had a bad or judgemental response from family, friends or the services and I was no different. Unfortunately, I have past experience of questioning service providers and making a complaint. I had the benefit of being supported through that process but it was still extremely difficult and stressful. In fact, although I would still do the same again, the experience left me feeling less confident as well as

more isolated and labelled. It really isn't something any carer would consider lightly, because unfortunately there is also the additional fear that if you complain it will have an effect on the services and support available to your relative.

About six years ago I realised that, overall, I had seen, experienced and received some of the very best care and support from many professional and caring individuals. I was also very aware that at times we had also experienced the worst, and although in balance this was not always the case, I think that it felt worse because the bad experiences always seemed to happen at the times when we were most vulnerable, or had reached crisis point. Writing this has brought back many memories, good and bad, but I think it is important to try to give you something of what I was and still am recovering from. We were already on a path of recovery at that stage but I did not realise this at the time or understand that it can be a long haul, not down to any one thing but rather to a cumulative process often hard-won.

When I first heard about 'recovery' I really didn't understand the concept. I remember being angry and thinking that some people might be tempted to come off their medication. I also worried that it was some new term or process more suited to individuals with mild to moderate mental health problems, and that service provision might be monopolised around this new buzz word to become a tick box exercise around the positive outcomes required for funding. In itself this would not have been bad but I was extremely worried about how it would work for individuals with severe and enduring mental illness – a much more difficult and challenging thing to measure or address. The seed was sown, however, and I was soon thinking about how this would or could work for my son and the members of the centre where I worked. At that stage I was not thinking about recovery for myself; I was barely even ready to admit or consider my own need for recovery. But I was soon to realise, and see more clearly, that we were already on the recovery path, and that although our recovery paths were at times linked, we were both moving on towards our own individual experience of this process. This in itself was another link in the way forward.

My prospects

In 2003 I travelled to Holland with a small group of carers representing

Support In Mind Scotland[12] and took part in the first 'Prospect' self-development training programme organised for family and friends by EUFAMI[13], which was attended by carers and supporters from ten of the member countries. It was through my initial and continued involvement with this programme over the next eight years that my overall and personal understanding of recovery grew, enabling me to clearly see my own journey as well as the brave and limitless possibilities for everyone involved in the process. Back in 2003 I was overwhelmed by the fact that although I was with other carers from various countries, languages and cultures it was very apparent that we shared a common bond in terms of our understanding and experience of mental illness. In 2004 I returned to Holland and completed training to become a facilitator with the ability to deliver Prospect training; this was when I really got my teeth into Prospect, and when the words – Real, Worthwhile, Coping, Hope, Change and Recovery – really began to mean something real and achievable.

Prospect is based on a global philosophy that breaks the cycle of isolation, limitation and discrimination and enables participants to embark on their own journeys towards recovery. Initially made up of ten specific modules, it is a training initiative aimed at opening up fresh perspectives for carers, family and friends of individuals with mental illness. It stems from a need to provide a family education course that not only addresses the needs of carers in their own right but has also been developed in conjunction with them. At the heart of Prospect is a fundamental belief that, in the right setting and with the right support, carers CAN and WILL set about regaining control of their lives, allowing them to discover and recover skills and strengths within themselves. I have now seen this process work and begin to enable positive change in the lives of many carers over the past five years. All Prospect facilitators are required to be or have been a carer or supporter, and to have completed the course themselves. As a facilitator I feel that I gained an added perspective and overall understanding of this process, which was definitely more than just a course.

In 2006, Support In Mind Scotland successfully piloted the programme for a little over a four-year period. My involvement and my own personal experience as a carer over that period confirmed to me that 'recovery' is not a one-off event or course but an ongoing process which I now describe as my 'bag of

[12] A voluntary sector social care and campaigning organisation.
[13] European Federation of Families of People with Mental Illness.

tools', ready and available for me to use or add to in the future. The Prospect course itself is usually delivered over a residential weekend with a follow-up weekend three to six months later. The specific modules are designed to touch upon areas often excluded from formal education programmes and therefore not openly discussed. Although a group setting is used to deliver new and up-to-date information, the course itself is not based on information-giving but is experiential and based on group participation that allows for the exchange of experiences, problem-solving and the defusing of misconceptions and, perhaps more importantly, enables carers to offer each other solutions, hope and the support essential to improving their own quality of life.

Through EUFAMI in Holland, I watched and listened as carers throughout Europe began the process of positive change and recovery through Prospect. For me, the missing piece of the puzzle came when I was working in Scotland as a facilitator. I was witnessing and recording evidence that showed that when some carers began this process for themselves, it often led to the beginning of the same process for the cared for; it's as if it had a knock-on effect. Carers – myself definitely included – did not see this as a quick fix. We understood that we were at the beginning of the process of recovery and that, by trusting and adjusting the process, specific tools and skills to our individual needs, we could begin to make changes (no matter how small), reclaim our lives and have dreams and hope for the future of our relatives' journey on the path of recovery.

Taking my own advice

Many of you reading this will be aware that not everyone fits neatly into the box of service user or carer all of the time; we all have varied and different labels throughout our lives and, like everything in life, nothing is ever that simple. People's circumstances change over time and many, many carers develop physical and/or mental health problems. Many people with a serious mental illness also have a partner or friend with a similar illness, and usually the person who is well at the time becomes the carer. My own physical health had been greatly affected at times over the many years of stress. Part of my recovery was to allow myself to come to terms with the overall trauma and serious long-term stress that had taken its toll on my mental health. I suffered and was affected by stress and serious anxiety, and although I now knew the reasons why this had happened and that it was often common in carers, I still found it difficult at times to take this on board and seriously consider

my own needs. My son was always my first thought in the morning and my last at night. I advised carers that to go on the long haul they had to be good and look after themselves, but I didn't always take my own advice. Looking back, I realise that my son had become very dependent on me and had grown to expect me to manage his illness in many ways. This was really difficult at times because some of the resentment he usually felt towards his illness would be focused on or towards me.

Much had improved but we still struggled and did the wrong things, sometimes for the right reasons but sometimes just because it was all we could do to manage through yet another crisis. I was handling things an awful lot better but emotions can take over and I often forgot the knowledge and skills I'd gained and developed, particularly when it came to myself. I distinctly remember that on two separate occasions when I arrived to facilitate at a Prospect residential weekend, I was desperately trying to keep my own emotions in check.

Like many carers, I was busy trying to juggle various responsibilities, dashing around trying to fix things and looking after everyone else. I was going down the slippery slope of not looking after or making time for myself again, and forgetting that it was okay for me to have a bad day; I needed to allow myself to grieve as part of the healing process. Sitting through some of the modules as an observer, I thought, 'I know all this, so why am I not doing it?'. So for me the timing couldn't have been better, because there I was again bringing out my bag of tools. It was more than just the modules – it was being in an environment with others who had or were having the same experience but were, as a group, full of hope and determination. This was really helpful as it allowed me to feel supported and to stand back and get things in proportion. I picked myself up and became more determined than ever to really start to make the hard decisions and changes that would be instrumental in my own journey of recovery.

Drawing back

Many carers became friends through Prospect and have since set up their own support network so they can stay in touch and support each other whenever they wish. Prospect also allowed me to explore and work through the acute distress, shock and trauma that mental illness had caused in my life, and I began to rebuild my confidence and self-esteem. Mutual understanding

and peer support enabled me to reactivate, identify and go on to use coping strategies and plans. I began to plan routes forward with a strong and determined sense of hope and a desire for positive change. My new thinking was about 'what's possible', i.e. what could realistically change. Even if I started small or failed in my first attempts, I was determined to try and to move forward. I also felt braver about this now because I'd witnessed the benefits and changes in the lives of many of the carers who'd engaged in the process of recovery through Prospect. They were all given the opportunity to tell their personal stories while attending the Prospect weekends and it was inspirational for me to hear what they had to say, particularly on the follow-up weekends.

Like many other carers, my biggest worries were about what would happen to my son if I wasn't around – how would he manage on his own? In some respects the time might never have been right for him to leave home and get his own place, but I wanted to try this out while I was still able to offer support and a safety net of sorts. I had learned that given time, hope and the right support, so much can be achieved. He has now had his own flat for nearly five years. It hasn't always been plain sailing, particularly in the beginning – I had to learn to draw back in stages – but the rewards have been great for us all. He slowly learned new skills and his independence grew, which initiated a new life with new choices over which he had control. He still receives support to maintain this quality of life and independence but, looking back, I am sure that no matter how scary or risky it seemed at the time, it was definitely the right decision. He loves having his own space and now I have mine. It was nobody's fault but we'd got to a point where we were stifling each other. Now we are able to spend quality time together, and our relationship is better on a more equal basis.

Learning to trust again

Over recent years I have learned the importance of not getting stuck in the past. I did not want to be caught up in bitterness as it could have damaged my own mental health and affected me moving forward. I am now also in a position to realise that trusting my son's care team was another part of my recovery – I was learning to trust again. He has a very good consultant and CPN whom I trust implicitly, and it is reassuring for me to know that I can speak to them if necessary. On a lighter note, the last CPA[14] meeting I

[14] Care Programme Approach.

attended – where I joked that hopefully they wouldn't be seeing me again for a very long time – was nearly two years ago. This was a huge step for me, and if someone had told me even three years ago that I'd one day get to this stage, I probably would not have believed them.

I'm still on call but very much on the back burner. I learned the hard way that to survive the long haul you have to take care of yourself. We can all give advice but it can be hard to take it – and even harder to do something about it – if we're not given the right information and support. It has definitely been a 17-year journey, and although it's probably not one I would like to repeat I have met so many inspirational and courageous people along the road. I've gained a wealth of knowledge and experience and, just as importantly, regained my sense of self, my own identity. I now have a greater understanding of how my life was affected in many ways, particularly emotionally. For many years it felt like I was fire fighting; I'd got used to being on a high state of alert, ready for any crisis. My own health needs didn't really come into it as long as I was in what I thought of as 'survival mode'.

I was lucky enough to be in the right environment and to have the right support, which enabled me to stand back from crisis mode and clearly see the benefits of positive change while repairing some of the damage, trauma and effects of long-term stress. Whenever I felt like I was drowning in a sea of hopelessness I clung desperately to the good times (some of which were *great* times) when we never lost our sense of humour or hope for the future. In life you can easily become such an expert at hiding your own true feelings, keeping secrets and trying to convince the world you are coping that sometimes you can even fool yourself. I have learned to give myself days when it's okay for me not to cope and, over time, the bad days have become fewer. I still have periods when I am affected by anxiety, and I know I have more work to do on my own recovery path, but both myself and my son are now in a place that previously would have seemed unreachable. This was achieved in small steps with a lot of hard work, heartache, determination, support and – most importantly – hope for the future.

For my ongoing recovery I need to learn to be good to myself, to make time for my own needs and to be confident in my ability to make use of the experience, knowledge and understanding I have gained over the years. By using, sharing and adding to my bag of tools, I'll be ready for whatever life throws at me.

Key learning points

- If you want to be there for the long haul, you have to look after yourself and acknowledge your own needs.
- Given time in the right setting and with the right support, individuals CAN and WILL regain control of their lives, recovering strengths and skills from within themselves.
- Recovery can be a cumulative process, often hard-won. Remember the importance of hope and build on small achievements.
- Sometimes you have to write your own manual to survive and to make progress. This can be very hard as it means taking risks and chances with the person you care for, but it can improve the longer-term outcome for your relative and yourself.
- We often learn the hard way, with no training and little or no support. Finding your own path involves making mistakes; remember that you're only human, and that bitterness and guilt can be destructive emotions. Seek help and forgive yourself for things you could have done differently.
- Services often confuse behaviours and personality, and they may use this as an excuse for not offering support or intervention – particularly when things are at their most complex and difficult.
- It is hard enough trying to cope and come to terms with mental illness but this is often made even more traumatic when you try to get help and support from the services, no matter how well-informed you may be.
- Being supported by people who are non-judgemental is key; even if service relationships have been bad in the past, there's no reason to think that that will always be the case. Try to move forward and in time you will relearn trust.
- Professionals need to listen and instil a sense of hope, balancing real communication with understanding and compassion using a holistic approach and an understanding of the unique circumstances of the people they support.
- Don't isolate yourself or your relative, and try to keep your own identity. Meet and learn from others. Hang on to the good times and keep your sense of humour and hope.

Chapter 11

Hearing the music and remembering to dance

In Scotland, Elinor Dowson

To introduce this story, I first need to tell you what it is that I am recovering from. Towards the end I will describe what recovery means to me, what has helped and what would help now.

Being a reasonably optimistic, resourceful person with a strong sense of fairness and justice, it came as a shock to enter the world of mental illness as a carer and find myself, at times, completely at a loss as to how to cope with what was happening to my loved one and me. I spent nearly three years realising that all was not well with our relative but was unable to persuade medical staff to listen. If a person is able to present themselves as seemingly OK, even if it is apparent to family and friends that they are acting out of character, they will not necessarily tick the right boxes to be given help. These are that you are considered 'a danger to yourself and/or to other people'. Of course we did not know about these boxes then – we just needed help, and could not understand why it was not forthcoming! We were amazed by how many different professionals told us our loved one was just eccentric or, even worse, that there would be some incident and the police would probably reel them in. This was bewildering and very frightening, as our loved one had never had any connection with the police. What did it all mean?

No one seemed willing or able to put themselves in the shoes of the family, acknowledge our stress or give us any support whatsoever. It was only when I broke down at my own GP's surgery that I was finally listened to and deemed worthy of help. However, I was aware even then that this was probably just because I had a good relationship with the GP and things had been going on for a very long time. The offer of help came as a result of my very great distress, not the wisdom of the professionals. Much later on I came to the realisation that a late intervention can affect the path of the illness; this has given me some feelings of guilt but I try hard to reject them, because I honestly believe I tried every possible avenue to get help. However, I do think appropriate, imaginatively delivered, non-stigmatising early intervention is

something staff must consider much more proactively if they are truly to support recovery, and if it is to be seen as a right.

When professional help finally came it was completely misdirected, as staff did not listen to my advice and all sorts of bad practice occurred as a result. I realised, then, that in order to safeguard the welfare of our loved one I would have to take control of the situation myself. I was completely exhausted at this point but knew I had to protect our family member, so summoned up the courage to tell staff that enough was enough and they needed to do as I said. Our loved one, as a result, received help, but the cost to us all in stress, heartbreak and stigmatisation that day was huge, and its bittersweet legacy will stay with us always. It helped shape my thinking about what a powerful role the family can play if it wishes to support and, if need be, protect the service user. At the time, though, the idea that we should have to protect our relative from professional staff was a disturbing one. Were they not supposed to be there to help us? After all, I had been supporting our loved one, often in very difficult circumstances, for the last three years, without anyone wishing, despite my asking, to become involved. I had taken it for granted that the intervention of mental health staff would give us all a new beginning and that we would work together for the good of our relative. The fact that mental health professionals seemed completely unaware of the stress they caused us all that day was very hurtful and very concerning.

It also made me realise very early on that poor communication from professional mental health staff can be a fundamental hurdle for the family to surmount. It would be so good if they always thought before they acted (or not) about the likely impact of their behaviour, be it emotional or practical, on the service user and their family. It can be a great obstacle to recovery, and we are very likely to have gone backwards on our journey of recovery or stopped altogether as a result. When I spoke of this at a training event for staff, a nurse who had been there when my relative first received professional help came up to me later and said that she'd never given a thought to the idea that staff's behaviour could affect the whole family but, on thinking about it further, she'd realised that of course it would have had an effect. It was good of her to tell me this but very worrying that the training she'd been given had not prepared her to understand our feelings. Our whole family incurred lasting stress that day which, with foresight, could have been prevented.

The diagnosis, when it was finally given, found my loved one and me surrounded by professionals. I tried to hold my head up so that others would

not see the tears coming into my eyes, particularly my relative. It was a label that was incomprehensible to me, and now it had come to our family. What did it mean for us? Then they all swept out of the room, leaving me feeling overwhelmed and so alone. My relative, having realised this, hurried back into the room saying not to worry and that things would be all right. They gave me a quick hug. I was shocked that none of the professionals realised my distress or, if they did, acknowledged it. A kind smile, the offer of a cup of tea and the promise of some help in understanding the diagnosis would have meant so much to me at that moment. It is an experience I have never forgotten. It left me struggling to come to terms with the fact that I would never again be seen as just the relative of that person, entitled to the normal respect and affection that role would bring. My loved one, it seemed, was now in the hands of the professionals, and through them – without anyone giving them permission – the State had taken over my role. The State, it appears, has been imbued with an understanding whereby it does not 'do' emotions!

From our experiences I realise it is essential that professional mental health staff understand emotions and know how to deal with their own, and other people's, appropriately. Good emotional intelligence is essential, particularly in the caring professions. For too long professionals have either been taught to keep emotions out of their practice or they were not mentioned at all. I believe that an understanding of their own emotions is an essential skill for their wellbeing and welfare, as well as the wellbeing and recovery of the service user and carer. Staff should be trained to try and put themselves in the shoes of the service user and the family, and should be given this training, I believe, by service users and carers. An appropriately kind or thoughtful word would, at times, have made such a difference to my experiences and helped prevent feelings of isolation and alienation on my part. I sometimes felt I was being addressed by non-empathetic robots unable to understand the human condition, which was very frightening.

As I have said, emotional support has to feel appropriate. I have experienced both the silent handing over of the box of tissues by the psychiatrist and their being tossed across the room to me by a busy nurse who felt it should have been someone else's responsibility to give me an important piece of information. How I might feel to be suddenly confronted with this startling change of plan did not appear to concern her or, even worse, to have entered her mind. She did not try to put herself in my shoes. She was busy. Her behaviour also added considerably to my shock. It is interesting to wonder why, in the voluntary sector – which is staffed by a high number of social

workers and mental health nurses originally from the statutory sector – services are delivered primarily with kindness and consideration, and even hugs are considered routine. It is the person-centred training which I believe makes all the difference, and their being encouraged to show compassion and realise that emotional support matters, at times, just as much as practical support, in that it makes us feel acknowledged and valued and can stop us feeling overwhelmed by events.

Staff spend a lot of time thinking about and assessing risk. If they are to genuinely support recovery, their decisions must be risk-aware rather than risk-averse and they must assess the risk of their decisions, not only to the service user, but also to the carer and the wider family, and be aware of trying to minimise harm to them all. The fact that this is very rarely done often stems from staff not fully understanding or acknowledging the part the family members play when they wish to be involved as key partners in care, and the importance of everyone working together to achieve the best possible results for the service user. In my experience they often seem not to realise that by not supporting or listening to the family, they are affecting the cared for adversely. They are often totally unaware of the effects of their actions, not just on our family member but also e.g. on Granny, who has been playing a huge part in recovery but is now feeling depressed because no one is listening to her. If staff do hear of it, they often think it is nothing to do with them.

This is because many staff have received no information about working with families in their training, a situation which I believe needs to be remedied as soon as possible if they are to work in a genuinely recovery-oriented way. For staff to suddenly believe that, through their professional role, they know your loved one better than someone who has known them all their life is thoughtless and disorientating to the family in most instances, but also downright arrogant. How would they feel if they were in our position? Just like us, I would imagine – angry and confused at times, especially when we can see the benefits of working together as a team and that information can be passed on quickly to prevent relapse. However, before this can happen meaningfully and be effective, our part in the team has to be acknowledged and valued by the professionals.

For example, my relative, at the very beginning of their care and as the result of a conversation in which they asked me lots of questions, revealed to me, with amazing clarity, the 'triggers' for their mental illness. Things not understood by me at the time of their happening now had a 'reason' and

I could piece things together in a logical manner. I could understand why they had acted/thought as they had, at the time. I felt thankful for our close relationship and empowered for the future in that I could now recognise these ideas or triggers and would not have to feel confused, fearful or angry about what was happening. That conversation has proved invaluable over the years, but I have never really felt that mental health staff were at all interested in these 'triggers' and my early recognition of them. At best they have just said they were monitoring things or not acted at all, which at times made the situation feel hopeless and hard to cope with and made me feel that staff were on a completely different wavelength to me. I wanted to see change in my loved one. They seemed happy just to see him, which is not the same.

Also, when I have shared knowledge about why I believed my loved one was not wishing to do a particular thing and how my knowledge of these 'triggers'/'ideas' told me it was best presented in another way or even not at all, staff have interrupted me, looked at the ceiling or said that the meeting had to finish at a particular time. This lack of listening left me feeling extremely dispirited and at times despairing – all the more so because my relative had given up attending meetings. At one point my loved one left a full-size, named, cardboard cut-out model of themselves on a chair prior to a meeting at which they were expected. Staff laughed and said, 'Fancy them doing that!'. Sadly they did not focus on the real reason for their not being there, namely that they did not feel necessary to proceedings or listened to, either.

This has put a far greater burden on my immediate family and me, whereby we have had to rally round to solve problems. I believe that staff may, at times, have used our family member's non-appearance, whether knowingly or otherwise, to do what they felt to be right, rather than what I believe was best for them and their recovery. Sadly, because they did not feel worthy, they gave staff the power – and staff have not sought to give it back to them! This lack of partnership working and listening by staff has, I think, very seriously affected the recovery of my loved one and impinged on my own recovery and that of my family.

My wellbeing as a carer has come close to being overwhelmed by the fact that the world of mental illness does not routinely see the 'whole' person. In my experience, if you have a mental illness your physical health needs are not always readily understood by staff and your care can become seriously jeopardised. It is very stressful for me to realise that in the world of their

physical health needs my loved one is seen as a 'survivor' and equipped to cope on their own, but in the mental health world they are seen as 'frail' because of their physical health needs. This has led, in my opinion, to their care being seriously compromised at times. Of course the physical health world is not perfect either, and here the mental illness is often seen as a barrier to receiving physical health support because it is not understood by physical health staff, which has been very degrading for my loved one. This type of action is not recovery-oriented and can result in their being socially excluded, which affects the wellbeing of the whole family and is certainly not conducive to their recovery.

I must tell you this as it is so important: I have been caused worry, concern and a great deal of stress by the problem of staff previously employed in hospitals who are now working in the community. It is to be hoped that they will receive more training, so as to realise that people can receive help in the community and do not always need to be hospitalised at the first sign of anxiety or even issues to do with physical health. This happens even more frequently when there are long-term staff absences or staff holidays – people appear to panic because they feel they do not know the service user and do not always listen to the family. Again, this is a situation where, knowingly or otherwise, staff can wield power unhelpfully and one that training could resolve, otherwise it could be seen as an abuse of the rights of our loved one not to be hospitalised unnecessarily – which is certainly not in line with their recovery, or mine! What would help here, I believe, is more places in the community where people can receive early intervention, as the present number is woefully inadequate. This change of policy and new opportunity would hopefully encourage the doubters and 'fearties' to have the courage to support people in the community when appropriate, and to learn to risk assess this positively.

It would have made such a difference to me to have been able to go to care plan meetings and have my opinion valued, and to feel hopeful and positive that we were all working together for the benefit and recovery of my loved one, rather than feeling that I was in a debating chamber where I have had to resort, on occasion, to being adversarial to get my point across, or just feeling completely alienated or invisible because I am always asked for my opinion last, by which time staff have usually decided everything between them. It is much harder to change viewpoints from this position but carers have a passion when it comes to what they believe is best for their loved ones and they go on, despite the effect on their health. It has saddened and exasperated me

that staff have so little ambition for my loved one and that their talk always appears to be about maintenance of my relative rather than the adventures they might have that could make life worth living. Staff need to focus on and work with the creativity of people, rather than just their shopping lists, if recovery is to be inspired. On the very few occasions when there has been partnership working between us all it has felt wonderful – much more creative and productive.

My relative and I had to come to terms with the fact that not all our relatives or friends understand mental illness. Some, like my youngest son, know instinctively what is required. He knew right away what to take the first time he visited: juggling balls and a joke book. This was just right for us because we all had a turn and could not stop laughing, which was healing for us all. Later on I always took the dog because the dog is not judgemental and does not ask any questions; he was just pleased to see my relative, and they had some great romps together. Other family members and friends have given us unswerving support. They understand that the illness affects not just the service user but the whole family.

There are, however, some family members and friends who have never visited or even asked how we were getting on, which is hurtful. Others have sent gifts of toasters, kettles and even two very nice settees, but have never visited. This is sad and frustrating for us all – our loved one is in need of friendship and support but appears to have been quietly forgotten. In a moment of reflection when thinking about this problem, they asked me whether our family is dysfunctional. I think these family members, with their lack of knowledge about mental illness, would have been a bit surprised to hear themselves described this way. I have a feeling that it might have been how they were regarding our loved one!

I lost a best friend with whom I'd been working at the time my relative first received help. I was slightly late on the morning described earlier (when I had to take control of my relative obtaining help because staff had lost control of the situation). I had left word but apparently that didn't matter. Arriving in a state of shock after what had just happened to my relative, I was told that I should not have taken the job if my relative was going to become unwell. What did that mean? I was flabbergasted. I finished the contract and we have never spoken again. I have a feeling she is worried about stigma. Full marks to the understanding mature student who insisted on accompanying me to see my relative that day and produced some welcome sustenance (as I had had

no time for breakfast). The behaviour of my friend was very hurtful to me as she was my 'intellectual friend' and I miss those great conversations we had. But you just have to go on. It is only when people in the community lose their fear of mental illness that this kind of attitude will disappear and professional staff will listen to family members. Until that happens it will continue to hit families like ours very hard and impinge seriously on our recovery.

We also had to come to terms with another kind of stigma – one that, surprisingly enough, directly involved mental health professionals. This was a stigma that could result from their actions. Even their turning up at someone's door is noticed by neighbours, and if language and/or body language is patronising, cheeky, overly authoritative or assertive it is registered by those around as something out of the ordinary, causing tongues to wag. I have found this incredibly annoying and frustrating over the years but some staff seem oblivious or do not seem to care. I have been told on a number of occasions that 'Anyway, the people round about will know' our relative has a mental illness. I have had a visit from a senior social worker I had never seen before, who had extremely confidential information about my relative and was quite content to deliver it to me when I was sitting in my car surrounded by people who did not know that my relative has a mental illness. My relative was quite unrepentant when I told them off for doing such a thing and said they thought I would not mind. This was not the case at all.

Family and friends are very discreet and careful to protect the privacy of our loved one, as mental illness and recovery are not yet well understood in the community. We did not want them losing a tenancy because a neighbour has a fear of mental illness. Things can get blown out of all proportion, thanks in many instances to the press. I cannot understand why staff do not always seem to be aware of the person's recovery and what they can do to protect it, but putting people into housing that is known to be for people who have mental health problems and are therefore vulnerable is, in my opinion, even worse. This is not in the spirit of recovery, and it could put the person and their family at serious risk of persecution; worryingly, the person could even become a target just because of their address. This is so very hurtful when you know that that person just wants to feel normal, be allowed to find their independence with dignity and have their privacy valued, but now they have to deal with all these extra pressures. Would staff like this to happen to them, or to their loved ones? Again, they need to be able to put themselves in the shoes of the service user and the whole family, and try to empathise with them a lot more.

Another source of stigma we have had to endure, and try to prevent where possible, is the way some staff can be rather cavalier in their planned use of interventions to get people to do what they feel is right without having any idea of the stigma and alarm they can cause for the service user, the carer and the wider family, or the stress that can follow. And yes, before we go any further I do know about the Mental Health (Care and Treatment) (Scotland) Act 2003. For many carers, knowledge of this is their protection against unscrupulous use and their yardstick for what is acceptable and not acceptable. Do mental health professionals really think the service user is not going to get a shock if they are suddenly told that they are going to hospital, without any prior warning and for a physical health cause? How is this going to impinge on their mental health? Do they really think the service user is not going to be noticed by neighbours if a police car turns up and is sitting waiting? Have they wondered how they would feel if it was them? What is to be the long-term result of this for the service user if embarrassing thoughts prey on their mind whenever they recall the situation, and how does this help their wellbeing?

One thing that has never failed to astonish me is that, despite knowing that stress is something that can help precipitate relapse, staff do not seem to feel they should routinely modify their actions to prevent discomfort as far as possible. One would think that they, of all people, would be acutely aware of this need, but at times I have felt they were the last to understand. It has made me feel extremely stressed just to listen to their ideas when I know the effect they could have on my relative, and I've tried to persuade them to think of a more person-centred response. At almost all times when I have been directly involved, a more sensitive approach has resulted or no action has been taken at all. It is lucky that I have a sixth sense about when something not good is about to happen but there have been times when I've had to drive at great speed – which is a terrible pressure for me – just to make sure unsuitable decisions are not reached.

Let me tell you about another source of confusion and stress for me as a carer, which can happen when someone who's become part of the mental health system enters a new tenancy. Having been actively involved in the viewing of the premises and the decision-making regarding obtaining the tenancy, mental health staff stand back and leave you, the carer, to pick up the pieces. No discussions are had or decisions made as to what needs to be done, who is going to do it, what it is going to cost or who is going to pay for it. The place needed to be plastered, wallpapered, painted, carpeted, furnished and much, much more.

I wanted the best for my relative's recovery, so I felt aggrieved when another move was planned by the mental health professionals and another large sum of money incurred as more or less the whole process was repeated. This was even more concerning because my relative had not, to my knowledge, even expressed a wish to go to this new place. To me this is certainly not person-centred planning, and nor can it be seen as recovery-oriented when things are done to people because mental health staff think they know best, rather than because the service user is actively involved in decision-making with their views respected. It also leads to difficulty for me with our family member because they believe that it's my job to stop that kind of thing happening when they feel unable to stand up to staff, but this is not always possible for me because things are not always discussed openly, in my opinion.

I have not learned solely from my own experiences of mental illness; I've also formed friendships with other service users and their families that have lasted years. I realise the importance of good communication, discretion, a sense of humour and never being judgemental. We have had lots of fun with games of tennis, swims, walks, music sessions, shared art ideas, parties, telephone calls and lots of laughter. Another thing that gave me a lot of joy was being persuaded to become a volunteer at the local mental health association, which was mostly a very therapeutic experience and helped to heal me. I met so many wonderful people who empowered me so much in my understanding of mental illness and helped form my early views about 'recovery'. I had some great conversations too, and was puzzled when professional mental health staff asked me how I had been able to speak to 'these people' and expressed surprise at how involved in a conversation the service users could get. I do think that they could have known them better too if they had taken the trouble. This kind of conversation with staff left me feeling dismayed and concerned about how much change needs to take place in attitudes and skills, and when this is going to be addressed.

I later volunteered with a friend at the Salvation Army, in a city centre drop-in. This was challenging in that we had to cook all the packets of food that Marks and Spencer had donated and get them all ready at the same time, as well as welcoming the clients and assisting them in what they required. I was, amazingly, the unbeaten table tennis champion there (a skill I perfected when my relative was first diagnosed), and we spent a lot of time practising – they were determined to beat me. Anywhere was better at that time than the world of mental health, and we seized on every opportunity. My relative could beat me at badminton and we were about the same at tennis so we

had lots of good matches and got lots of other people playing too. This was a good way to get to know people without too many words having to be said by them at first. I had been a youth leader in the past but it was the knowledge and experience gained from my many friends who had mental health issues, and the experience I'd gained at the local mental health association, that empowered me to do as good a job as I possibly could there. Having a relative with a mental illness made me much more aware of the needs of those with mental health issues.

I remembered all the times when I'd not known where my relative was and hoped that someone was seeing they were OK. This helped me to know more about mental illness and I felt more capable and empowered in my caring role. I was becoming more aware through this volunteering that mental illness was certainly not just about medication. Through knowledge and experience I have realised that given the right tools – art, music, creative writing, sport, a dog, whatever – people can be empowered to support their own recovery. This helped my own wellbeing as I felt much more optimistic for the future, and once again it helped to form my early views about recovery for my relative.

After my long struggle to get help I was exhausted. The psychiatrist said that she marvelled at how I'd managed to go on for so long, but when I asked what else she thought I could have done she said she did not know. That was the problem! Very luckily, I saw an advert for a local mental health carers' support group run by NSF (Scotland), now Support in Mind Scotland. As soon as I walked through the door I knew I was home. These were people who understood me. I did not have to hide anything. I cannot speak too highly of them and what they have done for me, or of the dedication of the staff. Over the years we have laughed a lot, cried a bit, been empowered to understand more about ourselves, mental illness and medication, investigated psychological therapies, found out about our rights as carers, touched on legislation and policy, got in touch with our creative side and made many friends. They have been my lifeline, supporting me to care for my relative better and protect my own wellbeing.

If Support in Mind Scotland has been my lifeline, the Scottish Recovery Network has been my passion and joy and one of the really positive things in my life. I have been involved from the very beginning because I believe everyone in Scotland has the right to live well in the presence or absence of symptoms and be given the chance to have hope for the future, whether they're a service user or a carer.

At first, my focus when receiving help was very much on the recovery of my loved one with my being supported to assist them. Any therapies I received were, I believed, to help me keep well in order to support the person with the mental illness. You can feel almost guilty if you think about yourself without thinking of a benefit to the person for whom you are caring. I did not know anyone who had had a carer's assessment done, so that probably influenced my thinking too: I did not feel that carers were seen as high priority.

I was completely caught up with the recovery of my loved one right from the beginning. Their progress and welfare at any given time was (and still is) the main barometer for measuring my own wellbeing. When they are doing well I feel better. I was aware, when I was very stressed, that I had to do something to restore the equilibrium of my wellbeing as soon as possible in order to keep well. I have had respite twice through carers' support and this has really helped (I always hope it will be delivered, but it needs to be assessed by specialist mental health carers' support workers. The thought of councils assessing mental health carers' stress is alarming to me as it might lead to carers not getting help when they badly need it). Swimming, walking, working in my garden and massage have helped me relax, as have the support from carers' support workers specialising in mental health and the peer support of other carers. More recently I have benefited from WRAP (Wellness Recovery Action Plan) training delivered by a mental health carers' support worker.

During a particularly traumatic time when I was too numb even to realise how stressed I was, I lay on my settee and read – not the more serious classics I usually enjoy but light modern novels, more and more of them. I then bought even more. I have no idea what I read but the world of the novel was a place to get away from the pain. If I concentrated really hard on the text I could not be thinking about anything else. That was my escape, and I think it probably saved my sanity. I am always careful now to read some light-hearted literature; it is a good place to be when I'm feeling stressed. I also had – and still have – a great need to listen to live classical music and jazz. I once set off for a Tommy Smith concert in a snowstorm without being absolutely certain I could get home! I just knew it was a way of restoring my equilibrium and that it would prevent me from becoming unwell.

However, these actions do not deal with the accumulation of experiences you have to address if you are to truly recover as a carer instead of just restoring your equilibrium. I also think it is harder to deal with recovering, as a carer, if you do not believe that the person you support is at that moment

experiencing recovery; you know how hard they have tried in the past, only to be knocked back and discouraged by the barriers in society, such as access to employment, that can prevent real recovery taking place and the less-than-helpful system of paying benefits, which is not flexible or progress-enabling.

I recently had an interesting conversation with an Italian psychiatrist who felt that in order to fully recover and be free the service user and carer have to be able to examine the baggage they are carrying, acknowledge their losses, discard them and then move on. I think this may also depend on the length of time of the illness. The sooner you get quality help, the less baggage you are likely to have to lose and the smaller your losses will be. Likewise with your experience of caring. It is not enough, he asserts, just to live well in the presence or absence of symptoms, as this could lead to people who are not ambitious for themselves leading a life that is not challenging enough for them. They could end up just existing and not much more, and this is not really recovery.

I think this is where a lot of carers find themselves, because nobody has acknowledged their need to recover their lives or said that they must be actively supported not just to help their loved one but to remember if they wish to recover their own lives. This depends, I believe, on whether the individual feels hopeful enough to engage with the process and how self-motivated they are, but also on the empathy of support workers, the support being person-centred and the quality and relevance of the support offered.

Recovering fully is a challenge because the systems around the individual are not wholly in place. You may have ambitions but the mental health system can stigmatise you and make it hard for you to move on, leading at times to feelings of helplessness and possible self-harm. This is why staff and others must be so careful of their actions. It may not just be in that moment that they are affecting the service user and the carer but in the future also. For this reason, service users and carers who have been in the system for a while may need specialist help to kick-start their recovery and give them hope.

Hampering my own recovery and requiring much thought is the following problem, which is very painful to deal with. I can accept the diagnosis, the vagaries of the mental illness and the lack of understanding about mental illness in the family and the community because it is natural for people who have not had experience or education about something to feel fear and prejudice. What is harder to examine and discard is all the mistakes the

professionals have made through not listening to my loved one and me. We live with the consequences of these mistakes every day. You might think you have examined them and discarded them but, because of their severity, you may only have slammed the lid on them temporarily – in which case they'll keep coming back to haunt you. The memories make me weep even when I least expect it so I am not free, but I believe I should be able to be as free as possible. I deserve to recover my life and I don't think it's arrogant to say I deserve support to help me do so. I did not plan to be a carer, I just have to deal with the issue by hoping that what I'm saying will be taken seriously and that staff will receive training. And because it is service users and carers who are the experts by experience, it is they who should be delivering this training!

Like service users, carers should be entitled to systems of protection from those professionals who harm or threaten to harm them and the effects of their actions on the wider family and siblings. I believe a lot of the problems stem from a previous system where mental illness was seen as a tragedy about which nothing could be done. Better training must be given so that staff realise that the things we have endured hinder our recovery and that, in Scotland, recovery is a right. I also believe that they must have a better understanding of their role in supporting recovery and what helps, and that this must be continually evidenced and evaluated. Likewise, whether services are really recovery-oriented must be evaluated by service users and carers, with action taken immediately if they are not. It is an ongoing process. The passivity of the past has to be replaced by genuine partnership working between the family, service users and professionals, with good communication becoming the norm and good person-centred planning offering choice and creativity. The importance of the carer and the wider family (when they choose to be involved) to the recovery of the service user must be better understood, with more use made of the service user's existing relationships.

However, as the years have rolled on I have found myself realising that my own life is passing and things that I might have liked to do have not been done. I also realise now that I am not always capturing the equilibrium like I did in the beginning. I, who tried my hardest not to let it happen and had such high hopes for partnership working with staff, have become worn down by the system at this moment in time. It is my belief that the mental health professionals could have made a much better job of understanding my relative if they had listened to us both a lot better. As for my wellbeing, if things had been done differently I would not have suffered such a lot of pain and stress and I might have had more choice about how I lived my life. I often wake up

finding I am weeping as I remember things; I still have some way to go in my recovery as a carer as I have lost a lot of my hope. For the sake of my loved one, my family and me I shall have to find it again!

One way I have found of dealing with this stress positively is to take part as a carer in selection, teaching, assessment and research at the nearby university, and to have a different social work student shadowing me every year. I introduce them to my life as a carer and it is such a rewarding experience to hear them telling contemporaries in a presentation or essay about my experiences as a carer, and general issues in mental health. It makes me very proud that they are so keen to understand and make a difference, and of course I learn from them too; this is a far superior approach to that of 'book learning only'. I am also involved in the Doctorate of Clinical Psychology programme at another university in a similar role. I am particularly keen to get involved in this way because I feel that cognitive behavioural therapy is a particularly superb way to support recovery. The therapist and the service user/carer are on an equal footing, which is the very basis of person-centred planning and therefore of recovery. It is also an excellent means of putting the service user and carer in control, and may result in less medication being required.

I do hope that the system will respect the knowledge of these students, and that the 'old hands' will be inspired to learn from them. I saw a brilliant student nurse in action recently. His communication skills were quite amazing. He suddenly appeared just before the care plan meeting and offered my relative and me a cup of tea. That thoughtful gesture and his communication had the effect of making my relative feel empowered to attend a meeting for the first time in many years. He was successful because he was a people's person and genuinely interested in them – and, most importantly, he had empathy. He also spoke to us as equals. With staff like this around, it is possible to feel hopeful.

I have also been part of the selection process for a new psychiatrist recently. It was such a joy to hear this young man speaking passionately about recovery, and to hear from other service users and carers that this is what he is genuinely about. I am only sad that my own relative will not be able to benefit from his skills, as he has since moved out of our area.

I also support two other people who receive older people's services. Here the services are about empowering people to stay in their own homes. They seem

much more responsive to the needs and choices of the people concerned, and more in line with the principles of recovery. Adult services need to learn from this model, I believe. They need to give up some of their power, take part in person-centred planning and really listen to the service user and the carer.

At the beginning, before I was weighed down by the trauma of mental illness, I used to laugh and dance a lot. I hear the music now but I do not always remember to dance. Caring has robbed me of a lot of my spontaneity and confidence. A service user asked me today if I am still in love with life; the fact that I had to stop and think for a moment made me realise that I still feel numbed by my experiences. I have to find a way to recapture that joy of life and own it again if I am to truly recover as a carer.

I have only shared a few of my experiences, as many of the others are too painful or personal for me to recount. I am grateful for the support I have received as a carer and for this opportunity to share my thoughts, but I think my recovery will be a little while in coming. I still have too much baggage to lose.

What would immediately help? For carers and their needs to be taken seriously, and for their role in their own and their loved one's recovery to be better understood. It is not just about restoring one's equilibrium but about recapturing a life. Staff should understand the importance of positive risk assessment, good emotional intelligence, good communication and creativity of approach in their dealings with service users and carers, and be aware of and make good use of psychological therapies and respite. They also need to understand that carers and service users are experts through experience and should therefore be the teachers of the future. If we are to be serious about recovery for service users and carers in Scotland, a lot of change has to happen, because our lives are happening now and we want to be able to live them to the full. Is it not our right to have that choice?

Chapter 12

Recovery together

In Sussex, Anon

Recovery for me is a developmental process and some of it is very painful and sad, even today. The story I am going to tell here is about my development as a young Iranian girl coming from a different and war-torn place to live in England and growing up with a brother who was diagnosed with schizophrenia.

30 years ago

30 years ago my brother became unwell and was admitted to hospital. I was with my mother, who did not speak very good English. I asked the doctor what was going on. He just looked at me and said, 'Chronic schizophrenia'.

'What's that?' I asked. He just walked away – that's all the explanation he gave me. Mum and I were bewildered. We had never been to a mental health institution before. It was scary. We didn't know what was going on and we dared not ask any questions. Then they said to us, 'Please don't come in here – please don't visit' because they were going to medicate him. Well, hang on a minute – this is my brother and I want to know what is going on. They said they could not tell us because of confidentiality. My mother was crying. Nobody came to give us any comfort or tell us what was happening. My mum was saying, 'This is my son, I am not going home – this is my son, I want to know what's going on!' The more upset we became and the more we wanted to know what was going on, the more the staff didn't want to deal with us.

Eventually we had to go home anyway. But they didn't ask us what happened in our lives. Nobody asked for our history – it was all so medical model. They called us in the morning and said they would be giving my brother ECT[15]. We asked what that was and were told it was electric shock treatment. We were scared by the thought that someone we loved would be receiving this treatment and had no understanding of what it meant.

[15] Electroconvulsive Therapy

Nothing was ever explained properly. My mother didn't understand the language and I was a naïve young girl not educated in mental illness. It was very lonely and we just kept wondering whether we were making the right decision about whether my brother was in the right place.

Days passed and we kept going there. My mum wanted to take food to the hospital because my brother wouldn't eat English food. He liked Iranian food. The staff didn't understand the cultural issues around what food meant for us. It was such a different set-up – so far from my mother's culture. She didn't understand and still doesn't. At that time, over 30 years ago, my country had a revolution and war and my father was stuck there; we didn't know where he was, so we were all very distressed about what was happening in our homeland and our family. We thought that my brother becoming ill might be linked to our cultural background but nobody wanted to hear our story. The difficulty was that we were all depressed as a family and traumatised by the losses at home. Our friends had been killed. We had to live on without anyone understanding what was going on for us.

Eventually they medicated my brother. At first he looked like a zombie, and that was scary too. When we asked, nobody explained why he was like a zombie. They gave him the ECT as well. In a way my mum and I just surrendered to what they were doing. We didn't understand so we put all our faith in the professionals. He was in hospital for three or four weeks. He came home and was a bit better and more settled. But even when he came home there was still no explanation about how we were going to deal with him there. Nobody talked to us as carers about how we could be with him. Our hope was that he would come home and go back to being the person he was before the schizophrenia. We had no idea at all that he might have to go back to hospital again and have more ECT and medication. Carers at that time were not recognised as carers. We were not seen as people at all – most of the time we were just invisible. Even when we were visible, we were just family who were troublemakers. Carers didn't mean anything then.

Two or three years later

Two or three years later my brother was regularly going back and forth to hospital. We were getting angry with him for not getting better and he was getting stressed because we didn't understand what he was going through. At about that time I decided I wanted to learn more and understand.

Someone gave me the number for the National Schizophrenia Fellowship and I rang them up. They were a lot more helpful than the doctors and I became very involved, asking them questions. After that I launched the National Schizophrenia Fellowship in Eastbourne, which is now known as RETHINK Mental Illness. Then I became involved with the Community Health Care Service – which doesn't exist anymore – and became a member of Business Professional Women. We all had to present in the community so I went to the community of mental health and became very active in it.

The more involved I became in the community, the angrier I got about how myself and my mother were being treated. It was really out of order, so I started to organise a carers' group in my own house. A few carers came and, as a result of this, I ended up running a group in a Community Mental Health Team with a psychiatric nurse for 15 years. Meanwhile I went and studied, and gained a diploma in counselling. I then studied psychotherapy for four years, which made me realise how traumatising the system had been for us as a family. I went into my own therapy because of this. I saw how distressed I was as a person and how our family dynamic had been affected by the trauma back in my homeland, the silence in our treatment and the stigma. This and having to justify ourselves all the time left us feeling even more isolated and lonely. Every one of us in the family (I have two sisters as well as my mum) felt lonely in themselves and had their own issues around this. It was very difficult to give a language to all of this and speak to each other about what our brother's illness was doing to us. It caused a lot of conflicts between us, but still there was no help for the family about how we could be there for each other and for my brother.

Ten years later

Ten years on from diagnosis, I was going to be married and bring someone new into the family. My partner didn't understand what was going on and didn't want to understand how my brother was. There was also a lot of conflict around this. My father was still stuck in Iran but I wanted him to be here for my wedding. So we paid people to smuggle him out to Yugoslavia. The local MP helped us get him from there to England. The sad part was that my brother is the only son. When my father came back from Iran he was also traumatised from the tortures in our homeland. When he saw my brother it was a distressing meeting. He had come from one awful situation to another awful situation. He was very sad to have lost his only son to schizophrenia.

My father felt like a failure. He had lost his homeland, his security and now his son. All of these issues didn't help my brother. He was always stressed and upset, which caused more conflict in the family. Once again nobody wanted to understand these dynamics – it was always about giving more tablets and more medication. If only they could have listened to our story. It would have been more helpful to him and to us. I did get married and my father did give me away, and that was the nicest part. The difficulty was that my father became depressed with all the torture from Iran, the mental torture of being called every day and receiving death threats. One of my sisters became depressed and one became anorexic. My mother suffered from heart problems and anxiety. All of this was not very good for my brother, causing him more stress and more hospital admissions. Instead of listening to our problems, they changed his drugs – and when things started to deteriorate again, he was put back on the same old drugs. With the new drugs he just became more crazy and mad, and this upset all of us. For weeks and weeks he would stay in hospital to settle down and again we would have the situation of carers not being understood. I feel that my brother's body was very much abused by all these changes in medication. He never got back to how he used to be. Things just got worse and worse. I kept thinking that if only there was some psychological input in all of this instead of just medical input, it would be much more helpful.

Seven or eight years ago

My training in psychotherapy was good training and I learned to understand the family dynamics. Having personal therapy helped me. Still, the more I understood about the hospital situation and the systems, the more upset I became. I thought, 'If only I'd known then what I know now, I could have helped my brother'. This is why I still feel very angry and distressed that nobody ever explained things to me and my mother. At one point, about seven or eight years ago, it was decided that my brother needed some psychological input, so we received family therapy. This was good but late, and not always resourced to work effectively with the language barriers. Because my mother didn't speak good English, we needed to be the interpreter for her. This was difficult because she was speaking from her emotions but didn't want to upset us. They did briefly bring in an interpreter so that we wouldn't have to do the translation but it turned out to be too expensive and was stopped. Being the interpreters between the system and my mother caused a lot of problems, as my mother would think we were not translating things as they should be

and vice versa. This problem of language and interpretation was also missed as a barrier to therapy. In the end, my mother had more rapport with the interpreter than the psychologist!

We have always felt misunderstood and judged because of our differences. Instead of people in the system being able to embrace our difference, lack of understanding made them misinterpret what was going on. But the same was also true of us: my mum was judging of the services as she was not familiar with their culture. It was us as well as them misunderstanding and missing each other. The trauma of cultural difference caused more misunderstandings and stress for my brother too. The other problem was lack of continuity and the way changes kept happening without any explanation to us about them. Nobody looks at the stresses that constant change and making new relationships all the time can cause to a family and the person who's suffering. There was not a good facilitator to bring us and the system together.

Recovery alone

We do have some psychological input now – the family therapy still. But again this feels late because so much was missed and not heard before. We cannot turn the clock back on this loss. Receiving personal therapy in my training gave me a sense of hope and who I am – a sense of self – identifying in me the real difficulty within the difficulties. I mean that, regardless of how angry I was with the system and how angry and hurt I was with the people who didn't listen to me, the training gave me the understanding that the system did not have the knowledge either. This gave me the capacity to forgive the people in the system, as they had no more education around what was happening than I did. But the biggest forgiveness in all this was about forgiving myself, because if I had known what I know now when my brother first became unwell, I could have helped him more. I didn't know at the time and it is okay not to know. The key message here is that if you don't know something it is okay to ask and to challenge and to find out more. Just because someone is a professional doesn't mean they know more than you. Quite often they don't. Hopefully there will soon be more psychological input in the system rather than just the medical model.

We users of services can see the stresses and low morale within the system and the staff. If the staff are not being looked after by the system, how can we be looked after by the staff? Appreciating the difficulties for the staff

themselves when the system changes with every new government helped me to see them as people too. Sometimes we see that they are just running on empty, and sometimes they don't even know if they have a job or not – which causes real problems for the people they are caring for. In particular, we can see mental health issues within the staff as well. This is very scary for carers and for me. When I completed my training and could see the problems, I felt that there was nothing I could do, and this brought a sense of hopelessness. What would happen to my brother if we died? Questions of this sort have been asked many times in our carers' group. It is always difficult as the carers never feel assured about that. This question is still asked and carers can get very anxious about it as many people like my brother are often abandoned by families or outlive them. When I visit my brother in residential care I see many people who have no families to visit them and I can see how difficult it is for them.

To be able to talk about all of these traumas is a very important part of my recovery, as is having learned the skills to help other people. I am who I am, and if my brother had not been ill I would not have taken this path. One of the biggest obstacles to my recovery has been the feeling of loneliness I've talked about here. I don't mean just being alone – I mean not feeling listened to or able to share different points of view, and the destructive feelings that can come from this anxiety conflict. I see this dynamic at work often, particularly in the way the system still finds it really hard to listen to carers or recognise that we are there. The system needs to understand the need to have someone to facilitate listening and shared understandings between these dynamics. When you feel lonely it influences your thoughts, feelings and behaviours, and has consequences for health and wellbeing. Loneliness happens a lot within families looking after someone who is ill. Often the carer gets angry or upset with staff, who then treat them as a nuisance or ignore them, which results in the carer feeling even more angry or upset. This cycle goes round and round, becoming a more and more negative snowball.

Recovery together

Running the carers group' was also an important part of my recovery, contributing to a more positive snowball effect. The people there often told me that they felt listened to and understood, which felt very satisfying for me. Knowing that you can help just by listening and hearing someone's perspective has the power to dispel the destructive effects of loneliness. It

helps me to reach people and empower them to look after themselves; to understand that their loved one is not the only person in the world and that they exist too. If they don't look after themselves the mental health of the loved one can suffer. I learned to nurture myself by doing things I liked, e.g. giving myself massages. I wanted to help carers learn that they have lives too.

This often gets missed because people focus on the person who is ill and not on themselves, but recovery is for both people. For a long time, the focus of my life was my brother and everyone else was forgotten. This gave my brother the sense that he was important because he was ill. Making the person who is ill more important makes them more self-centred and puts them in the victim position of becoming their label (the schizophrenic), so their recovery gets missed too. Not looking at our own recovery can actively harm the recovery of the person loved and cared for. We have discussed the importance of carers making time for themselves a lot in the carers' group, as it is one of the best ways for a carer to find their own importance. I used to find my importance in going to meetings and fighting for my brother and never fighting for my own self because I didn't see myself as important then. It was only later on that I realised I am important too.

Looking back, I realise that I started my journey like a child who expects their parents to be perfect and then gets angry with them for failing to live up to expectations. As I have grown, I have come to understand that nobody is perfect and that recovery might be about accepting this in myself and others and learning to forgive. This does not mean acceptance of bad things but rather of the fact that the people in the system did not intend to hurt us. They intended to make my brother well in the best way they knew how but this was limited, and they didn't try to hear or understand us. There is a difference between loving and caring for someone. I love my brother unconditionally for who he is, and sometimes my anger at his poor care is not understood by the people who provide that care but don't love him like I do. Sometimes, though, my anger has been caused by unrealistic expectations that the services should love my brother as much as I do. Recovery is not just about me learning all of this – it's also about sharing it with services and carers so that we can all work together to help my brother and people like him. I have trained many mental health nurses about carers and cultural differences, and some of my ex-students are now involved in my brother's care. We have started to reach a place where recovery for me, my brother and the people providing services is now looking more realistic, but I know that this is still not commonplace.

Practical tips to support recovery together

1. Realise that good intentions are not enough – actions or the lack of action have an impact.

2. Engage with carers instead of isolating us as troublemakers.

3. See us as people who can help, not as people who makes things worse. This makes us defensive and breaks the relationship before it starts.

4. Communicate problems without breaking confidentiality.

5. Recognise carers as individuals and the impact mental illness can have on a family.

6. We all need to develop and grow, so don't exclude carers from this.

7. Provide a reliable human face for carers to relate to – the absence of this can be emotionally destructive, leading to loneliness and anxiety.

8. Don't dismiss carers when they are angry or upset. It may have taken them a long time to get to that place. Contain and respond rather than controlling and reacting. That means listening and helping to defuse destructive feelings instead of fuelling them with more negative energy. This would help the person-hood of all parties to be listened to and recognised.

9. See everyone as a human being. See the person in the carer and the persons in the system. When there is conflict we see the other person as the enemy, an object with no feelings; when we see them as a human being we want to communicate and talk.

10. Share opportunities for education and facilitate learning from different perspectives.

Chapter 13

Making sense of it all

Ruth Chandler, Simon Bradstreet and Mark Hayward

During the collection process, the editors decided to step back as much as possible from their views to make room for caregivers to define recovery on their own terms. This was quite difficult to do, as each editor came into the collaboration with a view of recovery that informs the way they read the accounts and what they prioritise as important. The caregiver authors in this project also hold some very mixed views on whether recovery is or isn't meaningful, sometimes in the same account. Some of this is about vocabulary. The word 'recovery' does not always have to be used to talk about working holistically and hopefully with the person cared for while holding on to hopes and aspirations for the self. For some authors, however, core recovery attitudes like hope are just not relevant to their psychological wellbeing, and other attitudes associated with coming to terms with a loss, such as forgiveness and acceptance, are given much higher priority. How are we to make sense of these differences in perspective without forcing a consensus or prioritising one perspective over another?

Selection is unavoidable in any act of interpretation, and it is here that the question of the power to name and reframe comes to the fore. Instead of pretending that this power isn't there, we decided to put it firmly on the table of this concluding chapter. To maximise the interpretive agency of our authors, we asked them to name the most important points for them. The points were then put together, condensed to eliminate repetition and minimally coded as 'enablers' or 'disablers' of recovery and wellbeing for caregivers. The first part of this chapter takes these enablers and disablers as a frame to draw out learning from the narratives. Not everyone wanted to do this, which is an interpretive choice in its own right. Where this happened, the editors used the collective frame to draw out related points. In the second part, the editors step back in and offer reflections on their learning from the narratives from their range of personal and professional perspectives.

Learning from the authors

1. The importance of 'care for the self' in recovery and wellbeing

The importance of **care for the self** is a repeated theme throughout the narratives, whether it is currently happening or out of reach. Many authors describe caregiving as an emotional roller coaster in which there is a relentless double-whammy of coming to terms with deep personal losses, previous hopes and expectations and adjusting to new realities, often involving a great deal of personal effort and ongoing sacrifice of personal hopes and aspirations. Nobody reports caregiving as easy and, as Cathy tells us, many feel guilty about taking time out for themselves, which can lead to a build-up of resentment and conflict about not having any life or fun of their own.

You can feel almost guilty if you think about yourself without thinking of a benefit to the person for whom you are caring.

Authors report a range of individual strategies for taking care of the self – for example, *nurture myself by doing things I liked, e.g. giving myself massages*. Another talks about *collecting pebbles* of special moments (memories) to sustain wellbeing when he feels like the rock of day-to-day living is too big. For another, personal, religious faith provides a foundation of support as she comes to terms with the loss of her partner while supporting her son.

Being able to share experiences and be listened to in support groups is also reported as a huge source of care for the self in both Scotland and Sussex:

Knowing that you can help just by listening and hearing someone's perspective has the power to dispel the destructive effects of loneliness. It helps me to reach people and empower them to look after themselves; to understand that their loved one is not the only person in the world and that they exist too. If they don't look after themselves the mental health of the loved one can suffer.

The sense in which loneliness is expressed by this author is not just about being alone but about *feeling* alone, even in the company of other people. Where authors belonged to support groups that had an explicit recovery focus, this sense of loneliness was challenged head-on; recovery for the self was understood not only as a relevant category of experience for caregivers but also as a key to recovery all round. Patricia recounts how involvement in 'Prospect', a self-development training programme organised for family and

friends by EUFAMI (European Federation of Families of People with Mental Illness) *enabled me to see clearly my own journey and at times the brave and limitless possibilities for all involved in this process.*

Where support groups did not have an explicit recovery focus, opportunities to express negative feelings or frustrations about the person cared for without feeling guilty or judged were also highly valued in individual recovery pathways, as were opportunities to share skills or develop new ones in community settings. However, recovery for the self was never straightforward for caregivers, no matter how well supported organisationally. Most authors saw their recovery as inextricably linked with recovery for the person cared for, and this could be a good or bad thing for their wellbeing. As Elinor puts it:

I was completely caught up with the recovery of my loved one right from the beginning. Their progress and welfare at any given time was (and still is) the main barometer for measuring my own wellbeing. When they are doing well I feel better.

This could also work the other way around, with one consultant seeing the absence of the caregiver at meetings as a barometer of her relatives' wellbeing:

My daughter takes medication really on time, she set up an alarm and everything that way – she manages her illness herself. At the moment, I don't even know what dosage of medication she is on because it has been so long. When she goes to see the doctor, I mean her psychiatric doctor, he says, 'Oh, your mum is not with you because you are better now, you know'. He knows only when she is not and she can't go out on her own and I am with her – if she is anxious, I am with her... When she is better I still have to carry on, even now – jokes, and making her laugh and after, it never stops. And your recovery, my recovery is meeting people outside her and doing my own things. And letting her go and do her own things.

In Sussex, one anonymous author suggests that putting the recovery of the person cared for first all the time could unwittingly reinforce 'sick roles' and be detrimental to recovery for both parties:

For a long time, the focus of my life was my brother and everyone else was forgotten. This gave my brother the sense that he was important because he was ill. Making the person who is ill more important makes them more

self-centred and puts them in the victim position of becoming their label (the schizophrenic), so their recovery gets missed too. Not looking at our own recovery can actively harm the recovery of the person loved and cared for. We have discussed the importance of carers making time for themselves a lot in the carers' group, as it is one of the best ways for a carer to find their own importance. I used to find my importance in going to meetings and fighting for my brother and never fighting for my own self because I didn't see myself as important then. It was only later on that I realised I am important too.

This point is also made the other way round. Cathy reports her husband as saying, *I may be mentally ill, but I am not stupid*. She talks about how, in finding her initial identity in a caring role, *he felt I always treated him as someone who could not think or feel for himself. I had to change this in order for our relationship to flourish*. Her husband had never asked her to take responsibility for him or his recovery. As Cathy becomes more aware of this and takes a step back, she also starts to feel better within herself.

What was happening was that I was beginning to reclaim my life, and that could only be a good thing.

There is no right or wrong here as each view comes from a very different place in terms of what was helpful at the time. It is clear that being able to step back and make room for self-care can be a positive enabler of recovery where this is supported in the triangle of care. Many of the narratives report invaluable support from other family members and friends as a resource both for their wellbeing and for the person cared for. This is not always the case, as some authors report breakdowns in friendships and relationships that leave them feeling very isolated and with fewer resources for care of the self. But just listening to the understandings of the person cared for can also be an enormously helpful part of recovery for caregivers. For example, Elinor reports her relative explaining their key triggers for mental distress, which proved invaluable in helping her to make sense of what was going on.

Throughout the collection, authors also stress the importance of a **whole family approach:** *Mental illness affects all family relationships. Close family members (siblings, children, parents) will have different needs and responses but they all need help.* Caregiving relationships can also be very complex and place heavy burdens on ageing relatives who might rightly be expecting to receive some care themselves. As Jennifer Robertson puts it:

In my case I am a carer of my daughter – even though she is married – and her child – even though she was adopted. My sister, as church elder and a member of a caring group, has recently had to help a 75-year-old grandmother with terminal cancer who is the sole carer of a five-year-old grandson whose mother, aged 40, is a lone parent with schizophrenia.

Although this is an extreme example, many caregivers expressed worry about what would happen to their loved ones if they were no longer around. Where the triangle of care is not working so well, or has never been in place, caregivers also report lasting damage to their wellbeing:

Anna Karenina famously begins, 'Happy families are all alike; every unhappy family is unhappy in its own way'. But families with severe mental illness are alike in their suffering, as this book shows – living on a knife-edge of horror and grief, along with the total disruption of 'normal' life. For myself, to sum up, I am like another character in that novel who 'did not want to talk of her sorrow, but with that sorrow in her heart she could not talk of outside matters'. My sorrow, because of my daughter's tragic plight, has eaten me up, and I find no therapy for that wound.

2. The importance of early support and information for caregivers

All of the narratives talk in different ways about an initial period of confusion and a need for good information and education early in the process as a key support for caregiver wellbeing. This can be difficult, for, as one author puts it:

The slow, insidious onset of an illness is initially hard to diagnose but this early time, when the inner and outer worlds of the patient and the family are beginning to fall apart, is precisely when help, structures, relief and coping skills need to be given.

When it is your job to deal with people who are experiencing mental health difficulties on a routine basis it can be easy to forget that new caregivers often have little or no mental health experience to draw on, and can become very frightened in their own right and worried about how best to help. Mr and Mrs P point to early completion of a caregivers' assessment *on first hospital admission* as key to accessing the help that already exists in the system. As a strong family with a clear sense of their entitlement in the triangle of care, Mr and Mrs P demonstrate the effectiveness of seeking out relevant information

about the diagnosis and your rights as a caregiver early on, and show how this can be both very empowering in establishing mutually respecting and assertive relationships with mental health professionals and supportive of better communication with the person cared for:
We have a better understanding of the entire approach to treating psychosis – including the psychological aspects – and that helps when we communicate with my son. We are also able to assist other carers with our newfound vigour and, in many cases, offer some guidance on the best way to approach the mental health system and its pitfalls.

For long-term caregivers these points are particularly poignant, as they are often working through a legacy of poor information and support that can undermine their confidence to assert their own needs alongside those of the person cared for. Carers' Assessments have been historically variable in terms of both quality and accessibility, often leaving caregivers out on a limb when it comes to their own support. While Carers' Assessments are an entitlement in the UK, very few people identify as a caregiver when their loved one first becomes unwell:

They are just a mum, dad, husband or wife, sister, brother or friend – and feel it is simply part of their function to look after the people they love.

Many of the narratives describe navigating complex mental health systems alone at initial onset, while still coming to terms with what is happening to their loved one. Retrospectively, this can be a source of much bitterness and guilt. As Tricia puts it:

We often learn the hard way, with no training and little or no support. Finding your own path involves making mistakes...

While recovery for caregivers can be about seeing setbacks as part of an overall process of growth and learning from things that could have been done differently, some lessons from the 'school of hard knocks' may still be best avoided by services who wish to take the initiative on giving good early information.

Initial onset is a confusing time for everyone but it can be made even harder to navigate when there are language barriers and/or very different cultural understandings of both the meanings attached to mental health and the different meanings that may be attached to everyday behaviours. The anonymous author from Iran talks about the importance of giving food to her

family and how attempts to share this are consistently misread as disruption to meal times on the ward. Alternatively, it is a cultural dominant that young people should be encouraged to seek early independence, leave home, get a job, etc., and these values are often implicit in the recovery goals service providers see as important. For one Asian family in this collection, however, young people simply do not leave home until they are married, even boys. While it would be unhelpful to generalise from either account, the small amount of time needed to find out the normative expectations and practices in a family could go a long way towards establishing a platform for shared communication and help to avoid simple misunderstandings.

3. The importance of relationships with services

My 'recovery' is not complete, and of course it never will be, but with my care of my daughter and her subsequent blossoming, my ability to 'read' her mental state and the knowledge that I have back-up, I can remain in a state of what I would like to call 'recovering'.

The authors also make it very clear that it is their relationship with services that often determines whether recovery is an option for caregivers or not, and this point seems to be borne out by the number of empowering stories connected to good, trusting relationships with services, contact with supports and recovery-oriented training aimed specifically at caregivers. Where the triangle of care is working well, caregivers in this collection report being able to share their knowledge of the person cared for with professionals, point to things they have achieved or could yet achieve and have their own hopes and right to a life beyond caring recognised and supported, whether this is called recovery or not.

On my first visit to the Bethlem, I was introduced to all the members of staff. I was also invited to discuss any issues with and ask questions of and with the Staff Nurse and Primary Care Nurse, invited to ward rounds once a week at a time to suit me and asked to collaborate in my daughter's care from day one. Her consultant questioned me, listened to me and expected me to be part of the team. The staff were endlessly supportive and kept me informed as to any changes in my daughter's wellbeing, kept in touch with me and offered advice – and, above all, we all trusted each other. The consultant's attitude was that if I was not strong, healthy, informed and trusted, how could I care for my daughter when she returned home? The entire turnaround of my former experiences enabled a leap in my recovery.

Where the triangle of care is working well, **person-centred approaches** to medication are also reported as a source of hope, and highly valued by many of the authors as a support for recovery all round. A good example of this is offered by Mr and Mrs P. They describe writing a weekly letter to their son's consultant, which is listened to and integrated into their son's care:

I am in no doubt that the information we provided to the consultant enabled him to arrive at the best and most suitable medication for my son. He has the medication administered by monthly depot injection and experiences the mildest side effects we have witnessed since the onset of his condition. He has a Community Psychiatric Nurse (CPN) appointed whom he trusts, and we even had a say in the selection of that CPN.

A good relationship with services from early on can enable a sense of 'unified voice', which supports the triangle of care for all concerned, whereas a difficult relationship can lead to mutual distrust, conflict and disempowerment all round.

What makes a good relationship with services? Authors talk about the importance of **mutual trust**, being included from the start and the frustration and distress that they feel when they are excluded or ignored or when basic trust is compromised. One anonymous author reports being told to go out when a mental health worker arrives at the house to see his partner, and his subsequent attempts to communicate are rebuffed. Although there are issues of confidentiality that need to be worked through on a case-by-case basis, **seeing the caregiver as someone who can or wants to help,** rather than someone who just gets in the way, is a good starting point for service providers to begin relationship-building (or rebuilding) with caregivers.

Where the triangle of care is not working so well, the authors also report worrying levels of organisational hopelessness and 'iatrogenic stigma' – that is, stigma that is produced by contact with clinicians and services. As here, for example:

I can accept the diagnosis, the vagaries of the mental illness and the lack of understanding about mental illness in the family and the community because it is natural for people who have not had experience or education about something to feel fear and prejudice. What is harder to examine and discard is all the mistakes the professionals have made through not listening to my loved one and me. We live with the consequences of these mistakes every day. You

might think you have examined them and discarded them but, because of their severity, you may only have slammed the lid on them temporarily – in which case they'll keep coming back to haunt you.

Elinor describes the impact of a build-up of emotional 'baggage' from the past as being in conflict with recovery for herself. As she puts it, memories *make me weep even when I least expect it.* This has important implications for her understanding of recovery, which she defines as more than simply existing or maintaining equilibrium. Rather, recovery for her is about optimising potential and having the freedom to live well. Working through past baggage is key to this freedom to live well. Elinor suggests that she does not have this freedom yet but strongly believes that she and other caregivers have a right to be as free as possible.

4. A sense of shared humanity

See everyone as a human being. See the person in the carer and the persons in the system. When there is conflict we see the other person as the enemy, an object with no feelings; when we see them as a human being we want to communicate and talk.

A connecting thread in all of the learning points above is the importance of a sense of **shared humanity.** Service providers can help by offering non-judgemental listening to caregivers who may present as angry or upset. Understanding that caregivers might have taken a long time to get to that place could help front line workers to feel less blamed when this occurs and to respond sensitively rather than reactively or defensively. Recognition that long-term caregivers may be carrying deep – for some, irreparable – wounds is also profoundly important for establishing a platform for meaningful dialogue in the present. Mutual trust may need to be rebuilt from scratch, especially if caregivers have been repeatedly let down. However, much as repeated exposure to small acts of iatrogenic stigma can work against recovery, small acts of empathic communication can restore hope, as Elinor also tells us:

I saw a brilliant student nurse in action recently. His communication skills were quite amazing. He suddenly appeared just before the care plan meeting and offered my relative and me a cup of tea. That thoughtful gesture and his communication had the effect of making my relative feel empowered to attend a meeting for the first time in many years. He was successful because he was a people's person and genuinely interested in them – and, most importantly,

he had empathy. He also spoke to us as equals. With staff like this around, it is possible to feel hopeful.

There is a lot going on in this simple gesture – it is just a cup of tea after all, but the effect is huge in reaching across barriers to empowerment and social inclusion. Other accounts also point to recovery as a cumulative process of many small acts, helping a shift from relations of distrust to actively working together to optimise the possibilities for change in a situation.

Caregivers who have had repeated bad experiences of services can quite understandably make hopeless judgements about all mental health services and practitioners. However, being non-judgemental is a two-way street. Being able to forgive past practice and hold hope that this will not always be the case is identified as a platform for recovery together by more than one author:

Looking back, I realise that I started my journey like a child who expects their parents to be perfect and then gets angry with them for failing to live up to expectations. As I have grown, I have come to understand that nobody is perfect and that recovery might be about accepting this in myself and others and learning to forgive. This does not mean acceptance of bad things but rather of the fact that the people in the system did not intend to hurt us. They intended to make my brother well in the best way they knew how but this was limited, and they didn't try to hear or understand us.

The above are important messages for service providers to hear, as individual workers can often feel powerless and unhelpfully blamed. Staff also need to be able to believe change is possible, work hopefully in a situation and be recognised and supported in the work that they do. There are many examples in this collection that report transformations in caregivers' relationships with services through contact with inclusive and hopeful practitioners, as well as appreciation for the hard work that is put in:

The consultant psychiatrists have always worked tirelessly to find the right medication (no easy task as he is drug resistant), but in recent years the attitude towards carers and relatives has been so much more enlightened. The assertive outreach team have surpassed themselves, and their positive and persistent attitude has been likened to a 'dog with a bone' approach. I can only be grateful – in fact words cannot convey my admiration and respect for all the team members.

Exercise 4

Readers may find that they identify with some themes more than others, or have taken different learning points from the accounts. If you are using this book as a learning tool you might want to think about the following questions:

- Which narratives, if any, are most relevant to you?
- Are there any aspects of the accounts that are similar to your experience?
- Are there any aspects of the accounts that are very different from your experience?

If you used the recovery questionnaires at the beginning of the book you might want to see if your answers have changed.

Learning from Ruth

I went into the project with the naïve belief that we only needed to ask caregivers about what recovery meant to them and provide support for the telling in order to collect a spread of narratives about person-centred recovery for caregivers on their own terms. As this was a method I'd used successfully in the past with people experiencing psychosis I thought it would be much more straightforward than it turned out to be. As someone with long-term caregiving experience I really should have known better, but – and I suppose this is a good thing – the really challenging parts of that journey are a long way behind me, so I had forgotten how distressing they were. I am the close relative of someone who is living, and I say gifted, with high functioning autism. It isn't very easy to spot, and he did not get a diagnosis until he was 21. I had been through multiple psychotic episodes by that point, which strangely disappeared when I no longer had to deal with routine bullying of us both, or with schools that found it easier to blame families with mental health vulnerabilities than take a constructive approach to social inclusion.

At a personal level, then, collecting and reading these narratives was both intensely challenging and inspirational. Challenging because it forced me to revisit some deeply buried feelings that were hard to acknowledge but were ready to surface within my own recovery journey – it is nothing short of a travesty that people who routinely support the recovery of others should have so little support for wellbeing themselves. Inspirational because the strengths

and emotional integrity each narrative shows make me proud to be human, even when the account is very bleak.

The narratives have also forced me to question my professional beliefs about recovery and wellbeing for caregivers. I went into this process thinking about recovery as something that was personal to individuals. I have come out thinking about recovery as something for which there is a social and collective responsibility – the triangle of care. Another part of my learning in this project is that hope and hopelessness are in a relationship and do not turn up in isolation. People can feel very hopeless or very hopeful, but quite often they have mixed feelings. Person-centred recovery has not been very good at thinking about hopelessness, but if everyone were already hopeful there would be no need for person-centred recovery. In this sense, person-centred recovery needs to think more carefully about how it constructs itself as hopeful and other practices as hopeless. A strong message from the narratives is that it is simply not the case that medical recovery is always hopeless or has no part to play in living a meaningful life. For many of the caregivers in this collection, medical management of symptoms continues to matter a great deal in framing their sense of hope, opportunity and agency. When medical recovery works with caregivers as well as service users it can also be recovery-oriented in a person-centred sense. The range of accounts in this book point to a continued need to hold hope for social justice for caregivers and the importance of early work in sustaining wellbeing, so that hope for person-centred recovery is not needed for caregivers. Person-centred hope for the medical recovery of the person cared for continues to hold an important role in supporting the wellbeing of caregivers. However, caregivers should not have to live in hope that their roles will be recognised and supported. Rather, respectful partnership working in the triangle of care should be a **positive expectation** for all.

Learning from Simon

Anyone reading these narratives could not fail to be acutely aware of the intensity and enormity of the experiences being described. It is in no way an exaggeration to say that many of the things described in these accounts are at the extremes of human experience. What is, for me, most remarkable is the sheer breadth of emotion described, from the deepest despair, loss and isolation to heart-warming examples of strength, resilience and fortitude against the odds. As a parent, I frequently found myself reflecting on how

I might react in the same position as the authors who described assuming an unexpected caring role for their child. How might I negotiate the treacherous and complex interaction between loving and protecting while offering encouragement and positive risk-taking with little or no support, let alone cope with the unexpected and uncalled-for identity of 'mental health caregiver'?

As a professional who is paid to promote and support recovery, the narratives left me with a strong sense of clarity on how far there is to go before we can truly claim to have a recovery-focused system of support. I was, though, powerfully reassured that while recovery may feel for some like something of an alien concept – either for the caregivers themselves or for the person they are caring for – there is more than enough here to suggest that, where well supported and shared, the beliefs, principles and tools of recovery have much to offer people who find themselves in a caring role. What is equally clear from these accounts is that imposing recovery thinking on people in extreme circumstances who have understandably lost hope or whose own wellbeing has been drastically affected by their caring experiences is at best unreasonable and at worst potentially damaging. In retrospect, approaching this project with a stronger focus on caregivers' wellbeing from the outset (as a route into the more complex territory of recovery – a concept that, for some, was confusing and distant) may have helped.

In this book we have described the possibility of an equal and shared triangle of care as our hoped-for possible future. In this triangle of care, all parties have a valued contribution to make to supporting recovery, and information is appropriately shared and valued. For some of the authors, this is a distant and unrealised concept, but for others there are genuine and real examples of how potentially transformative this mind-set could be – from this I take hope. The experience of personal recovery tells us that it is important to start by understanding and building on your strengths, and within the experiences shared here strengths abound.

Learning from Mark

As a clinician, I had a tendency to 'side' with the person being cared for and would sometimes offer a space that was 'confidential'. This often led to the exclusion of the caregiver(s), but that was okay because they were not the designated person in distress and nor were they my client. How could I have

practised in such a naïve way and not appreciated the complex interplay between the needs of the caregivers and the person cared for? Why did I have to hear about carer distress on a training course before fully appreciating the pain that caregivers can also experience? At times, I may have been one of the clinicians who caused distress to caregivers by not seeing or responding to their needs.

I wanted to be a part of this project in order to assist other clinicians to tune into the needs of caregivers, see and hear the pain of caregivers and promote journeys of recovery by not making things worse. As clinicians, we don't always have the resources at our disposal to respond to the needs of everyone in distress, but this should not stop us from listening attentively, sympathetically and compassionately to the stories of distress that we are often told by caregivers. The very act of listening can be therapeutic, and we should not underestimate the use of ourselves as a resource in this respect.

What stood out for me in this collection of narratives was the emphasis upon 'help'! Whether help was for the self, the person cared or for the whole family, the request for help suggests that the task of caring and enabling recovery was perceived by the caregivers as being beyond their resources. When asked to help, clinicians must not make things worse. They should respond to the call for help by listening 'as best they can', hopefully with compassion. In order to do this, clinicians may have to take better care of themselves and ask their networks and organisations to support their own wellbeing.

Making the triangle of care a reality for all

One of the limits of a small narrative project is that the views expressed cannot be taken as representative of caregivers' experiences in either location. Nevertheless, research into experiences of caregiving echo these mixed views on recovery as a meaningful category of experience. The most extensive research literature has focused on burden (Baronet, 1999), stress (Hirst, 2005), coping (Fortune, Smith & Garvey, 2005) and psychological wellbeing (Chou, Pu, Lee, Lin & Kroger, 2009). Caregivers do not automatically identify as such when a person first becomes unwell. Becoming a caregiver may involve the loss of a previous identity, for example a professional identity that is given up to provide support and care, or a relational identity such as a partner who may undergo sudden significant change or rupture. Coming to terms with the loss of previous roles and the arrival of new ones that are unlikely to have

been chosen – and may or may not be willingly embraced – can place high emotional, practical and economic demands on caregivers that can build up into feelings of hopelessness for all concerned. Life Story Work like this project can help individual caregivers work through this. By putting experiences into a meaningful frame, caregivers are able to process and understand what they are going through, which can help stabilise their lives (Nicholson, 2009).

When family members are able to see themselves as caregivers this may help them to recognise the importance of taking care of themselves (O'Connor, 2007). However, it is not just caregivers who need this recognition. Research has shown that there is also a pressing need for professionals to recognise caregivers as a source of knowledge and information about the person they are caring for, as well as more connection and communication between all persons involved in the care, including the person cared for (Nordby, Kjonsberg & Hummelvoll, 2010)

Recovery aims higher than stabilising or coping, but does recognise that these are meaningful goals. Alongside the literature of burden, there is an expanding literature of hope that emphasises the positive aspects of caring. Grice *et al* (2009) illustrated that positive experiences were mostly seen within families, as they attribute responsibility to the service user for positive events while avoiding blaming them for negative behaviours and outcomes. By praising positive behaviours and outcomes, family relationships are strengthened all round. Coldwell, Meddings and Camic (2010) looked specifically at psychosis and discovered that when families and caregivers give service users an opportunity to positively contribute to the family, it is rewarding for both the service user and their family members.

There has never been a better time to press the case for more systematic investigation of the enablers and disablers of recovery and wellbeing for caregivers. Nevertheless, these collective endeavours are beginning to bear fruit. NICE (National Institute for Health and Clinical Excellence) guidelines (2011) on person-centred care make it clear that, where the service user agrees, clear pathways should be followed to fully involve caregivers in shared decision-making about treatment and care. Where the service user does not agree, another pathway is set out which makes sure the rights and needs of the caregiver are at least recognised and respected. Most importantly, this guidance is more than just a nice idea that service providers can choose to follow. Rather, it is a set of quality standards with financial implications for non-compliance. Accompanying this guidance, there has been increased recognition from

the Department of Health in England and the Scottish Government that the activity of informal caregiving, where it is well supported and well informed, is both of benefit to the person cared for (DH, 2010, 2012; Scottish Government, 2010), and a cost-effective strategy in terms of reducing hospital admissions, encouraging early help-seeking for the person cared for and providing low-cost health benefits to the person giving care to offset poor health outcomes related to the activity of providing unsupported long-term care. Ironically, it may prove to be the age of austerity that is most instrumental in pushing the needs of caregivers further up the human rights agenda. Recent evaluation of 25 English demonstrator sites concluded that precise analysis of the costs/benefits of supporting informal caregivers across different care groups and organisations with very different targets and systems may never be possible to calculate with precision. However, the *wide range of ways in which cost savings may potentially be made, given the relatively modest costs of providing carer support, suggest that continuing to expand support for carers, especially when caring begins, for those with intensive or long-term caring roles, and when carers experience strain, is likely to be a financially sustainable approach* (Yeandle & Wigfield, 2011).

Hoping beyond recovery

As the narratives in this collection show, it is not always easy for caregivers to hold hope in the face of overwhelming evidence to the contrary and it may be inappropriate to expect this. It is vital to find out more about the enablers and disablers of recovery and wellbeing for caregivers at early and later stages, not just to benefit people who use services, but also to make sure that the hopes and wellbeing of caregivers do not continue to come second or be missed out altogether. There has yet to be an investigation into the impact of organisational hopelessness on wellbeing for caregivers alongside and within the activity of caring, and the role of hope in transforming hopelessness also needs a stronger evidence base. But despite these limits, the narratives in this collection bear witness to tremendous resilience and love and a boundless capacity to forgive and heal, both individually and collectively. They point to something deeply compelling about hope in recovery as social justice for all, especially where conditions for wellbeing are not yet or have never been in place. As a long-term goal, we want to start thinking **beyond recovery** for everyone involved in the triangle of care, and the strong focus on wellbeing in this collection gives us a platform to start this work. We very much hope that it will be a real first step towards this unapologetically idealistic vision.

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Useful Resources

Online resources for caregivers

Carers UK
http://www.carersuk.org/ (Retrieved 29th April 2013)

Carers Trust
http://www.carers.org/ (Retrieved 19th June 2013)

CIRCLE Centre for International Research on Care Labour and Inequalities
http://circle.leeds.ac.uk/ (Retrieved 29th April 2013)

FACTOR (Family/Friends and Caregivers Together in Research)
http://www.mhrn.info/pages/family-members-friends-or-carers.html
(Retrieved 29th April 2013)

Fadden, Gráinne, James, Carolyn and Pinfold, Vanessa.
Caring for Yourself is a self-help workbook for family and friends supporting people.
http://www.rethink.org/carers-family-friends/caring-for-yourself-guide
(Retrieved 29th April 2013)

Recovery Innovations Arizona
STAND (Sticking Together and Never Doubting) Recovery Information for Family and Friends. http://www.recoveryinnovations.org/riaz/STAND.html (Retrieved29th April 2013)

The Scottish Recovery Network
http://www.scottishrecovery.net/Latest-News/carers-need-recovery-too-meeting-wrap.html (Retrieved 29th April 2013)

Online recovery resources

Beyond the Storms: Reflections on Personal Recovery in Devon, Recovery Devon. http://www.recoverydevon.co.uk/index.php/recovery-in-action/stories-of-personal-recovery/52-beyond-the-storms (Retrieved 29th April 2013)

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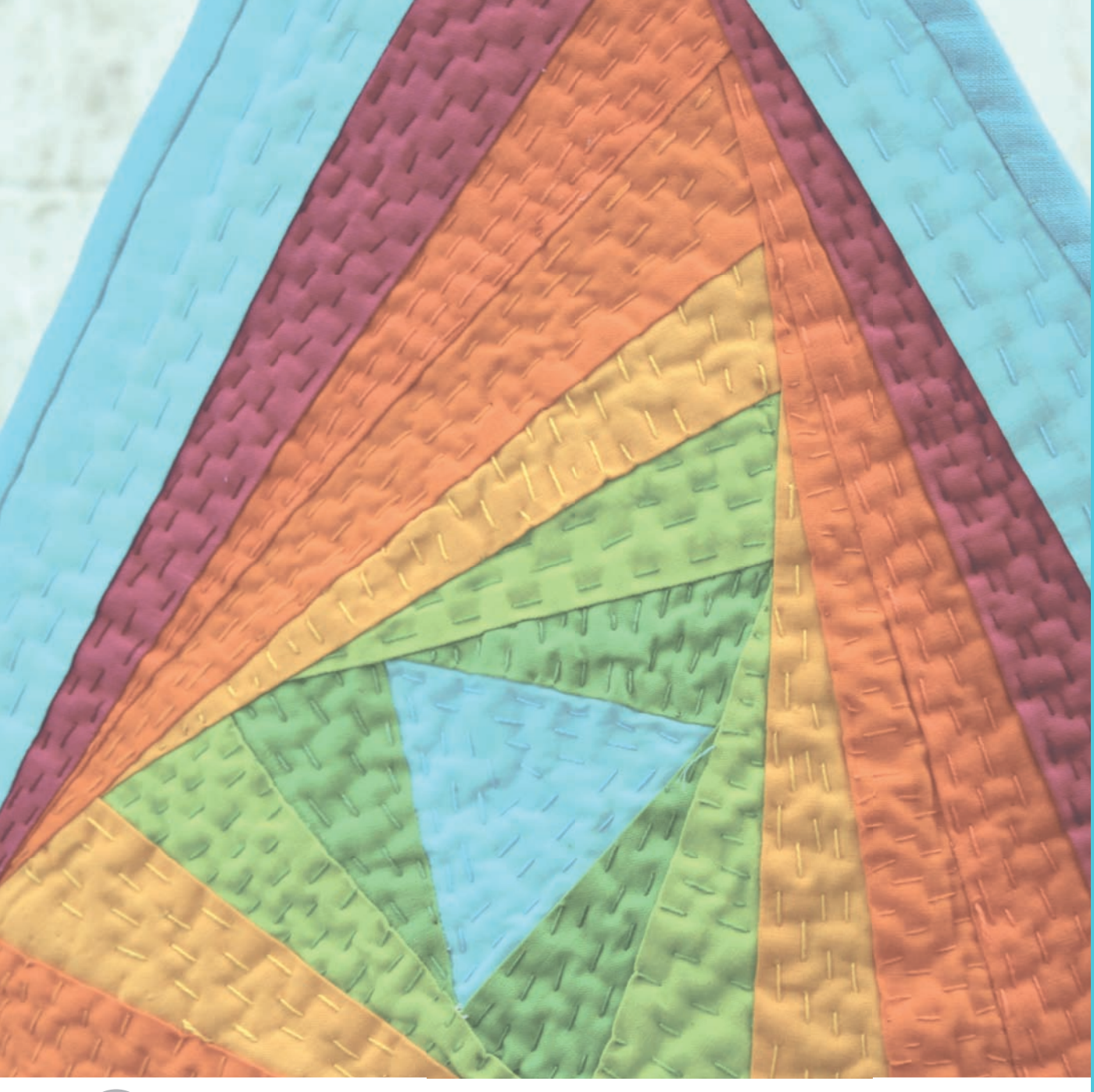
http://www.centreformentalhealth.org.uk/recovery/recovery_top_tips.aspx
(Retrieved 29th April 2013)



Scottish Recovery Network

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