

Voicing Caregiver Experiences: Wellbeing and Recovery Narratives for Caregivers



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Ruth Chandler
Simon Bradstreet
Mark Hayward

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

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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 hopeless 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