

Chapter 13

Making sense of it all

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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> (Retrieved 29th 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)

Hidden Talents: NHS workers who have personal 'lived' experience of mental health problems. 2012.

<http://www.dorsetmentalhealthforum.org.uk/pdfs/other/hidden-talents.pdf> (Retrieved 29th April 2013)

Implementing Recovery, Centre for Mental Health

http://www.centreformentalhealth.org.uk/pdfs/implementing_recovery_paper.pdf (Retrieved 29th April 2013)

Implementing Recovery Through Organizational Change (The IMROC Project)

<http://www.nhsconfed.org/Networks/MentalHealth/projects-and-resources/imroc/Pages/Implementing-Recovery-Organisational-Change-Project.aspx> (Retrieved 29th April 2013)

Recovery Plan (easy read), St George's Mental Health Trust.

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Making Recovery a Reality, The Centre for Mental Health.

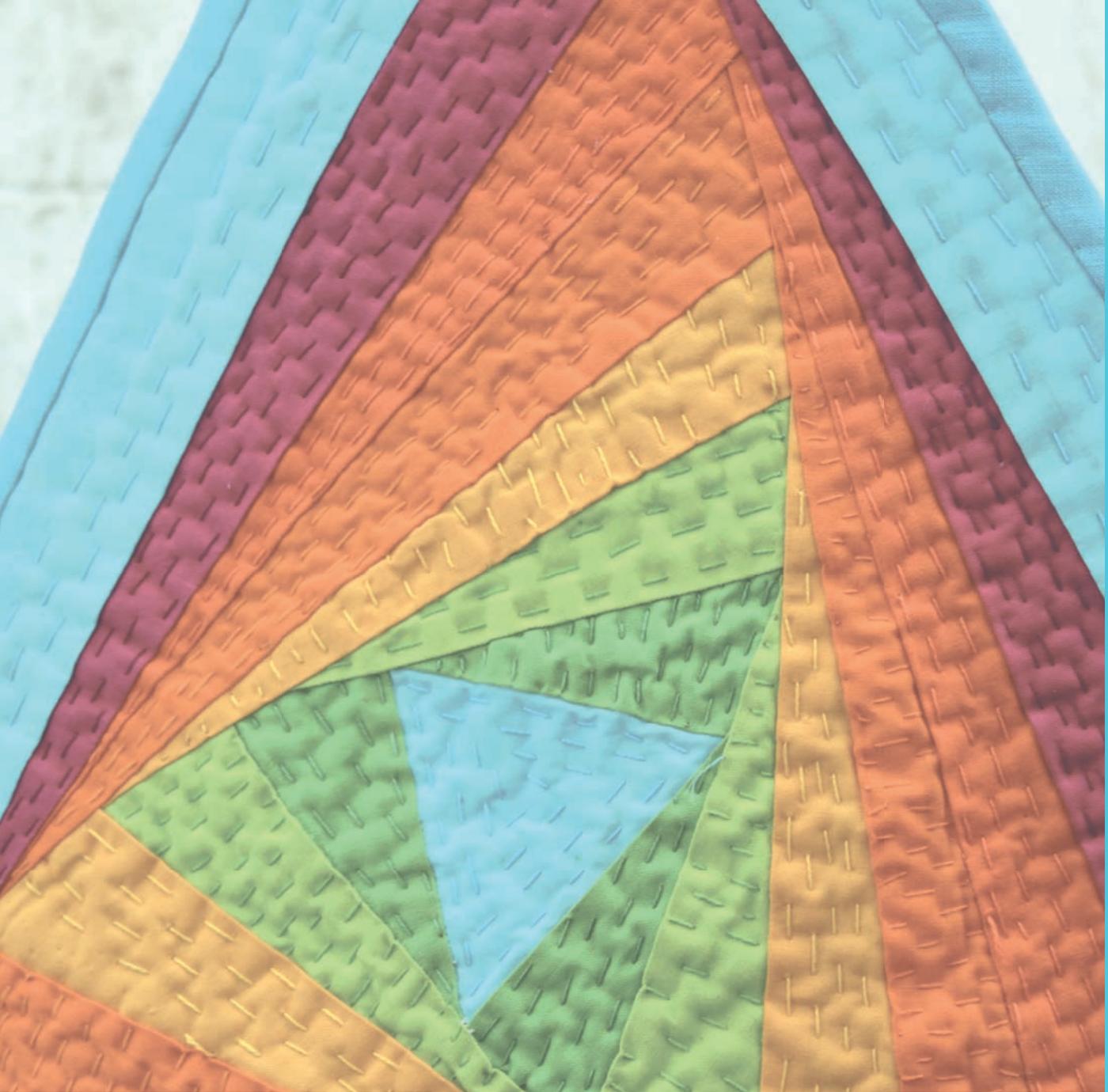
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<http://www.researchintorecovery.com/> (Retrieved 29th April 2013)

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(Retrieved 29th April 2013)

Top Ten Tips for Recovery, Centre for Mental Health.
http://www.centreformentalhealth.org.uk/recovery/recovery_top_tips.aspx
(Retrieved 29th April 2013)



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NHS Foundation Trust

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