ImROC
Implementing Recovery
through Organisational Change

Briefing

4. Recovery: a carer's perspective

Karen Machin and Julie Repper

INTRODUCTION

An estimated 1.5 million people in the UK care for or support a relative or friend who experiences mental health problems. We all want to know what it means for the person we care for and for ourselves. We all know the importance of trying to understand what is happening to them, listening to their accounts of what it feels like, providing practical and emotional support in a manner that they find acceptable and walking alongside them – 'being there' and believing in them. Yet it can be difficult to know how best to do this.

The concept of Recovery offers a framework which is relevant and constructive for both the person who experiences distress and their family and friends. Since it is not prescriptive, it can also facilitate the development of mutually supportive relationships.

This briefing paper examines what Recovery means for the families and friends of people with mental health conditions. It suggests ways in which these informal carers can support Recovery and looks at how mental health services can give the best possible help to do this. It also provides information about key resources, including the Triangle of Care and a Wellbeing Recovery Plan for families and friends.
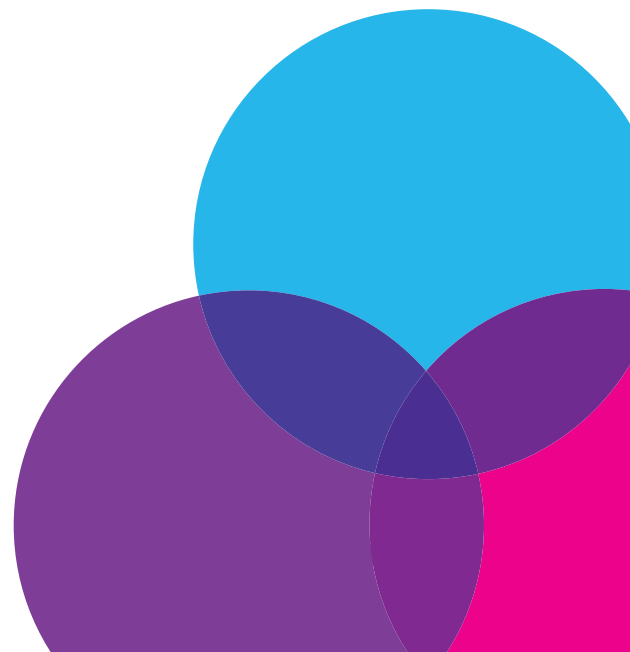
THE MEANING OF 'RECOVERY'

The value of 'recovery'

There has been some debate about the appropriateness of the word 'recovery' in the context of mental health. It is generally used to describe 'recovering from' an illness or injury through restoration of function, the eradication of symptoms and returning to a previous life and routine. People who have experience of mental health problems have challenged this notion of recovery. They argue that their emotional and cognitive challenges do not need to be removed in order for them to 'recover' meaningful lives. They argue that it is possible to live well with - and without - these challenges, emphasising the importance of hope and the belief that they can contribute and take control of their 'symptoms' if they have access to the same opportunities as other citizens. Indeed, they have demonstrated that they can recover different and even better lives than they had envisaged before their mental health problems occurred.

"Recovery is the process of developing a new sense of self, meaning and purpose in life - the journey of the individual and those close to them in rebuilding a satisfying, hopeful and contributing life with a diagnosis of mental health problems." (Deegan, 1989)

This concept of 'recovery' in mental health was a revolutionary idea at a time when people, including most mental health practitioners, believed there was no such thing as recovery from serious mental illnesses like schizophrenia. It was thought that to have hope was unrealistic and that people with mental health problems did not have the capacity to regain control over their lives and make the most of their opportunities.

Carers' concerns about recovery

"It was something like perpetual bereavement … My daughter, the person who I used to know so intimately, and who I loved and wanted to rescue more desperately than I'd ever wanted anything, was beyond my reach... My girl had become a stranger to me and I to her." (Varley, 2007)

The Recovery approach has caused considerable concern among many carers, service users and professionals. Some people have expressed concern that the term 'Recovery' is being misunderstood within statutory health services and is being used as an excuse to neglect people who reject support, or a reason for discharging those who say that they want to live independently. But this is not what the Recovery approach should be about. While independent living is an important aspiration for many, recovery focused services do not abandon people when they make progress and nor do they ignore the needs and concerns of carers. Recovery should not be seen as a way of 'selling' service cuts. It is about enabling people to manage their own lives, not reducing support or raising access thresholds.

Family members may have supported someone for many years, through several periods of crisis, perhaps including inpatient admissions and involuntary treatment. We may have requested support on many occasions without result, expressed our views without being heard, and not been given essential information (as have sometimes been this author's experiences). With such experiences, it is difficult not to lower our expectations. When services start to talk about helping our son, daughter or parent towards getting back to work or coming off medication, our experience warns against it. We may find ourselves saying, 'He'll never go back to work' or 'She'll always need medication'.

If someone has been stable on medication after a long period of distress, it can feel very threatening if 'recovery' is assumed to mean a life without medication. Similarly, employment may feel like an impossible target and a frightening change that family and friends fear might bring the risk of further relapse. These are completely understandable responses. Carers need to feel that professionals are taking them seriously and will work through the possibilities in an honest and respectful discussion. An understanding of recovery should help carers, service users and professionals to have such conversations.

Recovery does not assume that people all reach a stage when they do not need support. All of us find new endeavours much easier with the support of families, friends and experts – including those who have personal experience of the same journey or those with professional expertise. Thus, pursuing recovery should not equate with discharge, neglect or isolation and, far from excluding family and friends, it should be actively drawing on their support.

The term 'Recovery' can also appear to take little account of the individual in relation to their culture and the nature of their close personal relationships. These are especially important when, for example, experiences of racism, sexism or homophobia are factors in distress. These may be beyond the scope of health services or family carers to fix, but as Kalathil (Mind, 2008) asks, "If recovery is the process of moving on to more empowering and meaningful ways of being, what does that mean to a person whose everyday experiences of living includes racism and discrimination?".

If recovery may seem like a far-fetched idea for some of the people we support, we may have to change our ideas about what is possible, and when. We are used to seeing people with physical impairments encouraged and assisted to participate in society, but nobody would expect a blind person to wait until their sight is restored before they are 'included'. Why should this be any different for someone with mental health problems? Why should we have to wait for the problem to go away before considering goals and opportunities? Not only will people be less disabled by their challenges if they are doing something they value, but while we are waiting for them to 'get better' they are losing everything they value in life – work, friends, independence, a home. Shouldn't everyone be offered hope, choice and opportunities from their first contact with services?

A ROLE FOR FAMILY AND FRIENDS IN RECOVERY

"I would not be here if it were not for my family. I can always talk to my mum and she is great when I am really low. My Dad can sort things out in a crisis but he gets impatient with the way I live my life. It is my brother who really understands what I need when I'm feeling very bad." (Gow, 2010)

Some people prefer to describe recovery as a journey of discovery because it is about growth and exploration, developing greater understandings, finding solutions about who helps and who does not, how best to use personal strengths and when to call on others. If we define recovery as a journey of self-discovery, 'fellow travellers' are then also welcome and 'guides' can be useful. Carers, supporters and staff are also on a journey of their own alongside the person experiencing distress.

"Who are we? What are we? Why are we here? These are not simply moral issues, they are also political. Recovery came out of the civil rights movement of the 1960s and is about a vision of a life lived to the full – with passion, humour and style." (Urey, R., quoted in Mind, 2008)

Everyone's story of recovery is unique, just as each experience of distress is unique. Mental health problems may come on suddenly, or they may take years to develop. We may each identify different events that set off our distress and different times when we can pinpoint that something felt different. We may also have very different explanations about why it happened. Everyone can recover a more meaningful life, but this will always mean different things to different people. Nevertheless, 'recovery' is for everyone. We should therefore always be ambitious about it, filled with hope.

Family members and long-standing friends have a unique role to play in recovery because we know the person well, often before their distress. We can therefore serve as a reminder that the person is not solely someone with a mental health problem, but someone with talents and abilities, a person with qualities, interests, skills, beliefs and ambitions.

"It has been invaluable to have... my husband with whom I can test 'reality'. I let him know my perceptions and he gives me feedback. I am then able to consider that my perceptions may not be accurate and I modify my response accordingly if I wish." (Leete, 1989)

Paid supporters, by contrast, only know the version that they have been told: they have joined the journey in the 'middle'. Sometimes, that unfamiliarity can be an advantage, it can be reassuring to speak to someone who doesn't know you. People don't always want to tell family and friends what's worrying them, especially if it links to feeling ashamed, of being weak and helpless. And while a minority of families and relationships are abusive or cannot provide support, that is not the case for most of us, who desperately want to know what we can do to help.

"We assumed blame... We had let her down. An overwhelming sense of guilt swept over us. We kept coming back to the 'Why us?' question. The present felt grim and we feared for the future... Initially our personal feelings had the quality of an emotional roller-coaster, but as despair set in we found ourselves becoming exhausted and without hope. We all began to entertain the possibility of improvement... often tiny incremental improvements have combined to achieve remarkable progress. She now lives in a supported home, remains well-integrated with her family and leads a full and happy life." (Shiers, 2007)

We all want the best for our loved one. We are deeply and personally affected by their distress and often carry a burden of guilt, worrying that we caused the problem and that we should be able to help more. But we can benefit from our caring role. We feel good because we are in a position to support the

Tim

"Tim's illness began just over seven years ago, accelerating into crisis very quickly, at which point he was sectioned into hospital and given a diagnosis of schizophrenia. The impact of reaching that point in a few weeks after terrible worry, signing committal papers, psychiatric nurses trying and failing to take Tim forcibly from home, the Police eventually succeeding, the true terror and grief for the 'loss' of our son, and the dread of what the future would hold, were utterly devastating...

Over the last seven years we have learned patience. There are no quick fixes to recovery... we have spent many, many hours listening - often enough long into the night. I know that me being available to Tim at any time has been of immeasurable benefit... In the early days, I could only be a sympathetic and encouraging ear as Tim battled with the misery of his situation - his despair, depression, anxiety, anger.

He began to look around himself with new eyes and became deeply interested in understanding all he could of the human mind, and who better to teach me than Tim? He really has mined his own experiences for meaning and understanding, for growth and release... This exploration over the past years has formed the backbone of Tim's recovery.

"On very weary days, there is always the temptation to hide behind the protective shield of illness where little is expected of the sufferer... Our experience of the mental health world is that expectation falls quickly into the hole of 'we mustn't set him up to fail', which has the potential to keep everyone 'safely' in the world of the lowest common denominator.

We have worked with everything Tim is - in character, personality, potential, ability and inclination at every stage. In the past five years, Tim has tried a number of jobs, lived independently, travelled abroad, learned to drive his own car, taken up a wide variety of study, has been deeply involved in music, enjoys hill walking and badminton. There have been occasions where things haven't 'worked out', but that's fine, and we have never sought to wrap Tim up in cotton wool.

Today, as we look at Tim, we know he is all that he was meant to be – that the promise in the child is here in the man... He has at his command all the tools and strategies he has forged from his difficult journey, and the knowledge and mastery of himself." (Gould, 2005)

Reproduced with permission from the Scottish Recovery Network.

person we love. We are valued and we feel privileged because someone confides in us, pleased to have someone around to talk with, and aware that we are developing new skills. Family and friends have a huge contribution to make and a lot to gain. This is the essence of mutual support.

"I have now learned to walk alongside my sister, instead of trying to tell her what to do or to push her in the direction I think she should go in. For years, I did try to push and experienced feelings of frustration, annoyance and, at times, total despair for her chosen path or inability to see things from my point of view. At times of her despair, I felt it too and at her lowest ebb, I was with her too... for my sister, my door remains open when it needs to be opened by her, and that is the most important thing." (Action on Depression website)

HOW FRIENDS AND FAMILY CAN SUPPORT RECOVERY

"You have the wondrously terrifying task of becoming who you are called to be. Your life and dreams may have been shattered - but from such ruins you can build a new life full of value and purpose." (Deegan, 1993)

There are many ways in which family and friends can help. We may be the first to identify unusual behaviours and beliefs and recognise the situations that seem to cause upsets ('triggers'). We can learn over time what seems to help. We can provide early support and reassurance, making suggestions to alleviate further distress and offering practical support - cooking meals, doing washing, going on walks. We can also avert further difficulties, like sorting out housing to prevent eviction, explaining the situation to debt collectors to prevent destitution, etc. The importance of this protection of basic needs cannot be underestimated. But to support someone in their recovery, we also need to learn new skills and approaches to help them to build a life for themselves alongside their family and friends.

We suggest four areas where new skills might help family and friends build a new supportive relationship:

- recovery planning,
- building on strengths,
- developing helpful relationships,
- handing back control.

Recovery planning

Everyone makes plans in their lives to some extent. But until we understand the unique nature of each person's recovery journey, we don't know where to start to help someone else plan for the future. At the start, we have no idea how long it will last, what the options are or whether things will get better.

Despite all these unknowns, family and friends have a central role in helping people to hang on to roles and relationships that are important to them, helping them to understand what is happening to them and always working towards their personal goals - aims that are important to them, rather than to us. We can help them to keep well, prepare for potential challenges and remember who they are. We can encourage and support the person to develop their own Recovery Plan and then help them share it with those who can offer support.

Building on strengths

When a person is distressed, it is all too easy to begin thinking negatively. They may hear voices reinforcing this message. Or they may be facing the all too real results of over-spending or self-harm. They may feel that the world is against them, that they are complete failures and everything that can go wrong will go wrong, so what's the point of trying?

Having someone who can remind them of the positives can make a huge difference. This is not to deny the challenges, to pretend they don't exist, or to insist that it is within the individual's power to remain positive in the face of very real difficulties. But when people fall, it is important that their family and friends don't fall with them. We have an important role in pointing out that they tried and what they have achieved. We can remind them of little things they have forgotten. It is very important that we hold on to our hope when they find it impossible to see the light at the end of the tunnel. It is our constant and enduring belief that things will get better that can help them through the darkness.

Developing helpful relationships

When we are providing a substantial amount of support, it is all too easy to get stuck in the experience of distress, forgetting our own needs and centering everything on the distressed person. This can create cycles of negative behaviour with all of us identifying the problems so that these become self-fulfilling as all the positive opportunities are removed.

The whole family can benefit from looking at their roles and relationships, including what strengths and skills each person brings and what people find most and least helpful.

Carers often talk about the difficulty of treading a tightrope between encouraging someone to do more and allowing them to rest and be supported. This isn't easy - but it is helpful for everyone to talk about what helps them, what they find difficult in their relationships, and what options are available for coping more effectively.

Handing back control

Family and friends can easily get trapped into a position of doing more and more. We may gradually take responsibility for major tasks such as controlling money or paying the rent. Other, smaller, daily tasks such as washing and cleaning may slip into our domain of responsibility during periods of distress and these habits are difficult to break. We sometimes even find that we don't trust a person to take their own medication and we start to take over control of that too.

Once these patterns build up, it can be hard to let go. It may feel 'risky', but unless we are prepared to hand back control and let the person manage their own life again, they cannot grow. Obviously, we must not ignore safety issues, but decisions about how to move forwards safely need to be shared between the person, their family and friends, and their professional team, with everyone supporting the individual to move on safely towards their chosen goals.

"That a person recovers means that the other people in his or her surroundings also have to recover; the unequal dependence relationship that was established between the person and his or her social network during times of deep distress must change. The helper must step down from this one-sided role and be prepared, not only to disengage, but also to perhaps now be the recipient of the person's concern and advice." (Topor *et al*., 2006)

HOW CAN SERVICES SUPPORT FAMILIES?

To fulfil these important and challenging roles, family and friends need effective support from mental health services. This support can come in a number of forms and will, of course, need to be tailored to every situation. Key actions for services include:

• identifying carers,
• tackling stigma and discrimination,
• understanding the impact of caring,
• delivering family interventions,
• developing carer peer support,
• offering education not therapy.

Identifying carers

Government guidance defines carers as people who "provide unpaid support to family or friends who couldn't manage without this help, whether they're caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems" (Department of Health, 2012).

Identifying carers is not, however, a simple task. Many people do not consider themselves to be carers when they are supporting someone they care about: they are just friends, mothers, brothers, neighbours. They provide care as part of their natural social roles. If people don't identify themselves as carers, they will have difficulty accessing Carers Centres, Carers Allowance, Carers Grants and Carers respite.

Many family members describe walking past signs and posters using the word 'carer' thinking they refer to paid care workers rather than informal, unpaid carers such as partners, friends or parents. Carers UK research (2006) suggests that 65% of people with a caring responsibility did not identify themselves as a carer in the first year of caring and for 32% it took over five years to be recognised. Carers from Black and Minority Ethnic communities also provide proportionately more care than White British carers (Carers UK, 2011).

It is likely that carers for people with hidden illnesses such as mental distress aren't so easily recognised as those looking after elderly relatives. Even some carers' organisations might prefer to refer mental health carers to specialist agencies. Young carers may be particularly challenging to identify and less likely to seek help.

The updated national carers strategy acknowledges the specific difficulty of identification for carers supporting someone through distress: "The onset of mental health problems and the process of seeking help can be particularly traumatic for families. Those supporting people with mental health, personality disorder or substance misuse problems can be wary of seeking help outside the family because of the stigma, discrimination and bullying that are still too often associated with these conditions." (Department of Health, 2010)

It is also worth noting that many people can be both a service user and a carer. While NHS Trusts may gather statistics for the number of carers (including young carers) who support their service users, they are not required to collect data on the number of service users who also have caring responsibilities. Once people identify as carers, they may be able to access support as a carer, including carers respite and breaks. Providers should therefore routinely ask service users about their caring responsibilities and signpost them to appropriate support.

Tackling stigma and discrimination

Families who stand by someone through distress risk being affected by discrimination through association. This is now recognised in the Equality Act (2010). Carers Direct (2012) highlights the specific stigma experienced by carers, especially in the workplace, where colleagues might make assumptions about why they have to take time off. Carers may also feel unable to take time off work because they don't want to mention the reason.

"They never knew at work. If I told them, I'd have to tell them about his problems. And he never wanted to do that because he hoped to get through it and didn't want people to know. I didn't want to break that confidentiality."
(Anonymous carer in Machin, 2006)

Time to Change (www.time-to-change.org. uk), the anti-stigma campaign, provides materials and a message that appeals to a wide audience. This may be an effective way to help services to engage with hidden carers.

Understanding the impact of caring

The caring role can affect carers' own health and wellbeing. A recent national survey found that 87% of carers thought caring had a negative impact on their own mental health and 91% said they were affected by anxiety or stress (Carers UK, 2012). Indeed, forthcoming Royal College of GPs commissioning guidance suggests that all carers should be screened for depression (2013, in press).

However, carers may not feel able to mention their own distress. They may feel they have to continue to cope and, in comparison to the person they support, they may be seen as relatively 'well' or able. Young people in particular may be torn between wanting to support a parent and wishing to join in the everyday activities of their peers.

Noble (2008) has shown that carers of people who experience a stroke are three times more likely than average to experience symptoms of PTSD (post traumatic stress disorder). People who support someone through crises of psychosis or self-harm may be similarly traumatised by what they have experienced, but no-one usually thinks to ask. Staff on wards who witness suicide attempts will usually have de-briefing sessions and be offered support, but this is seldom offered to family and friends, although they may have witnessed far more and have a much greater emotional attachment.

Family members and friends of people who experience mental health problems therefore need support to think about their own recovery, not just in terms of practical help to get on with the business of living, but also emotional help. For many of us there is a huge sense of loss when we think back to the people we used to be and our hopes and dreams, both for ourselves and the people we support. Unless we can come to terms with this, it is hard for us to celebrate subsequent achievements and development.

For professionals, we can be a frustrating group because we are so focused on the support of our loved ones. It is all too easy for us to assume that if only the right support was available then everything would be fine and we are quick to blame services when our loved one does not recover quickly. Too often we believe that if we could rely on someone else to provide that support, then we would not be anxious or distressed and we would have the freedom to take a break and to share our worries.

Delivering family interventions

Although there is very little research into the experience of caring for a person with mental health problems, there is extensive research that demonstrates the effectiveness of psychosocial interventions for family members. Such interventions are based on the theory of Expressed Emotion (EE) which developed out of studies of the impact of family members on people with schizophrenia (Brown *et al.*, 1962, 1972). The 'EE' interview provides a measure of the 'amount' of negative emotion displayed, typically in the family setting, usually by a family or care takers and measured on indicators of hostility, emotional over-involvement and critical comments.

Research has shown that EE provides a relatively robust measure of relatives' emotional attitudes towards people with numerous psychiatric conditions (psychosis, anxiety, depression, borderline personality disorder) and physical illnesses (Wearden *et al.*, 2000). High levels of negative emotions are strongly associated with a high risk of relapse.

Family interventions are generally delivered by trained specialists, either with individual families or in larger family groups. They focus on improving communication skills, reducing high 'EE' (mainly criticism and hostility) through enhanced problem-solving, thereby improving relationships within the family. Studies in several countries have found that they are effective in reducing the risk of relapse and readmission (Pharoah, 2006).

Developing carer peer support

Carers can become isolated and feel alone in their experiences. Many find that it helps to meet with other carers in groups, receiving and giving support to their peers. This may be particularly effective for carers in marginalised groups including families of people in secure services (Canning *et al.*, 2009).

The last few years have seen the development of mutual support in mental health services with the employment of Peer Support Workers (Repper & Watson, 2012; Repper & Carter, 2011; Bassett, Faulkner *et al.*, 2010). These new workers have training in skills such as active listening, recovery planning and story sharing. The focus of their work is on strengths and recovery, rather than problems and symptoms. But their unique gift is that they have been there: they have had a similar experience and are willing to share it. They can pass on a message of hope that mental distress can be survived and that many people who have been through it have achieved valuable, satisfying and contributing lives beyond illness.

Nottinghamshire Healthcare NHS Trust has extended the idea of peer support to include 'Carer Peer Support Workers' employed to provide information, signposting and practical support for family members based on their own experiences. Although only two posts have been in place for 12 months, carers who have received peer support are unanimously positive about their experience. They report that peer support is qualitatively different from professional support, giving them hope and belief in their ability to cope because of the roles modelled by the carer peers.

"I bring my own experience as a carer to the work I do with family carers to help them understand what has happened, help them have a better understanding of how the mental healthcare services work and to get them out and about again, encouraging them to take up interests or work and to look after their own health needs. I make sure they know they are entitled to a carers assessment if they haven't already had one and am a point of contact if they feel the need to talk. We share our stories and look at ways of coping that have helped me, such as changing the language I use with the person I care for."
Judith Machin, Carer Peer Support Worker, Nottinghamshire Healthcare Trust

Offering education not therapy

Carers are usually thrown in at the 'deep end' when it comes to caring. They are often not asked if they want to be a carer and not given any training for their new role.

The ImROC project emphasises a move away from a service solely providing therapy, towards educating people, providing them with understanding and skills to manage their own lives and make their own decisions. This is the thinking behind Recovery Colleges (Perkins *et al.*, 2012) where peer trainers work with professionals to co-produce and co-deliver a range of courses for people who use services, their families and friends as well as staff. Courses need to be developed specifically to meet the wishes and needs of family, friends and informal carers so that they all learn together. Courses may need to be delivered outside working hours so as to include working carers.

A number of courses have also been developed specifically for carers by other organisations. These include the Caring with Confidence (2009) course produced as part of the National Carers Strategy, a series of workbooks called 'Caring for Yourself' developed by Rethink Mental Illness (2012), a staff training DVD developed by Rethink Mental Illness (2011) and the Meriden training for staff and family members (Fadden & Heelis, 2011).

The Triangle of Care

The 'Triangle of Care' (Worthington & Rooney, 2010) aims to be, 'a therapeutic alliance between service user, staff member and carer that promotes safety, supports recovery and sustains wellbeing.' It attempts to ensure that NHS staff are aware of carers' needs including the identification of people who take responsibility for providing support and providing the necessary information, overcoming problems created by confidentiality requirements.

Based on the experiences of many hundreds of carers, the Triangle of Care identifies six elements which create a framework for better collaboration and partnership between staff and carers. Since its launch in 2010, the Triangle of Care has been endorsed by 80% of Mental Health Trusts (by December 2012). Their staff are in the process of implementing the six elements.

The Triangle of Care recognises the important role played by families and friends and makes six suggestions to achieve better collaboration and partnership with carers.

Achieving better collaboration and partnerships with carers

1. Identify Carers and the role they play at first contact or as soon as possible thereafter.

2. Train staff to be 'carer aware' with carer engagement strategies and a clear understanding of carers' rights in relation to their own assessment and the disclosure of information.

3. Ensure that policy and practice protocols re confidentiality and sharing information are in place.

4. Create defined post(s) responsible for delivering and sharing good practice in relation to carers.

5. Provide carers with an introduction to the service and staff with a relevant range of information across the acute care pathway.

6. Provide a range of carer support services along with a self assessment tool.

More information about the Triangle of Care project and ongoing developments can be found here: http://professionals.carers.org/health/articles/triangle-of-care,6802,PR.html.

Meriden Family Programme worked with Rethink Mental Illness to develop a workbook for family and friends. This is built on a wealth of experience and expertise and helps carers to work out ways of coping successfully with the challenges of supporting someone with mental health problems (Fadden *et al.*, 2012).

CARERS' RECOVERY PLANS

Carers may find it helpful to read and complete the ImROC health and wellbeing plan for family, friends and carers, which guides you through developing your own support plan including:

Your health and wellbeing maintenance plan

This is about identifying the activities and relationships that are important to you, how you might be able to make time for them in your busy life, and things you need to do to keep yourself feeling on top of things.

Your health and wellbeing 'first-aid kit'

This helps you to think through what you can do to get yourself back on your feet when you feel upset, angry, discouraged or stressed out.

A plan for managing difficulties that arise and things that get to you

What you can do when things happen that knock you off balance, wear you down, upset or anger you... to stop them getting to you too much.

A plan for what to do when everything is getting too much for you

Despite your best efforts, there are likely to be times when difficulties drag on and escalate. All of us sometimes get to the point when we have had enough, feel unable to cope and just want to give up. It is important to think about what you can do to cope at times like this, but this may also be the time to ask for help.

The plan is available from the ImROC website at www.imroc.org.

CONCLUSION

While recovery may be a unique and personal journey, none of us follow it in isolation. Recovery planning must therefore consider the needs of our family and friends, and our community.

Services need to identify carers and staff need to recognise the immensely valuable and sometimes challenging role that we play - without us, they simply could not cope. They need to acknowledge that we may not naturally come forward for many reasons including stigma and discrimination. Work can then begin to ensure that carers have the information and support that we need to be a 'fellow traveller' in the recovery of the person we care for. We must also become experts in our own journeys of recovery.

Useful web sites

There are a number of web sites where you can read about the experience of other relatives and friends:

www.carers.org

www.carersuk.org

www.mentalhealthfoundation.org.uk

www.rethink.org

www.scottishrecovery.net

www.time-to-change.org.uk

www.channel4.com/health/microsites/0-9/4health/mind/pex_managing.html

www.healthcentral.com/depression/c/5570/17635/dealing

Acknowledgments

Thanks to Ruth Hannan from Carers Trust and Steve McIntosh from Carers UK for their comments about this paper, and to Alan Worthington for his input into the Triangle of Care.

About the authors

Julie Repper is recovery lead at Nottinghamshire Healthcare NHS Trust. She is also associate professor of recovery and social inclusion at the University of Nottingham and service user engagement fellow for East Midlands and chair of the Advisory Group for MHRN Carers in Research group (FACTOR). Julie is also a senior consultant on the ImROC programme and on the Genio funded Advancing Recovery in Ireland project.

Julie draws on her professional and personal experience of mental health problems to work with peers to develop innovative training, research and service developments. She is currently director of the Nottingham Recovery Education Centre and course director for the Peer Support Course at Nottingham University. She has written widely around recovery and leads several related research and service development projects.

Karen Machin works freelance within the mental health field, and has an interest in outcomes, communities and digital media. Based in the North West of England, she has worked universities and trusts, CSIP and Time to Change, in a variety of roles using skills including facilitation, research, events organisation and film making.

In the last 12 months, she has delivered training including peer support worker courses and Caring with Confidence courses.

Her user involvement experience includes setting up local organisations for service users and for carers, and fundraising for specific projects including young carers support, arts exhibitions and the world's first carers complaints choir. She is one of the founder members of the ROLE network CIC, a social enterprise formed by service users/survivors and carers across the North West.

REFERENCES

Basset, T., Faulkner, A., Repper, J., Stamou, E. (2010) *Lived Experience Leading the Way: Peer support in mental health*. London: Together.

Brown, G. W., Monck, E. M., Carstairs, G. M., *et al.* (1962) Influences of family life on the course of schizophrenic illness. *British Journal of Preventive and Social Medicine*, **16**, 55-68.

Brown, G. W., Birley, J. L. & Wing, J. K. (1972) Influence of family life on the course of schizophrenic disorders: a replication. *British Journal of Psychiatry*, **121**, 241 -258.

Canning, A., O'Reilly, S., Wressell, L., Cannon, D., Walker, J. (2009) A survey exploring the provision of carers' support in medium and high secure services in England and Wales. *Journal of Forensic Psychiatry and Psychology*, **20**(6), Dec 2009, 868-885.

Carers Direct website, *Stigma and Discrimination page*. Available at: www.nhs.uk/carersdirect/yourself/takingcareofyourself/pages/stigmadiscrimination.aspx [accessed 13 February 2013]

Carers UK (2006) *In the Know: the importance of information for carers*. London: Carers UK.

Carers UK (2011) *Half a million voices: Improving support for BME carers*. London: Carers UK.

Carers UK (2012) *In Sickness and Health.* London: Carers UK.

Caring with Confidence (2009) course materials available online at www.nhs.uk/CarersDirect/carers-learning-online/Pages/resources-for-training-providers.aspx [accessed August 2012]

Action on Depression website, *Valerie's Diary*. Available at: www.actionondepression.org/community/valeries-diary [accessed 13 February 2013]

Deegan, P. (1989) *A letter to my friend who is giving up*. Connecticut Association of Rehabilitation facilities, Cromwell, CT.

Deegan, P. (1993) Recovering our Sense of Value after being Labelled. *Journal of Psychosocial Nursing*, **31**(4), 7-11.

Department of Health (2012) *Carers* www.dh.gov.uk/health/category/policy-areas/social-care/carers/ [accessed August 6 2012]

Department of Health (2010) *Recognised, valued and supported: next steps for the Carers Strategy*. London: Department of Health.

Fadden, G. & Heelis, R. (2011) The Meriden Family Programme: Lessons learned over 10 years. *Journal of Mental Health*, **20**(1), 79-88

Fadden, G., James, C. & Pinfold, V (2012) *Caring for Yourself – self-help for families and friends supporting people with mental health problems*. Birmingham: Rethink Mental Illness and Meriden Family Programme

Gould, V. (2005) *A carer's perspective on the recovery journey*. Available at: www.scottishrecovery.net/Submitted-thoughts-and-stories/a-carers-perspective-on-the-recovery-journey.html [accessed 13 February 2013]

Gow, D. (2010) *My Recovery Story*. Paper given at Nottinghamshire Healthcare Trust Recovery Conference.

Leete, E. (1989) The treatment of schizophrenia: A patient's perspective. *Hospital and Community Psychiatry*, **38**, 486-491.

Machin, K. (2006) *Living with mental distress: the family's experience* (DVD)

Mind (2008) *Life and times of a supermodel*. London: Mind.

Noble, A. & Schenk, T. (2008) Posttraumatic stress disorder in the family and friends of patients who have suffered spontaneous subarachnoid hemorrhage. *Journal Of Neurosurgery*, **109**(6), pp. 1027-33.

Perkins, R., Repper, J., Rinaldi, M. & Brown, H. (2012) *Recovery Colleges*. London: Centre for Mental Health.

Pharoah, F. M., Rathbone, J., Mari, J. J. & Streiner, D. (2006) *Family intervention for schizophrenia*. Cochrane Review 2006.

Repper, J. & Carter, T. (2011). *Using personal experiences to support others with mental health problems*. London: Together.

Repper, J. & Watson, E. (2012) A year of peer support in Nottingham: lessons learned. *The Journal of Mental Health Training, Education and Practice*, **7**(2): 70-78.

Rethink Mental Illness (2012) *Caring for yourself*. Available at: www.rethink.org/ living_with_mental_illness/caring/caring_for_ yourself.html [accessed 13 February 2013]

Royal College of General Practitioners (2013, in press) *Commissioning for Carers*. London: Royal College of General Practitioners. This guidance will be available at: www.rcgp.org.uk/carers

Shiers, D. (2007) Why us? in Hardcastle, M. *et al. Experiences of Mental Health Inpatient Care: Narratives from Service users, carers and professionals*. London: Routledge.

Topor, A. *et al.* (2006) Others: the role of family, friends and professionals in the recovery process, *American Journal of Psychiatric Rehabilitation*, **9**:17-37.

Wearden, A., Tarrier, N., Barrowclough, C., Zaastovny, T. & Armstron Rathill, A. (2000) A Review of Expressed Emotion in Healthcare. *Clinical Psychology Review*, **20**(5), pp. 633-666.

Varley, J. (2007) Frustrated and angry in Hardcastle, M. *et al. Experiences of Mental Health Inpatient Care: Narratives from Service users, carers and professionals*. London: Routledge.

Worthington, A., Rooney, P. (2010) *Triangle of Care*. Available at: www.rcn.org.uk/ development/mental_health_virtual_ward/ triangle_of_care [Accessed 13 February 2013]

Recovery: a carer's perspective

This briefing paper has been produced for the Implementing Recovery through Organisational Change programme, a joint initiative from the Centre for Mental Health and the NHS Confederation's Mental Health Network.

The pilot phase of ImROC ran from 2011-12 and was supported by the Department of Health, together with contributions from the participating services. The continuing work of ImROC is endorsed by the Department of Health and managed and supported by the Centre for Mental Health and Mental Health Network.

For more information on the current work of ImROC, please visit **www.imroc.org**.

ImROC, c/o Mental Health Network, NHS Confederation, 50 Broadway, London, SW1H 0DB
Tel: 020 7799 6666
imroc@nhsconfed.org
www.imroc.org

Centre for Mental Health

Centre for Mental Health is an independent national mental health charity. We aim to inspire hope, opportunity and a fair chance in life for people of all ages with or at risk of mental ill health. We act as a bridge between the worlds of research, policy and service provision and believe strongly in the importance of high-quality evidence and analysis. We encourage innovation and advocate for change in policy and practice through focused research, development and training. We work collaboratively with others to promote more positive attitudes in society towards mental health conditions and those who live with them.

Maya House, 134-138 Borough High Street,
London SE1 1LB

Tel: 020 7827 8300
contact@centreformentalhealth.org.uk
www.centreformentalhealth.org.uk
@CentreforMH

Charity registration no. 1091156. A company limited by guarantee registered in England and Wales no. 4373019.

Mental Health Network NHS CONFEDERATION

The NHS Confederation's Mental Health Network (MHN) is the voice for mental health and learning disability service providers to the NHS in England. It represents providers from across the statutory, for-profit and voluntary sectors. The MHN works with Government, NHS bodies, parliamentarians, opinion formers and the media to promote the views and interests of its members and to influence policy on their behalf.

50 Broadway, London SW1H 0DB

Tel: 020 7799 6666
mentalhealthnetwork@nhsconfed.org
www.nhsconfed.org/mhn
@NHSConfed_MHN

Charity registration no. 1090329.