



# Carers and supporting recovery

A report commissioned by the Scottish Recovery Network

August 2009

## About the Scottish Recovery Network

The Scottish Recovery Network (SRN) is an initiative funded by the Scottish Government to raise awareness of recovery from mental health problems. We are a *network* in two senses. Firstly we are a loose affiliation of individuals and organisations with a common interest in recovery and secondly we work to share information and ideas as quickly as possible.

Main aims of the Network:

1. To raise awareness of recovery from mental health problems, in particular longer term problems.
2. To learn more about the recovery experience, and the factors which help and hinder it, and to share that learning.
3. Share ideas and encourage and support action nationally and locally for the promotion of recovery.

For more information about this project or SRN please contact Taryn Carlton on [taryn.carlton@scottishrecovery.net](mailto:taryn.carlton@scottishrecovery.net) or 0141 240 7790.

## About the Author

Dr Hester Parr is a Reader in Human Geography at the Geographical and Earth Sciences Department at the University of Glasgow. She has recently published a book on mental health and social inclusion entitled *Mental Health and Social Space: Geographies of Inclusion?* (Blackwell, 2008).

This report was first published August 2009.

## Acknowledgements

The Scottish Recovery Network would like to thank everyone who has helped or contributed to this long standing project. In particular, Michel Syrett for his initial work on the project and the Carer Expert Reference group for their assistance and guidance throughout this project.

We would also like to extend special thanks to all the individuals who contributed to the questionnaires and discussion groups. We greatly appreciate you sharing your thoughts and experiences with us and we hope that you are pleased with the result.

## Feedback

We would welcome any comments or thoughts from organisations or individuals about this work. We would be particularly interested to hear suggestions or ideas about how this information could be disseminated or used to influence policy and practice developments.

Please contact us via [info@scottishrecovery.net](mailto:info@scottishrecovery.net) or 0141 240 7790 to share your comments.

## Contents

Summary .....	4
Introduction.....	6
Selective literature review .....	8
Methods.....	12
Survey interpretation .....	14
1. Recovery and carers .....	14
2. Recognising recovery.....	15
3. Practical steps to support recovery .....	17
4. Carers and services .....	19
5. Barriers to recovery .....	20
6. Concluding issues .....	22
Exploring carers experiences of recovery .....	23
1. Understanding further dimensions to recovery .....	23
2. Time and pace in recovery scenarios.....	23
3. What carers do: providing intensive care .....	25
4. What carers <i>could</i> do: relationships with formal services .....	26
5. What carers know: recovery and the importance of social life .....	27
6. What carers find difficult: managing risk and ‘letting go’ .....	28
7. Carers experience of their own recovery .....	30
8. What barriers to recovery carers negotiate: stigma and community life ..	32
9. The benefits of caring: experiencing co-recovery .....	33
Conclusions .....	35
Further reading.....	37
Appendix 1: Survey responses and analysis .....	38
Appendix 2: Survey and group discussion materials .....	42

### Summary

This small scale qualitative research study involved four carer support groups in Scotland. There is a lack of research on the role of carers in mental health recovery and this small study partially addresses this gap. The study was intended to highlight carer perspectives on recovery and their role in supporting recovery from mental health problems. It is partial in scope and only addresses these items from the carer perspective.

A short questionnaire survey was sent to four carer support organisations. This survey also formed the basis for the structure of follow-up focus groups which took place in February, March and April, 2009.

The survey results combine to form an evidence base consisting of 'positive knowledge', whereby carers responded in ways that demonstrated action-orientated practices and outcomes.

From the survey results, recovery was constructed as:

- A recognisable state indicated by physical and social characteristics.
- A state that could be influenced by various behaviours and practices.
- A process that could be influenced by co-working between the carer, the person being supported and formal services.
- A process that may be negatively influenced by a lack of recognition of the carer's potential role in negotiations with formal service providers.

Focus group evidence revealed insights into the dynamics of caring relationships and helped to provide qualitative reflections on key themes and 'tipping points' in recovery processes.

Key themes emergent in focus group discussions:

- Time and pace in recovery scenarios.
- What carers do: providing intensive care.
- What carers *could* do: relationships with formal services.
- What carers know: recovery and the importance of social life.
- What carers find difficult: managing risk and 'letting go'.
- Carers experience of their own recovery.
- What barriers to recovery carers negotiate: stigma and community life.
- Benefits of caring: experiencing co-recovery.

The key themes emergent in focus group discussions emphasised that carers are well placed to influence the progress and direction of recovery because of their intimate knowledge of the person they are supporting. Key 'tipping points' for successful recovery scenarios were identified as associated with:

- Insights and acceptance in the person being supported.
- Allowance of risk taking.

- Co-development of social opportunities and knowledge.
- Positive relationships with formal services based on good communication.
- Carers involved in self-recovery and respite.

### **Conclusion**

This was a small-scale qualitative study which partially addresses some issues connected to the role of the carer in mental health recovery. More research could be undertaken to fully understand the dynamics and potential of caring relationships with regards to recovery. Key conclusions are:

- There is a distinctive call from carers to be more valued and recognised in formal services for mental health support.
- Co-working between informal and formal services has the potential to assist those in recovery from mental health problems.
- Carers support groups provide an essential point of knowledge transfer for carers and this is key in promoting recovery based practice.

### Introduction

This report is the outcome of a commissioned survey of four carers support groups concerning attitudes towards the concept of recovery and the experience of caring *for* recovery. The research undertaken was qualitative and the exercise had the following aims and objectives:

#### Aims and objectives

- To give voice to carers and supporters with regards to the recovery concept.
- To collect data for a written report applicable to different audiences on the topic of care and recovery.
- To raise awareness amongst carers and supporters about recovery.
- To allow for participatory and uncertain outcomes.

This brief study emerges out of a commitment from the Scottish Recovery Network (SRN) to investigate and promote all aspects of the recovery process with all key stakeholders. Carers can play an important role in the lives of people with mental health problems. SRN facilitated this first-step exercise in raising awareness of recovery amongst carers, and also listening to life experience from those in the front-line of caring and supporting.

The study will be prefaced by a short literature review to provide some context and orientation to the general issues surrounding carers and supporters of others' mental health. The methodology for the short survey will then be outlined and the main findings then profiled.

Preliminary conclusions based on the findings will be presented at the end of the report, along with details of further reading.

#### Terminology

The report uses the term 'carer' as a shorthand to describe the role of parents, family members, friends or supporters who help assist another person with mental health problems. We realise that many people do not identify with this label straight-forwardly, but it has been adopted by support organisations and for the benefit of mobilising resources for carers, and for these reasons we use it here. In addition, we also use the term 'loved one' to describe the person with mental health problems that is in receipt of care or support. This is a convenient phrase to denote the significance of the person for whom most of the people who contributed to this survey care for, however it may reference an emotion which is not always felt as appropriate by all and we acknowledge this here.

### **Caveat**

For this project we spoke only with individuals who could be identified as being carers. Many of the people we spoke with were parents or family members and because of this the data collected reflects a positive view of family involvement. We acknowledge that the data collected reflects one side of a caring relationship and we accept there is an underlying assumption being made that the loved one wants to have their parents and/or family members involved in their recovery. We recognise that this may not always be the case and individuals may choose not to have their families involved or vice versa.

With this report we do not intend to assert as to whether or not families/carers *should* be involved in an individual's recovery process. However, the findings do support existing research (see selective literature review) that carers/family member involvement can play an important role in recovery.

## Selective literature review

'Families are rarely systematically included in discussions about recovery.'  
(Dixon 2000, p444)

In her extensive survey of family caregivers Stengard (2005, chapter 2) writes of the history of family caring. She notes that the context of the family has been very important in the support and care of people with mental health problems throughout history, and especially before the provision of public asylum systems in Western countries. At various points in time, and in different places, family care has been valued in different ways. One of the most famous examples of positive family care for mental health problems was the model at Gheel in Belgium, which was used as a blue print for care in other geographical contexts (Philo, 1989), and suggested that domestic residence was the *most beneficial* setting for good and recovering mental health (also Goldstein *et al*, 2003 and <http://faculty.samford.edu/~jgoldst/>). Research by the Scottish Recovery Network on narratives of mental health recovery also points to the importance of positive social relationships in this regard, and this includes family members and networks (Brown and Kandirikirira, 2007, p98).

Stengard (2005) charts recent changes in the understanding of the family's role in treatment and rehabilitation since the 1950s. She notes that different theories have existed about how best to conceptualise the family. Research has revealed negative commentaries about family as dysfunctional and stressful, but also produced positive readings of family care as the best possible community resource for someone who is unwell. This author notes, however, that in the large field of family research 'the feelings, experiences and needs of family members themselves are ignored' (Stengard, 2005, p18).

In very recent times, the rapid organisation of carers into support groups, influential at the national and international level, has helped to provide an informational resource that addresses some of the gaps identified above. Nonetheless, since the 1970s Stengard (*ibid*) notes 3 different main types of research *on* carers i) family reactions to mental illness, ii) more advanced measures on family attitudes, burdens, stigma and expressed emotions and iii) more theoretical conceptualisation of the notion of 'care burden' and psycho-educational research. In each of these genres an explicit focus on family and recovery experiences is limited at best.

In a sweep of major online databases for literature on recovery in the context of carer and informal support for this report, there was *little evidence* of this subject area (but see Bland *et al*, 2002, Mackensie, 2006). However, some brief general points can be made. Much literature on caring is focussed on negative aspects of caring relations for carers: stress (Amir *et al*, 2000), family treatment needs (Badger, 1996), stigma (Struening *et al*, 2001) and barriers to good relationships with formal care givers (see references listed in Stengard, 2005, p55). These are important factors to consider when understanding the complicated dimensions to the caring experience for family members.

However, *underestimating* the strength and resilience of family members is to neglect their unique role in helping people with mental health problems develop pathways to social recovery that may help them combat their experiences of actual illness (Finkelstein, 2000; Marsh *et al*, 1996). Some literature points to how families can improve the social situation of their cared-for loved ones, but only with particular kinds of externally provided education (Gasque-Carter and Curlee, 1999), or family therapy, while others are more positive about the *in-built* coping strategies of carers (Early *et al*, 2000). The literature on gains, strength and resilience amongst carers and families who cope with mental health problems is relevant to understanding the recovery context (Patterson, 2002). As Addington *et al* (2001, p272) also argues with reference to education for carers:

‘Intervention programmes respect the importance of the context of the family as *crucial to recovery* and incorporate assessment processes which seek to document the strengths and resilience of the family – but overall an emphasis on ‘psycho-education’ – does not equally value expertise by experience – even in early intervention services.’

The point here about carers being sources of expertise by experience can also be seen when looking at creative literature. There is an enormous amount of informal literature about caring relationships which exists as the testimony of parents and supporters of children and family members experiencing mental health problems. This literature is prevalent especially in Western contexts and in the US, Canada and UK (see the Further reading section at the end of this report). This may be an untapped source of material and insights into realities of family struggle and how recovery might happen in difficult and particular circumstances. A qualitative analysis of these texts may help to address some aspects of the research gap in understanding the role of family carers and supporters in assisting different kinds of recovery for the person with mental health problems.

Overall, there is a wealth of research about carers and a wealth of research about recovery – but little on both (but see Lefley, 1997). Dixon (2000, p444) argues this is partly a matter of historical politics:

‘The separation of family from the recovery movement is probably also linked to some of the historical tensions and rifts between the family and consumer movements.’ (Dixon, 2000, p444)

This, coupled with a dominant focus on burden and resilience in the care-giving research literature base, may mean that the *role of carers and supporters in recovery is underestimated or unknown*. Indeed, in previous research the SRN have argued that:

‘More focussed research that identifies the positive aspects of relationships and investigates particular types of relationships... would provide a better understanding of how people develop relationships that support recovery and how services and policy can

potentially assist in the building and maintaining of these relationships' (Brown and Kandirikirira, 2007, p98)

This preliminary report seeks to partly address these concerns by commenting on the experiences of a small number of carers in Scotland, UK. Further reading, compiled from a range of resources, is included at the end of the report

### References

- Addington, J, Addington, D, Jones, B and Ko, T (2001) 'Family intervention in an early psychosis program', *American Journal of Psychiatric Rehabilitation* 5, pp272-286.
- Amir, N, Freshman, M, and Foa, E. B. (2000). 'Family distress and involvement in relatives of obsessive-compulsive disorder patients'. *Journal of Anxiety Disorder.*, 14, pp209-217.
- Badger, T. A. (1996). 'Living with depression: family members' experiences and treatment needs'. *Journal of Psychosocial Nursing in Mental Health Services*, 34, pp21-29.
- Bland, R., and Darlington, Y. (2002). 'The Nature and Sources of Hope: Perspectives of Family Caregivers of People with Serious Mental Illness'. *Perspectives in Psychiatric Care* 38, pp61-68.
- Brown W and Kandirikirira, N (2007) *Recovering Mental Health in Scotland: Report on Narrative Investigation of Mental Health Recovery* (Scottish Recovery Network). ISBN 978-0-9556359-0-8
- Dixon, L (2000) 'Reflections on Recovery' *Community Mental Health Journal*, 36, August, p444.
- Early, T. J. and GlenMaye, L. F. (2000). 'Valuing families: social work practice with families from a strengths perspective'. *Social Work*, 45, pp118-130.
- Finkelman, A. W. (2000). Psychiatric patients and families: moving from a catastrophic event to long-term coping. *Home Care Provider*, 5, pp142-147.
- Gasque-Carter, K. O. and Curlee, M. B. (1999). 'The educational needs of families of mentally ill adults: the South Carolina experience'. *Psychiatric Services*, 50, pp520-524.
- Goldstein, Jackie L. and Godemont Marc M. L. (2003). 'The legend and lessons of Geel: A 1500-year-old legend, a 21st century model'. *Community Mental Health Journal* 39, pp441-458.
- Lefley, H. P. (1997). 'The consumer recovery vision: will it alleviate family burden?' *American Journal of Orthopsychiatry*, 67, pp210-219.
- McKenzie, P. (2006, April). The Holding of Hope: Exploring the relevance of the recovery vision for carer/families. Paper presented at the Partnerships Towards Recovery Conference, Elsternwick, Victoria: Australia.  
[www.vicserv.org.au/publications/new\\_para/pdf/2006/mckenzie0906.pdf](http://www.vicserv.org.au/publications/new_para/pdf/2006/mckenzie0906.pdf)
- Marsh, D., Lefley, H., Evans-Rhodes, D., Ansell, V., Doerzbacher, B., LaBarbera, L. et al. (1996). 'The family experience of mental illness: Evidence for resilience'. *Psychiatric Rehabilitation Journal*, 20, pp112-131.
- Patterson, J. M. (2002). 'Understanding family resilience'. *Journal of Clinical Psychology*, 58, pp 233-246.

- Philo, C. (1989) 'Enough To Drive One Mad": The Organisation Of Space In 19th Century Lunatic Asylums'. In Wolch, J. And Dear, M. (Eds) *The Power Of Geography: How Territory Shapes Social Life*. Unwin Hyman. London, pp. 258-290.
- Stengard, E (2005) *Journey of Hope and Despair: the short-term outcome in schizophrenia and the experiences of caregivers of people with severe mental disorder*. Dissertation, Faculty of Social Sciences, University of Tampere, Finland. ISBN 951-44-6239-4.
- Struening, E. L., Perlick, D. A., Link, B. G., Hellman, F., Herman, D., and Sirey, J. A. (2001). 'Stigma as a barrier to recovery: The extent to which caregivers believe most people devalue consumers and their families'. *Psychiatric Services*, 52, pp1633-1638.

## Methods

### Participation

An open call for participation went to all organisations who had originally registered for a carers conference organised by SRN in 2008, but which was subsequently cancelled. Invites also went out to additional support organisations for carers and informal supporters. This research project began in February 2009.

Five organisations in four cities were chosen to participate, and in the end four organisations in Edinburgh, Glasgow, Perth and Aberdeen took part in surveys and focus groups and these were:

- Edinburgh Carers Council
- Charlie Reid Centre Carers Support Group
- Tayside Carers Support Project (Perth)
- Aberdeenshire carers peer support project

60 short questionnaire surveys were sent to these organisations and 22 were returned. The surveys were used as the basis for the structure of follow-up focus groups which took place in February, March and April 2009. Focus group numbers varied from four to 25 and overall approximately 60 people took part in the group discussions. Each group discussion was taped on a digital dictation machine with the permission of those present. Group discussion varied from 1.20 to 1.40 hours and all recorded materials were transcribed verbatim. This amounted to six hours of recorded discussions over the four groups.

The results of both the survey and the focus group transcripts have been entered into the NVIVO software package and coded for emergent themes. These themes and the qualitative materials have been used in the writing of this report. All submissions were anonymised and only the age of the carer and the length of time spent caring are recorded in association with quoted materials. The limitations of the numbers involved mean that only a qualitative analysis is attempted here.

### Focus groups

In organising focus groups each organisation sent out an information sheet about the research and a call for participation to its members. The information sheet detailed the aims, procedures and outcomes of participation and highlighted that confidentiality through anonymity would be guaranteed. Informed consent was presumed by voluntary participation in the focus groups and separate consent forms were not used. The structure of the focus group discussion was planned around an iterative research method whereby the previously completed qualitative survey was used to structure key questions for discussion. These key questions provided a focus for the first half for the

focus group (40-60 minutes of discussion). Following a break, a second session was planned in which a fictional story of a carer was used as a means to prompt responses regarding recovery practice. This method was deliberately chosen as a way to corroborate the general discussion of the first session and help form an iterative knowledge based on carer experiences and perspectives. In practice, although we profiled the fictional story in each focus group, it varied as to how much the planned story was used. See Appendix 1 for the analysis of the survey data and Appendix 2 for materials used in the survey and discussion groups.

## Survey interpretation

Taking each of the questions in the survey, we can elaborate on the responses recorded. For further details of the survey responses and analysis please refer to Appendix 1.

### 1. Recovery and carers

#### Question one: What does recovery mean to you?

The survey responses suggest that there is no one standard definition of recovery and carers differ in how they think about this term. Some respondents named what they considered to be 'recovered behaviour', while others reflected on the term itself and what it means for them. For some this is was an inappropriate use of language:

*'In my experience of 20 years caring I find the word 'recovery' inappropriate as very few people with severe and enduring mental illness recover completely.'*

- (Carer for 20 years, aged 40-56)

*'Recovery is the wrong word and could give false hope to carers and service users. Hope is a better word.'*

- (Carer for 10 years, aged 40-65)

For these carers recovery was likely to be related to an 'absence of illness' and therefore something that they perhaps had no experience of, given the long-term nature of some experiences of mental health problems. More often carers pointed to quite different ways of understanding the term recovery, and how it was related to a sense of process and/or movement in the situations and health of the people they care for:

*'When things become more flexible, less rigid, then recovery is on its way.'*

- (Carer for 31 years, aged 40-65)

For some carers the term means something connected to the recovery of the family and themselves. The impact of mental health problems is something shared by the whole family and so recovery is experienced collectively and not just by individuals. Recovery is thus associated with a sense of wellbeing, and one shared by the carer and not just focussed upon the person that is unwell:

*'To be able to look after my own wellbeing, to remember to have hope.'*

- (Carer for 15 years, aged 40-65)

Many carers in the survey responded with flexible definitions of recovery, noting that senses of recovery are related to changed and changing expectations about quality of life:

*'You first have to recognise that recovery does not mean life as it was before the illness. Once I realised that and accepted it, the meaning of recovery changed.'*

- (Carer for 10 years, aged 40-65)

For some, the sense of hope that is bound up with the term recovery is problematic, as it is acknowledged that recovery can come and go over time:

*'I've seen glimmers of hope where I thought that recovery was possible, only to have it slip away again and you have to start again.'*

- (Carer for 22 years, aged 40-65)

Re-visioning what counts as recovery was key to the acceptance of the term for some respondents. One key risk to this was to compare current life experience with an imagined life experience free from mental health problems:

*'If I stop and think too much about the life he should have had I cry and I try not to think about it and just concentrate on how good his life is now, and how far he has come. I don't want to waste any of the life he has now thinking back on what should have been, and miss the good times he has now. I just want to enjoy what he has now.'*

- (Carer for 10 years, aged 40-65)

Based on the responses we can state that the meaning of recovery is different for different carers, and a range of other definitions and reflections were offered as detailed in the table in Appendix 1. Despite this range there was a predominate association with a sense of having to rework life expectations in the context of renewed and renewable hope and enjoyment in the lives affected by mental health problems.

## 2. Recognising recovery

### Question two: How do you recognise recovery?

If recovery as a term has different meanings for different carers, then it follows that how carers recognise recovery in the people that they care for also differs. For some carers recognition was bound up with the receding of symptoms and the absence of mental health problems:

*'The absence of psychosis.'*

- (Carer of 30 years, aged 65-75)

*'Return of conversation without the interruption of auditory hallucinations.'*

- (Carer of 10 years, aged 40-65)

For a small proportion of carers, then, recognising recovery was associated with the demonstration of good health and resumption of former life experiences and capabilities:

*'When someone recovers completely and can hold down a job and manage all their own affairs.'*

- (Carer of 20 years, aged 40-65)

For the majority of respondents recognition of recovery was associated with specific behaviours of the person they cared for in relation to their socialisation (ability to socialise), relationship work, bodily characteristics, activities and insight. For example, recovery can be witnessed in association with social characteristics:

*'A sense of humour re-emerges and risks can be taken with language, humour, criticism even.'*

- (Carer of 31 years, aged 40-65)

*'When the person can express themselves adequately.'*

- (Carer of 31 years, aged 40-65)

These social benchmarks can also be accompanied by a return in the interest in other family members and having friends outside of the mental health system. For some carers the signs of recovery were related to more bodily characteristics and the appearance of new daily routines:

*'A lightness in their eyes.'*

- (Carer of 10 years, aged 65-70)

*'Something as small as my son speaking again.'*

- (Carer of 10 years, aged 40-65)

*'Having some personal hygiene.'*

- (Carer of 5 years, aged 40-65)

*'Being able to laugh.'*

- (Carer of 14 years, aged 40-65)

These small signs may be accompanied by simple practices such as opening the curtains, going for walks and being able to volunteer for different activities. In general terms being busier and having a positive attitude were thought to be important and recognised as the beginning stages of recovery. Other behaviours that were noted by carers included:

*'Not using alcohol or drugs.'*

- (Carer of 5 years, aged 40-65)

*'Keeping himself safe.'*

- (Carer of 5 years, aged 40-65)

*'Cleaning his flat.'*

- (Carer of 10 years, aged 40-65)

These small changes were reported to be somehow related to bigger changes, for example the demonstration of insight into experience, and the development of some degree of self confidence and self determination. So in these terms, carers recognised recovery by noting:

*'Gaining of insight, accepting what cannot be changed and changing what can be on their own terms.'*

- (Carer of 40 years, aged 40-65)

*'Strengthened self-determination.'*

- (Carer of 40 years, aged 40-65)

*'Him recognising his own success.'*

- (Carer of 12 years, aged 40-65)

### **3. Practical steps to support recovery**

#### **Question three: What practical steps can be taken by carers to support the recovery of people with mental health problems?**

The *actions* of carers can be important for people with mental health problems, and many carers who responded to this survey were clear on the range of helpful actions that they themselves undertook to bring about experiences of recovery. In part, these are related to the attempts made by carers to constantly communicate with services (from GPs to CPNs to psychiatrists):

*'Keep communication with services and turn up to reviews.'*

- (Carer of 10 years, aged 40-65)

*'Write to consultants and GPs and ask to be included in meetings.'*

- (Carer of 12 years, aged 40-65)

Very high on the agenda of many carers were the resources for co-support through and with other carers via support groups:

*'Go to carers groups for support and advice to deal with the difficulties and complexities which arise when caring for someone.'*

- (Carer of 42 years, aged 40-65)

*'Support groups are crucial fundamental 'tools' in recovery.'*

- (Carer of 31 years, aged 40-65)

In this regard, one of the crucial dimensions to a support group was the co-learning to care for oneself. Here carers reported that to invest in their own self development, self awareness, and self-care was very important as a practical step in supporting the recovery of the person they cared for. This issue will be returned to later in the report, but here this was reported as being crucial in helping carers to have patience and sustained energy in the relationships they were part of. Specific advice was also given via the survey about 'what works' as part of caring relationships:

*'Listen to them, and don't talk down to them.'*

- (Carer of 22 years, aged 40-65)

*'Talking to them, calming them down.'*

- (Carer of 6 years, aged 40-65)

*'Be as consistent as possible and be clear in speech and actions so there are no ambiguities.'*

- (Carer of 31 years, aged 40-65)

*'Don't be critical.'*

- (Carer for 5 years, aged 40-65)

For some carers, they find this constant 'relationship work' taxing and advise that it is better to

*'Have no expressed emotions.'*

- (Carer for 1 year, aged 25-40)

in dealing with their loved one, although this is almost impossible to achieve and this hints at the behavioural burden that falls on the shoulders of some carers.

One key practical aspect in beneficial caring relationships was named as the ability of carers to allow for risk-taking and self-development:

*'PERMIT the development of independence in someone who may need to relearn it.' (original emphasis)*

- (Carer of 40 years, aged 40-65)

*'Encourage independence and safe risk taking.'*

- (Carer of 7 years, aged 40-65)

*'Allow the person to explore things and take risks.'*

- (Carer of 5 years, aged 40-65)

*'Take a step back.'*

- (Carer of 15 years, aged 40-65)

This is a challenge for many carers due to shared protective instincts and this theme will be explored later in the report.

In summary, carers report that *their own* behaviour and actions are key aspects of the practical steps that can be taken to help achieve recovery outcomes:

*'Encouraging and motivating someone with mental health problems can be exhausting but also very rewarding when you share the good times.'*

- (Carer of 14 years, aged 40-65)

There are lessons here for how we understand recovery from mental health problems and that this is partly bound up with how carers and supporters recognise and respond to signs of recovery.

#### 4. Carers and services

##### **Question four: How can health and social services best work with you to support recovery?**

Many carers answered this question in negative terms, indicating that they feel that health and social services *do not* assist with the intensive recovery work that carers themselves undertake. Carers felt that they had specific needs that services should be meeting to assist them with their role. These needs are orientated around education and information about mental health problems, and these should be specifically about directing the efforts of carers to be most effective:

*'There needs to be more input initially from professionals about the illness, what to expect, when to intervene, when to leave alone.'*

- (Carer of 5 years, aged 40-65)

Carers are often willing to work with services in the best interest of the cared-for, but it is rare for carers to feel valued as an important part of the building blocks for recovery:

*'Listen, in my experience I am not heard.'*

- (Carer of 14 years, aged 40-65)

*'Professionals need to include carers and remove some of the barriers to working with us in the guise of confidentiality.'*

- (Carer of 42 years, aged 40-65)

Carers can provide important insights into the daily lives of their loved ones who use of formal services and therefore be important sources of information for services. For carers, they are concerned that the person behind the mental

health problems is visible to the formal care providers, as this helps in creating a personalised treatment/recovery plan:

*'A more personal approach is needed to learn about the person and not always concentrating on the illness.'*

- (Carer of 15 years, aged 40-65)

In particular, carers were concerned that services remained consistent when a) crisis occurred but also b) when recovery began. For some carers, services seemed to retreat at the first signs of recovery, when longer term support to secure recovery was necessary:

*'Helping to secure the next phase of recovery rather than tailing off services when things improve.'*

- (Carer of 40 years, aged 40-65)

Overall, carers called for services to be creative and personal in their treatment philosophy and practice. There appears to be a potential opportunity to help secure recovery for people with mental health problems by engaging further with carers who are willing to co-work with services, and this theme will be returned to below:

*'Keeping red tape to the minimum and willing to be creative to solve minor problems: asking carers for ideas!'*

- (Carer of 20 years, aged 40-65)

## 5. Barriers to recovery

**Question five: What do you think are the barriers for carers as they seek to help people to recovery?**

The responses to the questions in the survey above show that carers can be a valuable resource in helping to effect and recognise recovery for people with mental health problems. Understanding the barriers to recovery practice is particularly important in the case of carers as they spend such a significant amount of time with the people they support. Interestingly, some of the issues that people with mental health problems face are also faced by their carers. Social stigma can also be experienced by carers and is implicated in their abilities to ask for help, to understand the resources they are entitled to, and to enlist friends, neighbours and other community members in recovery orientated social practices:

*'Socialising with my spouse after psychosis is very difficult, there is the whole stigma issue and acceptance.'*

- (Carer of 31 years, aged 40-65)

More attention to carer's experiences of the social stigma of mental health issues and caring for people with mental health problems could be beneficial.

In more general terms, the respondents to the survey felt that the role of the carer is experienced as an ambiguous and under-valued role in society and in relation to services specifically.

*'Not enough respect for carers and their input, we do know the person and can give valuable insight.'*

- (Carer of 10 years, aged 40-65)

*'I would love just a little respect for my feedback and observations.'*

- (Carer of 14 years, aged 40-65)

Many respondents felt that they could offer potentially valuable information and input to the work of formal service providers, but were often prevented from doing so because of a mixture of attitudes to family carers and concern for patient confidentiality:

*'Drs are unaware of how much carers know and do and rarely take their views into consideration.'*

- (Carer of 16 years, aged 40-65)

The carer is often the most consistent point of contact for the person with mental health problems and therefore could be a useful lynchpin between different kinds of mental health services that are used over a period of time. The potential for the carer to be part of a 'joined up' service is felt to be unfulfilled because of the under-valuing of their role and status. This is thought to act as a barrier to recovery:

*'Services are not joined up to support phasing recovery.'*

- (Carer of 40 years, aged 40-65)

As a result, we can infer that carers often feel isolated and unsupported in their role and there is an acutely felt need to support carers with information and appropriate respite resources:

*'There is no support in place to help carers so you end up traumatised, anxious and depressed.'*

- (Carer of 15 years, aged 40-65)

Such experiences can work against recovery practices:

*'It's easy to feel pessimistic if recovery takes a long time.'*

- (Carer of 5 years, aged 40-65)

Despite much evidence of pressures and burden upon carers in the survey, there is a sense in which they are very much champions for improvement and progress. As one carer puts it:

*'Service users should not be allowed to dwell in comfort zones because it is easier for everyone else.'*

- (Carer of 7 years, aged 40-65)

## 6. Concluding issues

The survey raised a variety of issues relating to the carer experience of recovery. Although there are mixed understandings of the benefits of the term 'recovery', most survey respondents related ways in which they support and recognise recovery when it happens. The survey raised important issues relating to what carers can do to assist recovery and how barriers to recovery could be removed by the help of health and social services working in partnerships with informal and family supporters. These themes are explored in the next sections, which examine further the carer experience of recovery.

## Exploring carers experiences of recovery

In this section *selective* aspects of the data collected by group interview will be drawn upon to help explore some of the issues outlined previously, in order to elaborate on key dimensions of the carer experience. Here again, this report deliberately highlights data which points to the practices which help recognise recovery and secure it. Difficulties with, and barriers to, helping someone to recover from mental health problems will be also explored in more depth.

### 1. Understanding further dimensions to recovery

The survey shows that people who are in a caring role have different understandings of recovery. While for some people this is a term that is controversial and does not feel appropriate for their experience, for others it suitably conveys the promise of a better life, a life lived *with* mental health problems:

*'For me, recovery is about hope, the hope of recovery, and having a life, rather than having it toned down and just managed.'*

- (Edinburgh discussion group)

*'It's a very emotive word because when you, when I think of recovery I want my son back like he was.'*

- (Perth discussion group)

Some carers we spoke with find it hard to understand what their role is in relation to this thing called recovery, even when they are already engaged with what others would identify as aspects of recovery-orientated practice:

*'What is it I should be doing? How can I help them with their recovery?'*

- (Edinburgh discussion group)

Rather than restate the range and variety of definitions of recovery (and there are many), it is perhaps more useful to look at some common elements carers use to discuss their observations and experience of recovery for the people they care for. This can help us to understand more about how recovery is envisioned and also how it might be assisted.

### 2. Time and pace in recovery scenarios

Time is an important factor in carer perceptions of recovery and their expectations relating to this term. For many it was only after many years of caring that they were able to recognise aspects of behavioural and social recovery:

*'The years just go by and then it's difficult to think, well, can there be any recovery? Even now after 22 years, in the last year, things*

*have been different and I think yes, there can be. It depends on what you think recovery is.'*

- (Glasgow discussion group)

*'...if you've went for years and it's all been black and then you see, 15 years down the line, you see recovery. You need to chase that up. Each time might be longer and you can build on it. As a carer, when I first heard the word recovery being used I really hated it, I resented it and I thought this is for the 75% of quite-well people, this is not for the severe and enduring and then... now I can genuinely see it... in the past 6 months he's has the best quality of life he's had in the last 15 years.'*

- (Glasgow discussion group)

Carers testified that they may have resented the emphasis on recovery *prior* to the behavioural and social changes that they themselves have witnessed and thus had been sceptical as about its value as a concept. Conversely, carers also felt that if they had known it may take 15 or 20 years to show signs of recovery in the beginning of their caring journeys, they may have felt even more daunted. There was no evidence from the group discussions for this research that there was a common time-line for recovery, rather, different carers pointed to improvements witnessed at a variety of time-scales ranging from months to many years. Importantly, even those caring for decades still report recent and significant improvements in quality of life amongst those they care for.

Questions of time can be bound up with questions of pace in the context of caring. Recovery may not be dramatically 'event-based' but emerge in relation to a variety of non-linear events over time. For some carers, a change in *their own* pace was perceived to have helped lead to changes for the person they cared for. For others this was relating to a 'speeding up' of social opportunities for their loved one, while for yet others this was related to a 'slowing down' of their caring practice: Pace was thus discussed as a potentially important 'tipping point' in the recovery process:

*'I thought 'Am I doing too much?' and it took me 10, 12, 13 years to do that and then think 'we're just going to take this at his pace' and that helped.'*

- (Glasgow discussion group)

*'There are dangers about taking things too quickly but there are also dangers about taking things too slowly as well.'*

- (Edinburgh discussion group)

While it was hard for carers to identify aspects of their own practice that they could straight-forwardly identify as a 'tipping point' for recovery, the importance of finding time to reflect on the situation was raised, although this was acknowledged to be difficult:

*'You don't have time to look at things, it feels like just one crisis after the next, you don't have time to look at any reprieve and recognise it. Something else is always happening... even if it was wee things, you perhaps wouldn't recognise it because you were always going to the next drama.'*

- (Glasgow discussion group)

For some carers, it was very important to 'stand back' from the situation and the person they cared for in order to be able to see tipping points/what works for recovery. Carer respite is an important factor in this process and creating time for carers to reflect on their own practice and what works for the person they care for was deemed important. These issues are explored further below.

### 3. What carers do: providing intensive care

The carer is in a unique and intimate position to know the person they care for, their likes and dislikes, their stress points and tipping points in relation to mental health issues and recovery. Carers recounted the many things they do to assist their loved ones in daily life:

- Daily household chores.
- Helping with bills and official documentation.
- Providing meals and shopping assistance.
- Accompanying loved ones on trips and daily outings.
- Providing telephone support.
- Providing love, support and encouragement.
- Providing physical care when needed.
- Liaising with services and accompanying loved ones to medical appointments.
- Researching medication and recovery opportunities.
- Engaging in care support groups for mutual advice and experience sharing.
- Providing an over-view of the personal and social needs of the individual.

The intensive and wide ranging work of the carer puts them in a special position to be able to understand the person behind the mental health problem. Carers also spoke about the importance of reminding formal health services to nurture the *personhood* of the loved one/patient. Carers can provide crucial information which might impact on recovery opportunities and chances:

*'It's as if the system doesn't understand relationships. It understands symptoms and drugs to control symptoms and it forgets there is a person there... the same issue can come up again and again for the person (their emphasis), but it is treated as symptom.'*

- (Glasgow discussion group)

*'The individual is lost within the professional services. I know my daughter as an individual: she has lots of positives, lots of talents, a huge side to her person that they just didn't find out about it, or didn't allow themselves to find out about.'*

- (Edinburgh discussion group)

For carers to feed intimate information to formal service providers about 'tipping points', stressors, capabilities and social likes and dislikes could be a potentially crucial factor in personal improvement and quality of life, which are core aspects of recovery experiences.

#### **4. What carers *could* do: relationships with formal services**

The survey discussed in previous sections raised a set of largely negative issues relating to the relationships between carers and service providers. Many carers report feeling lost in professional systems of care, and recount their experiences with these by using metaphors of 'battle' and 'struggle'. Carers have also recounted experience of being stigmatised by services as 'just carers' or 'just family', labels they feel are under-valued or de-valued by formal providers. Although some carers have positive experience with certain individual practitioners, there is no doubt that systematic problems of communication exist between the formal care system and the informal carers. Despite this difficult background of experience, there were positive suggestions for change across the four discussion groups. Carers were clear that they could help formal providers learn from them so that the recovery chances of the loved ones/patients concerned were improved:

*'I think there's a lot that carers could contribute to, if they were pulled in. With OTs and CPNs and community workers, they could get very involved there, not for their own benefit, but because they care about the person, so it's about being able to contribute in an informal way, in discussions, looking at positive aspects about what they are doing, what they are good at. A lot more could be done here.'*

- (Edinburgh discussion group)

*'At the point where she started recovering a bit, it was at that point they could have done a lot more to find out about her, who she was, how she ticked, and they could have asked me - but they never did. I had to keep trying to say what would help her.'*

- (Edinburgh discussion group)

*'You do know your child in a way that could have a real bearing on their recovery.'*

- (Perth discussion group)

The willingness of carers to input to formal services to enable them to maximise recovery opportunities is dependent upon how they are valued within services, a point directly addressed within group discussions:

*'Health and social services need to equalise all relationships. That's between themselves and us. You know, we're all service users: they are, the sick person is; we are, and if it's looked at like that, it's equalised. I think there might be room for change.'*

- (Aberdeen discussion group)

From this we can conclude that formal services could benefit from working with carers as a means of developing supportive recovery focused relationships with service users. In SRNs narrative research project, people described recovery focused relationships as being ones that are supportive, trusting, consistent, accepting, reciprocal and where service providers took the time to 'get to know' the individual.

Carers could assist in this process of building these types of relationships by sharing personal knowledge about their loved ones and assisting service providers in 'getting to know' the loved one and their mental health. In a system where continuity in staffing can be an issue, service providers could benefit from working routinely with carers to assist them in developing well informed, recovery focused relationships with the people who use their services.

### **5. What carers know: recovery and the importance of social life**

The intimate knowledge that carers hold about the lives of their loved ones, can be a useful resource for reflecting on loved ones social lives; their social connections, abilities, fears and opportunities. Carers document the inventive and creative ways they have of trying to maintain the social skills of their loved ones:

*'When they get ill young it's really easy for them to lose touch. Last year I went out and bought my son an IPOD because everyone else is using them and I don't want him left behind in that as well. He's losing touch, things are moving on... he's not even 30 yet and he needs to know stuff like that. We both learned it. You have to think in practical terms about this sort of thing when they are young, so they have to keep in touch with the world if they are to re-enter it. You have to be aware of all that so to help them to recover in that way... you have to make a conscious effort to think of these things.'*

- (Glasgow discussion group)

Other carers relayed the ways they helped people they cared for stay in social contact:

- Keeping in touch with friends outside the mental health system.
- Encouraging participation in groups.
- Encouraging participation in voluntary activities.
- Buying phones/practising computer skills.
- Downloading music and sharing these skills.

- Asking for help from the people they care for.
- Encouraging daily and weekly trips outside the home.
- Taking holidays together or separately.

The all-consuming and intensive efforts of caring can involve risks to the carers in terms of their own social connectedness and hence their abilities to help others have a social recovery:

*'(Carers) have been damaged as much by the illness, so much so that they get ill. It's very common. It can go on 25 or 30 years and carers can be isolated as well and lose all their social skills.'*

- (Edinburgh discussion group)

For both carers and loved ones there are benefits to remaining socially active and in touch with contemporary developments in technology, music and cultural life. Even small steps in these directions helps limit the feeling of being 'left behind' for both parties.

### **6. What carers find difficult: managing risk and 'letting go'**

*'On the surface, they can appear perfectly well and they are saying all the right things, but inside it's a totally different story and they are still fragile and they are still vulnerable...'*

- (Glasgow discussion group)

Because of their intimate knowledge of the strengths and fragilities of the people they care for, carers can find it difficult to facilitate some activities relating to recovery if they are fearful of the result.

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

- (Perth discussion group)

Carers can sometimes feel as though they are treading a tight-rope in relation to the crucial 'tipping points'. Carers question themselves about how much to push their loved ones to engage in activities and social life and when to draw back and let them experience *independent* success and failure:

*'Life's a risk isn't it? So along the way you've got to be prepared to, it's like letting go of the apron strings again, you know, when they leave school and that, it's that symptom all over again and having the confidence to say – you don't really have it – but you've got to appear as if you have the confidence to let them go and do their own thing.'*

- (Aberdeen discussion group)

*'I find a very difficult balance to treat her as an adult sometimes, I find it difficult not to start managing her, as she's almost asking to be managed, it's difficult because she also says 'no' to that, it's a difficult balance between being there and not being there and doing*

*all the daily stuff. I don't want to treat her like a child, but it's hard.'*

- (Edinburgh discussion group)

The very fact that carers are often parents, or family members, makes it very hard to let go of the carefully co-ordinated controls or parameters that can be in place. Parents, and perhaps mothers in particular, report it as especially difficult to know when their loving care needs to be *less intensive* in order to allow social recovery to occur. As the carers above testify, it is important to try to recognise when parental or caring relationships provide too much management, and when roles of 'parent' and 'child' are unhelpfully reinforced. Here, carers speak of the benefit of sensitive outside intervention, when formal service providers might assist with the delicate process of allowing risk and independence as part of attempts to recover:

*'I realised he was 36 years old and shouldn't be living at home... he just wants to be a little boy and looked after, that's all he wanted... I had said he cannot come home. It was a struggle... now he is functioning much better... It sounds tough and it is tough, but I had to get to that stage... the services left him with nothing and eventually I just said 'He is not coming back'... (and) it is much better now.'*

- (Edinburgh discussion group)

However, some carers find that formal services are only too willing to let carers continue in intensive support scenarios, for example a carer having to repeatedly request that a service find independent but supported accommodation for their loved one. Services and carers could work together to best understand dimensions of risk taking and 'letting go' in order to co-facilitate recovery scenarios. Some carers have discussed their own decision-making about risk, relating that very personal judgements about risk behaviours are sometimes called for in ways that facilitate trust and comfort in the person being cared for:

*'My daughter was sleeping with sharp knives under her pillow and we never told the hospital because if we did she would have been bought back in and we made the judgement that if she went in there again it would be bad news. You take risks... as the parent or carer you are in a huge position of responsibility. We couldn't talk to anyone about that because they would have lost their nerve.'*

- (Edinburgh discussion group)

Although such a scenario as this is perhaps extreme, this demonstrates the range of ways that carers have to manage risk and make judgements about risky behaviours.

In the complex business of 'letting go' and allowing loved ones to take risks (in relation to work, social life, medication use, behaviours, independence), carers experience a range of emotion from fear to guilt to pride. Allowing risk to happen is an emotional time, and carers often need support in order to manage this process:

*'It's very hard to see someone teetering on the edge of a chasm... it's hard to 'just' be family and stand back and watch that.'*

- (Edinburgh discussion group)

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

- (Perth discussion group)

Although risk-taking is clearly an uncertain process, many carers were adamant about the benefits of doing this, and therefore were clear about the importance of risk for helping to bring about recovery. Ironically, it is often a personal crisis, physical illness or pure exhaustion that enables carers to 'let go' of their intensive caring management role, often with interesting results:

*'When you are in a crisis you throw everything you have at it, but 20 years down the line you can't keep doing that, I think what I've learned is that if we can get on with our lives, then that allows the other person get on with their life. There's perhaps something they need to do in response. That doesn't mean ignoring a person or not caring about them, but just not building your life totally around them. It means pushing for better services and better support...'*

- (Edinburgh discussion group)

Carers testified to the difficulty of risk taking but discuss how taking the risk to 'let go' can help loved ones respond differently the world around them. It may also enable carers to find their own pathways to recovery.

## **7. Carers experience of their own recovery**

It has been documented above that carers perform extremely intensive support roles for the people they love, and the needs of the carer should not be overlooked nor underestimated in terms of recovery scenarios:

*'I think it's important to have a recovery process for carers, do any of us have the life we want? and that goes for professionals as well. I think it's good to think about recovery as a process and a process that applies to everyone... we are all on the journey.'*

- (Glasgow discussion group)

Carers are clear about the devastating impact of mental health problems on family life, and this, coupled with the demands of balancing the needs of other family members can result in physical illness and/or exhaustion for the carer. The need for carer respite is acute if social isolation and stress is to be avoided:

*'We have to look after ourselves, we can't do everything and we have to realise that, or we will become isolated. You hope that he will get*

*the help, but sometimes you think perhaps I am a hindrance because I am doing too much.'*

- (Glasgow discussion group)

Some carers take many years before they engage in their own recovery, and for some the realisation that they too may have to make a journey of recovery is a revelation:

*'It's now my turn to recover, there's nothing more I can do and it's now me whose got to recover and get my life back.'*

- (Edinburgh discussion group)

For some people this is another form of 'letting go' and 'standing back', a deliberate 'distancing' exercise that is bound up with a profound need for respite. For others there is also the recognition that loved ones can and should exercise some independence and responsibility:

*'Sometimes you have to take a step back, I have done it for years and I had run myself ragged.'*

- (Glasgow discussion group)

A mixture of emotions can accompany the road to recovery for carers such as fear, guilt, relief, especially if the reasons for deliberate distancing is because of personal stress and/or physical illness:

*'You feel you're giving up on your son because you're handing him over to somebody else to look after because you can't cope any longer and you feel responsible, you know, it's very, very difficult to speak about...'*

- (Perth discussion group)

In group discussions carers reported that these personal recovery decisions, or forced periods of respite, sometimes enabled loved ones to take more self-responsibility, or take on small family-related responsibilities. Others reported that this had been a turning point and the start of recovery journeys. This may well be related to the length of time of being unwell, rather than any partial absence of the carer, but some carers reflected on whether these moments enabled loved ones to change in some ways.

Many carers were adamant about the need for space to reflect on the journeys that had been undertaken by themselves as well as their loved ones, and as such new training and respite courses that are available were discussed as particularly valuable. Details of these can be found in the Further reading section at the end of this report.

## 8. What barriers to recovery carers negotiate: stigma and community life

The survey findings detail some of the barriers to supporting recovery and this theme is explored further here. Several carers discussed their experience of social stigma, and described feeling the taint of negative attitudes towards mental health issues. For some, this means that they are reluctant to reveal their caring status, and therefore often do not ask for help or assistance in their caring role. For others, this stigma was bound up with services and being treated as a problematic person because of their carer status and their need to fight for good mental health provision:

*'I used to think... they thought there's that woman complaining again... I used to sit in the car-park in tears... you (carers) get labelled as well. Personally, you do feel as if you've been stigmatized and that you've been damaged and traumatised.'*

- (Glasgow discussion group)

For carers in small communities or rural communities, the issues relating to stigma may be different, but can still act as a barrier to recovery for the carer and cared for:

*'I think that living within a very small community – village life – it's very claustrophobic compared to a town or a city where there's other little communities to go out to, but you know city neighbourhoods as well, they can be as supportive or as rejective as any rural area and it can be vicious and I think, I'm speaking for myself, but I think there's echoes everywhere else, carers can feel so protective of the person going out and they've got to let them go, you know: apron strings, spouses, sons you know, siblings it doesn't matter, but you feel protective.'*

- (Aberdeen group discussion)

The carer above relates the difficulty of life in small communities because of the risk of social rejection. Feelings of protectiveness are strong and this might lead to a temptation to allow loved ones to closet themselves inside the house or a limited friendship circle. For carers who lived in rural areas, these issues are pronounced and several went to great lengths to hide their caring status from villagers:

*'I go to Peterhead, because [XXX] is a small village and if anybody found out my son's got schizophrenia there'd be stones thrown at my window, and you know 'mad man' and all this it'd just be a nightmare, but I come to Peterhead for some carer support.'*

- (Aberdeen discussion group)

Other carers enlist formal service providers in this defensive action:

*'I actually tell the support workers and CPNs to park down the road a bit.'*

- (Aberdeen discussion group)

As one carer argued, such community context potentially exists as a barrier to working with recovery in mind as it is difficult to encourage loved ones in social experimentation and risk:

*'It's a difficult, what if you live in a community where you cannot even come out, you cannot be honest about it and you have to be very careful. I think it's interesting, how do you work in a recovery context?'*

- (Aberdeen discussion group)

These questions and issues exist as challenges to the service and caring community and could be further investigated, as different community and social opportunities seem to facilitate recovery.

## **9. The benefits of caring: experiencing co-recovery**

*'I mean what he's done for my life has been amazing really. You know, because it's made me a stronger person really, you know, going through all this syndrome with my son. It does.'*

- (Aberdeen discussion group)

In reflecting on the positive benefits of caring, several issues were raised about the strengths that were gained by carers. The groups reported feeling: more resilient, self-confident, strong and articulate, educated and as possessing qualities such as perseverance and diplomacy. From our discussions, part of the recovery journey for carers is being able to recognise the gains from their intensive caring work, and having some sense of positivity about their personal situations, which is more likely to assist their loved ones:

*'I like to keep the balance of the whole horror of the whole thing, and yet what one learns, I've learned how much of a stronger a person I am.'*

- (Aberdeen discussion group)

In reflecting on how carers keep on caring, and how they might care with co-recovery in mind, group discussions revealed a strong (shared) sense that to retain hope and positivity was centrally important:

*'We must always search for something positive, no one wants to be stuck. We have to look ahead and see what else is out there. There must always be a way to channel some energy or to get resources or whatever...'*

- (Edinburgh discussion group)

For those carers and supporters who have seen the benefits of co-recovery, the profound nature of even the small changes involved helps in translating the recovery concept from an idea to a valuable concrete experience:

*'Recovery is about when you can also see visibly when people are switched on to thinking that their lives could change, that they could change, it's inspirational. That's what I love about recovery and hearing about that life experience.'*

- (Edinburgh discussion group)

It is clear from this study that although recovery and supporting recovery are not straightforward experiences, having hope that a better life is possible and providing care in a way that encourages recovery both benefits the loved one and the carer.

## Conclusions

This report summarises a small scale study which has covered a range of issues relating to carer's experience of recovery and their understandings of this term in relation to their caring practice.

Carers have a complicated understanding of recovery as:

- A controversial term.
- A term signifying hope.
- A term signifying changed and changing expectations about quality of life for all of those involved in caring relationships.

It is also a label which relates to a variety of *practices and actions* which can help improve the mental health of others.

In general, the report demonstrates that in this small study carers have expressed both reservations about the recovery concept, but also a deep interest in it. Carers have reported innovative ways of creating recovery opportunities for their loved ones and carers support services could move forward in supporting carers to think further about their recovery-based practice. This might include adopting practical strategies involving recovery-orientated training for day-to-day caring, but also training for self-care and self-recovery amongst carers.

The study suggests that carers are key stakeholders in recovery, but many have often experienced difficulty with formal services in terms of attaining resources and support for their contributions in this respect. There are opportunities for the contribution of carers in recovery scenarios to be recognised further and there is also a need to develop ways of facilitating the integration of their skills and knowledge with formal health services. The carers in this study report that they are able and willing to co-work in partnerships with services and practitioners, but perceive themselves as often sidelined or undervalued. Systematic mechanisms of inclusion could be generated to facilitate carer's co-working roles, and indeed, this is a common request from carers.

## Further Research

This very preliminary study can only raise emergent issues and more systematic work needs to be done. There is a multitude of ways in which further research could be done in this area in order to support and advance the awareness of the recovery concept in informal care. This research could be led from different sectors (e.g. clinical, policy and/or academic). The evidence base could be developed to include further research on carer' perspectives and experiences of recovery with a view to sharing experience in an action-research capacity.

### **Next steps for SRN**

We recognise that this small study cannot speak for all carers or caring relationships and that this report represents a snap shot of experiences. However, the information presented here can be useful for continuing discussions with carers and raising awareness of carers' experiences.

At present, we are considering how this information can influence the continued development of the Scottish Recovery Indicator (SRI). SRI is a web-based tool that has been designed to help mental health services facilitate change in practice and to promote more of a recovery orientation.

We are also considering how to share this information with a wider audience. This may take the form of smaller publications with particular messages aimed at specific audiences.

### **Final words**

It is clear from this study that carers' lives can be complicated by the practical needs involved in caring, as well as the stressors of dealing with an unwell loved one and sometimes scarce services and resources. The feat of management that many carers perform is an intricate balancing act in which their needs and emotions are often contained and sidelined. The carer voices that pepper this short study pay testament to this complexity, but also offer hope that recovery-orientated caring practice is achievable and beneficial for carers and their loved ones.

## Further reading

### Online resources and reading

- For an extensive on-line and annotated archive of books and articles on families and mental health see:  
[http://www.ontario.cmha.ca/family\\_resources.asp](http://www.ontario.cmha.ca/family_resources.asp) (free downloads via PDFs)  
This includes international autobiographies of people caring for family members with mental health problems.
- For an extensive international reading list of academic literature relevant to carers see Stengard (2005):  
<http://acta.uta.fi/english/teos.php?id=10720> (free downloads via PDFs)
- For online chat forums:  
<http://www.carerscotland.org/Forums/>
- For information about work in European initiatives to support family and friends of people with mental health problems see European Federation of Associations of Families of People with Mental Illness (EUFAMI):  
<http://www.eufami.org>

### For carers/family members training:

- *Prospect* (a training programme developed by EUFAMI: European Federation of Associations of Families of People with Mental Illness) is currently provided in house by NSF (Scotland), with the aim to deliver training outside the organisation in the future. For more information contact the NSF (Scotland) national office on 0131 662 4359 or [info@nsfscot.org.uk](mailto:info@nsfscot.org.uk)

### Policy information and publications

- Government publication for carers and issues of rights under the New Mental Health Act:  
<http://www.scotland.gov.uk/Publications/2006/10/02103804/0>
- A UK Department of Health briefing paper on literature concerning carers and mental health:  
<http://www.sdo.nihr.ac.uk/files/adhoc/15-briefing-paper.pdf>

### Organisations

- National Schizophrenia Fellowship (Scotland) [www.nsfscot.org.uk](http://www.nsfscot.org.uk)
- Edinburgh Carers Council <http://www.edinburghcarerscouncil.co.uk/>
- Tayside Carers Support Project <http://www.tcsproject.org.uk/>
- Mental Health Aberdeen: Carers Support Service  
<http://www.mha.uk.net/>

## Appendix 1: Survey responses and analysis

### Survey responses

From 22 survey responses the following categories were generated:

Gender	Number of survey responses
Male	1
Female	21

Place	Number of survey responses
Glasgow	6
Edinburgh	5
Perth	3
Aberdeen	4
Not stated	5

Age	Number of survey responses
Below 16	
16-25 years	
25-40 years	1
40-65 years	16
65-75 years	5
75 years plus	

Amount of time caring	Number of survey responses
1 year and less	1
5 years and less	3
5-10 years	2
10-15 years	6
15-20 years	2
20 years plus	7
Not stated	1

For such a small sample no correlations can be reliably identified between variables such as age, length of time caring, place of residence and caring experience. However, we do see from the survey profile that the majority of carers are women, and the majority of 40 plus years old and have been caring for significant periods of time. Although there is a range in the distribution of time spent caring, the majority of responses come from carers who have been caring for in excess of 10 years. The experience of these carers is thus invaluable in understanding dimensions of the caring experience and many have had the opportunity to witness different kinds of recovery over that time period.

Questions	Positive	Negative	Other
<p><b>Q1. What does recovery mean you?</b></p>	<ul style="list-style-type: none"> <li>- A sense of process and movement</li> <li>- Positivity demonstrated</li> <li>- Evidence of forward planning</li> <li>- Witnessing motivation</li> <li>- Seeing independence</li> <li>- Achieving safety</li> <li>- Sharing responsibilities</li> <li>- Self-recovery and carer wellbeing</li> <li>- Reduced worry</li> <li>- Flexibility and less rigidity</li> </ul>	<ul style="list-style-type: none"> <li>- Recovery term has no meaning</li> <li>- Recovering term is inappropriate</li> </ul>	<ul style="list-style-type: none"> <li>- Changed expectations</li> <li>- The absence of psychosis/illness</li> </ul>
<p><b>Q2. How do you recognise recovery?</b></p>	<ul style="list-style-type: none"> <li>- Return of conversation</li> <li>- Increased abilities to socialise</li> <li>- Sense of humour returns</li> <li>- Expression and communication skills improve</li> <li>- Interest in people outside the self</li> <li>- Interest in friends outside mental health network</li> <li>- Activities like opening the curtains and going for a walk</li> <li>- Gaining insight</li> <li>- Being positive and busy</li> <li>- Self determination and self esteem returns</li> </ul>		<ul style="list-style-type: none"> <li>- Holding down a job and self-managing affairs</li> <li>- the absence of psychosis and illness</li> </ul>

Questions	Positive	Negative	Other
<p><b>Q.3 What practical steps can be taken by carers to support the recovery of people with mental health problems?</b></p>	<ul style="list-style-type: none"> <li>- Communicating with services</li> <li>- Attending carers groups for support and guidance</li> <li>- Sharing experience</li> <li>- Self-care for carers</li> <li>- Self development work for carers</li> <li>- Listen to the cared-for</li> <li>- Permit independence and risk taking</li> <li>- Consistency</li> <li>- Praise, love, positivity and belief</li> <li>- Standing back/positive distancing</li> <li>- Instil hope</li> </ul>	<ul style="list-style-type: none"> <li>- Have no expressed emotions</li> </ul>	<ul style="list-style-type: none"> <li>- Organise daily activities/paying bills and domestic work</li> </ul>
<p><b>Q.4 How can health and social services best work with you to support recovery?</b></p>	<ul style="list-style-type: none"> <li>- Support carer recovery and provide information</li> <li>- Education about carer interventions</li> <li>- Allocating time to carers/listen to their expertise</li> </ul>	<ul style="list-style-type: none"> <li>- They do not assist</li> <li>- Carers are treated with disrespect</li> <li>- Carers are not consulted</li> <li>- Carers fight for recognition in networks of caring relations</li> <li>- Barriers to carers' knowledge being shared and acted upon</li> </ul>	<ul style="list-style-type: none"> <li>- Consistency of services/providers required for all</li> <li>- Opportunities for a range of service provision from medication to CBT</li> </ul>

Question	Positive	Negative	Other
<p><b>Q5. What do you think are the barriers for carers as they seek to help people to recovery?</b></p>		<ul style="list-style-type: none"> <li>- Social stigmas surrounding mental illness</li> <li>- Socialising with family members who are ill</li> <li>- Lack of respect and valuing of the role of carer</li> <li>- Confidentiality legislation and how is it used</li> <li>- Carer isolation</li> <li>- Services allow people to 'dwell' in ill-stages</li> <li>- Lack of knowledge</li> </ul>	

### Survey analysis

The table above shows categories of qualitative responses to questions administered via the survey (see Appendix 2). The 22 detailed responses to the survey have been collated into common practical-categories of answer (answers which relate to actions or practices or observations in the world of the respondent), and these in turn have been ascribed a simple 'positive', 'negative' or 'other' status. This ascribed construct is more-or-less valid dependent on the question asked, but it does allow the responses to be grouped in such a way, as demonstrated, that much of the detail that carers provided via the survey can be categorised as forms of 'positive knowledge'. In other words, the actions, practices and observations that carers report upon in the survey can be seen as predominately positive in orientation as they report on experiential evidence that demonstrate how recovery is recognised *as well as achieved*. At the same time, the survey in its entirety broadly demonstrates that negativity is mostly associated with formal mental health services, and moreover, the carer's status within these services as well as the stigma that carers experience in relation to their role. Responses that are neither negative nor positive are also recorded, as these also point to important dimensions to the carer's definitions of recovery, and definition of their own situation and of the situation of the person they care for.

## Appendix 2: Survey and group discussion materials

### Part 1: Supporting Recovery Survey

*A survey to explore the experiences of supporters and carers and their role in recovery*

**This is a short qualitative survey to be completed in association with the SRN visit. The survey will be collated and summarised in a report by Dr Hester Parr of Glasgow University. All contributions will be confidential. We do ask your gender and age, so that we might learn a little bit more about how different issues impact on different people at different times in their lives as a carer.**

**We thank you for your time in completing the survey. The questions and answers will also provide prompts for the discussion group. Please answer questions as fully as you can and use examples from your own experience. Please hand this in to the group leader/convenor.**

Your gender (male/female): \_\_\_\_\_

Your age (please circle): below 16; 16-25; 25-40; 40-65; 65-75; 75+

Your support group \_\_\_\_\_

How long have you been supporting or caring?

\_\_\_\_\_

#### Question 1

What does recovery mean you?

#### Question 2

How do you recognise recovery?

**Question 3**

What practical steps can be taken by carers/family members/informal supporters to support the recovery of people with mental health problems?

**Question 4**

How can health and social services best work with you to support recovery?

**Question 5**

What do you think are the barriers for carers as they seek to help people to recovery?

**Any other comments/points (carry on a separate sheet if you need to)**

**Thank you for your time.**

## Part 2: Group Discussion - responding to carer profiles

*The profile is not a complete story, but a brief scenario to prompt discussion amongst yourselves as 'experts by experience' of caring. The profile does not necessarily represent a 'typical' carer story, or have it exactly accurate, but we offer it simply as a prompt for discussion around a series of questions, and as a way for us to learn more about the carer's role in recovery. I'll read this brief story based around Ishbel and then we can discuss her situation and try and think of ways to respond to her story in positive ways.*

### Profile 1: Ishbel's story

#### Back ground

Ishbel is a 60- year old widow who lives in Tayside. She cares for her 30 year old son, Robert, who is currently a part-time student at a college of further education and who lives with her in their own home. Robert was diagnosed with schizophrenia at the age of 19 after about five years of poor mental health which has resulted in various exclusions from his schooling and time off. At the time of his diagnosis, Robert was very ill and had two years of repeat hospitalisation, and Ishbel found it very stressful. She had a steep learning curve, learning a lot in a short period about mental health problems, the psychiatric services and medications. Over the past decade or so things have calmed down in that Robert and his service providers found the correct level of medication for maintaining his mental health, more-or-less, and he has not been compulsorily detained now for eight years. He is studying for his A/S levels, and has had good reports from his tutors, with whom he has good relationships, but he keeps missing large chunks of the timetabled sessions in term and has had to repeat his study year. He has done this twice now. He seems reticent about ever passing his exams and getting into paid work, and increasingly seems depressed about his situation. Ishbel is worried.

For some time Ishbel has encouraged Robert in his studies, and was forever telling him 'the world was his oyster' and that all he had to do was get out there. In the last few years, however, Ishbel has realised that Robert's options are probably going to be limited by his mental health experiences, and she feels quite depressed about that. She's tired of trying to find new ways to convince Robert of his own worth, and has stopped pressing him to get up in the morning and go to college. She no longer goes along to the local carer's forum as she did because she feels it's just like a talking shop, and she hasn't really seen much change anyway with the services. Over the years, her attention has all been focused on Robert, and what few friends she had have slipped away somehow, and she increasingly feels isolated herself. Robert seems to be heading for a period of stagnation rather than crisis, but somehow she doesn't have the energy or ideas to help him turn it around this time. She worries about how it will be when she is even older, and doesn't know how she is going to keep herself going, let alone Robert. She knows that there are some positives and stable elements about their situation, but somehow she can't really feel very happy or optimistic about anything anymore. Robert is aware of how she feels, but doesn't know how to help her, as he's not used to taking the lead in changing round situations like this.

### **The key issues and the questions**

*While feeling that both her and Robert have done well to stabilise their situation after his diagnosis and repeat hospitalisation, Ishbel is increasingly worried about Robert, unsure about herself and her own ability to cope, and is concerned about her and Robert's future.*

*I want to ask you some questions about Ishbel now to see how you might advise her if she was someone who came to this group/was your friend.*

- How can we help Ishbel make sense of her situation and feel more positive about things as they stand now and things in the future?
- What positive things has Ishbel already done to help Robert's recovery?
- What other things could she do to help motivate Robert?
- What would help re-motivate Ishbel?
- What is Robert's role in helping Ishbel to feel better?
- Do you recognise anything that might be termed a 'recovery' in this story?
- What role could be played by service providers/voluntary sector organisations to assist in this situation?
- Is Ishbel's mental health at risk?
- Do carers need other carers to help them understand family relationships and how they might change
- Could Ishbel benefit from re-establishing links with other carers?
- How would re-establishing links with other carers help her focus on 'recovery' for both herself and Robert?
- What other points should we make about Ishbel's situation?
- How does the current thinking about recovery apply to her and Robert?  
How can we help it to apply to them both?

**Generic questions that should also be asked in each group (for comparison)**

**Do you recognise any of the experiences in the profile?**

**How do the relationships in the profile affect the chances of recovery?**

**How might these relationships changes?**

**What positive steps and outcomes are possible?**

**How can change be achieved after years of status-quo?**

**What help do carer's need to support other people's recovery?**

**What are the barriers to recovery?**

'I mean what he's done for my life has been amazing really. You know, because it's made me a stronger person really' 'Sometimes you have to take a step back, I have done it for years and I had run myself ragged' 'We must always search for something positive, no one wants to be stuck. We have to look ahead and see what else is out there.' 'Recovery is about when you can also see visibly when people are switched on to thinking that their lives could change, that they could change it's inspired recovery was not mess. One d that it, the of ged' 'I've seen glimmers of hope where I

**Scottish Recovery Network**

Baltic Chambers  
Suite 320-323  
50 Wellington Street  
Glasgow G2 6HJ

0141 240 7790

[info@scottishrecovery.net](mailto:info@scottishrecovery.net)  
[www.scottishrecovery.net](http://www.scottishrecovery.net)

Published: 2009

Charity number (Penumbra):  
SC010387



Supported by the Scottish Government's  
Mental Health Division.

