



Recovery for Family Members and Carers

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Plan for session

- Background and context
- A Carer's personal perspective
- Models of recovery
- Strategies for supporting recovery for carers
- Time for discussion

Background and context

- Current health systems focus primarily on the individual presenting with the problem
- When carers and recovery are mentioned, the focus is generally the role that carers can play in the recovery of the service user rather than on their own recovery
- Serious and long-term mental health problems in the family have a major impact on all family members

Background and context

- Families can feel devalued (Struening, 2001) and can feel 'stigma by association' (Ostman et al, 2002; Jones, 2009; Gersen et al, 2009; Wong et al, 2009)
- Research on caregiver stress provides evidence of the major impact on the lives of family members – caregiver stress and impact on own health
- Reactions to the grief and trauma of the situation are common
- Coping can be difficult

Research and guidance on recovery for carers is scanty

- Commentary or guidance that considers recovery for carers
 - Lefley, 1997
 - Froggatt, 2007
 - World Federation for Mental Health, 2010
- Research on the role of carers in recovery of the service user sometimes includes a small section on 'Recovery for Carers'
 - Fox (Personal Communication)
 - Scottish Recovery Network (2009)

McKenzie, 2006 – 4 questions

- How to develop a recovery vision that is inclusive of carers
- How to offer a recovery vision to the carer movement
- Can collaboration between consumers and families be developed to develop training for families around recovery?
- What role should mental health services play?

Key issues

- Impact of caring
- The recovery journey for carers
- Turning points
- Facets of recovery
- Stages of recovery
- Concepts of co-recovery
- Positive benefits of caring
- Supporting family members on the recovery path

Impact of caring



Carers often don't have a choice about caring – it just happens

Individual experience and circumstances will affect the impact.

Majority of carers will:

- Feel a whole range of emotions of powerful emotions
- Need to make – sometimes major – changes in their lives
- Be vulnerable – at risk of becoming ill themselves

Personal impact of caring

Admission of 15 year son to adult psychiatric ward with psychosis

Initial emotions:

- Shock and despair
- Fear and Guilt
- Panic and not coping

Changes:

- More formal care for 2 year old son
- Couldn't afford to give up my part-time job
- Became physically and mentally ill

Second time

- Emotions similar but much deeper and quicker - slide into total hopelessness and despair
- Severe depression – suicidal

Why support carers?



“The service wasn’t there for me – it was to make my son/ husband/ daughter/ wife/ sister better”

With chronic illness, in particular, carer may have minimal or no support

Personal situation:

- **No knowledge of illness or how I as carer could help**
- **GP comment when asked for help**
“But you aren’t ill your son is.”
- **My own illness**

Why support carers?



When good recovery for person cared for - carers may still find it difficult to recover unless support in place.

Personal situation

Once had the right help, and in particular family therapy, recovery became possible for me and other family members too.

Co-Recovery

Your recovery may be dependent on the recovery of the person(s) you care for.

As a carer you may be:

- at least one step behind the recovery of the person you are caring for
- too affected by the impact of caring to recover without help

Personal Barriers to my recovery

- Beliefs about recovery
- I knew I would always be a carer
- Accepting recovery of youngest
- Separating out normal teenage behaviour from mental health difficulties
- Guilt
- Own mental health and lack of self-esteem



Recovery Journey



With help my journey included the following stages:

Setting Boundaries

Acknowledging that, as a carer, there are some things that you can do nothing about.

Detaching

Moving from a situation where you were a carer 24/7 to allowing your family member to take more responsibility for themselves.

Valuing Self

Starting to value your own health, life and needs – as an individual not just a carer.

Developing your own goals

Looking at what you can achieve as an individual in life and work and as part of a couple and family.

Supporting Recovery



Carers – as well as the service user - need support to recover

Helpful support includes:

- ✓ Discussions with carer and mental health professionals - not just about the service user's health
- ✓ Making sure a carer's assessment takes place
- ✓ Family work
- ✓ Referrals to extra help and support if needed

Supporting Recovery

Personal Experience

First time NO:

- X Support
- X Carer Assessment
- X Inclusion as carers
- X Recovery

Second time

- ✓ Lots of support
- ✓ CAMHS – whole family approach
- ✓ Early Intervention Service in Psychosis
- ✓ Family Therapy Work
- ✓ Carers Assessments and Carer grants

Benefits of Caring

- 😊 Stronger bond with family
- 😊 Increased resilience
- 😊 People around you
- 😊 Professionals
- 😊 Re-evaluation of what matters

Recovery for Carers

(Massey, Butcher & Benzies, 2003), Advice (1-6)

1. Taking responsibility
2. Develop a healthy self-regard.
3. Keep the focus on your own recovery.
4. Professionals develop a healthy regard for carers, and carers for professionals.
5. Get the support you need, e.g. see friends, join a support group, see a complementary therapist, counsellor; get emotional support e.g. talking things through with friends, reading self-help books, attend courses on grieving.
6. Be willing to invest in yourself, spend time, money and most of all for yourself. Do whatever it takes.

Recovery for Carers

(Massey, Butcher & Benzies, 2003), Advice (7-12)

7. Be gentle with yourself; allow yourself to make mistakes. Be forgiving. You have been through a lot.
8. Know that it will take time. The grieving process can take two years and personal growth is a life-long process.
9. Introduce things you love to do at times when you would have made a sacrifice to meet the needs of the person you care for.
10. Consult yourself daily as to how much you actually want to give.
11. Let go of obligations and responsibilities that are not yours and over which you have no power or control.
12. Have fun and enjoy yourself sometimes.

Recovery for Carers

(Massey, Butcher & Benzies, 2003): Vision

- Carers leading a full life
- Ability to detach with love
- Acceptance of what is
- Joy can return

Woodhams (2009) – personal model of recovery as a carer: STAGE 1

- Acknowledging the problem
- Coping with the emotions
- Going to work – not involving colleagues
- Good friends, not nosey ones
- Developing allies
- Understanding signposts
- Acceptance

Woodhams (2009) – personal model of recovery as a carer: STAGE 2

- Behavioural Family Therapy
- Setting goals and gradually achieving them
- Letting go
- Managing risks
- Recognising progress
- Reasonable normality in life

Woodhams (2009) – personal model of recovery as a carer: STAGE 3

- Getting involved
- Sharing experiences
- Promoting good practice
- Raising the voice of carers
- Enjoying life again

Rationale for supporting carers' recovery

- Costs of not doing so are high
 - Wellbeing of the service user and of other family members
 - If family members can't continue to support service users, the health and social carer system will have to (Carers in UK save government £87 billion per year)
 - If carer becomes unwell, there is a cost to the healthcare system

What can professionals and services do?

- Be aware of the support needs of family members in their own right
- Offer a family-focussed approach that addresses the needs of all family members
- Help family members to think about their own needs right from the start
- Develop services that adopt 'Whole Family' principles

The Meriden Family Programme

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