

# Recovery

## Rebuilding life with mental health problems

### A journey of discovery for family, friends and carers

Version 1

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Implementing Recovery – Organisational Change  
(ImROC) Programme

February 2011

## The experience of mental health problems

Mental health problems have a profound impact not only on the person who experiences them, but also on those who are close to them - their family, friends and carers.

The person who experiences mental health difficulties has much to contend with:

- They may have strange and frightening experiences that no-one around them believes or understands.
- Those ordinary activities of everyday life - things that they have always taken in their stride, things that most people do without thinking – may seem impossibly difficult.
- People start treating them differently – maybe friends and acquaintances avoid them, stop believing what they say.
- They may lose confidence in themselves and often feel very alone and frightened. Frightened about what is happening to them, frightened about the prospect of using mental health services, frightened that they will lose the things they hold dear – friends, work, their college place, their position in the community, and frightened that they will not be able to achieve their ambitions – do the things they want to do in life like raise a family, travel, get a good job, have an active and fulfilling social life.

But the effect of mental health problems on the lives of relatives, friends and others who are close to them is often equally devastating. The terrible strain of:

- Seeing someone you love – a child, grandchild, partner, sibling, parent, close friend – become distressed and disturbed, behaving in ways that you don't recognize or understand.
- Trying to make sense of what is happening and feeling that you may be in some way responsible.
- Trying to help them, to look after them, but of feeling unsure what to do for the best.

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

*Included in this are, of course, our other children ... They had not only to cope with their fright and sorrow for their brother, but also the horror of their parents’ grief and fear.”(1)*

*“We assumed blame ... We had let her down ... An overwhelming sense of guilt swept over us ... We kept coming back to the ‘Why us?’ question... The present felt grim and we feared for the future ... Initially our personal feelings had the quality of an emotional roller-coaster but as despair set in we found ourselves becoming exhausted and without hope.” (2)*

- Your changed relationship with your loved one, fear that you will lose those the life you share, the ambitions you had for them and your future life together
- Having to juggle all your existing responsibilities and roles with providing the help that your loved one needs.
- Struggling to help your loved one to get the help that they may not recognise they need.
- Negotiating the bewildering array of services and agencies that provide help and maybe feeling that your concerns and opinions are not fully understood or heeded.
- Deciding what to tell other people when they ask after your loved one
- Being treated differently by friends, neighbours, other family members – maybe they seem to avoid you or hold you responsible for what has happened. The prejudice, myths and stereotypes that surround mental health problems affect not only the person who experiences them, but also those who are close to them.

What is often forgotten by people who provide services, is just how important family, friends, and carers are. For us all, it is the people around us, not specialised services, who provide the vast majority of social, practical, and emotional support and for people with mental health problems this is no different. Recovery is supported, facilitated and enabled by family members, friends, neighbours, colleagues, employers, faith communities, fellow students and peers who share experiences of mental health problems.

*“It was something like perpetual bereavement ... My daughter; the person who I used to know so intimately, and who I loved and wanted to rescue more desperately than I’d ever wanted anything, was beyond my reach and everything which had seemed stable and reliable so recently was not. Her actions, emotions and discourse, and therefore my own responses, were unpredictable ... My girl had become a stranger to me and I to her” (3)*

*“What has it been like for us...? I will begin with what has always been most painful for me – those feelings of loss, grief, mourning ... the loss of the son I once had, because in many ways he is quite different ... loss of our expectations. We feel cheated of watching him mature and flower in the way adults do as they grow ... loss of some kind of emotional connectedness. There is also some inner sense of shame and humiliation I occasionally feel” (4)*



## What is recovery all about?

Mental health problems constitute a devastating and life changing experience – a kind of bereavement - for both the individual and those who love and care about them. Too often it feels that you have lost everything that makes life worth living - the relationships and activities you hold dear, the lives you shared, your hopes for the future.

But it doesn't have to be this way. It may not be possible to turn the clock back – to return to how things were - but it is possible to move forward. To discover new sources of value and meaning for yourself, in your loved one and in the relationship that you share. Many, many people with mental health problems and their families have shown us that it is possible to rebuild a meaningful, valued and satisfying life – and this is what recovery is all about.

While treatment and support usually alleviate a person's symptoms and problems, it is very difficult to predict how a person will respond to treatment. Whatever a person's diagnosis, response to treatment varies from one person to another.

- With the right sort of treatment and support, some people's problems and symptoms can be eliminated completely, but both you and they may still need help to come to terms with what has happened and rebuild your lives.
- Some people have symptoms and problems that come back from time to time. The challenge is, therefore, to make the most of times when they are relatively well – ensure that you and they are able to do the things you value in life and pursue your hopes and dreams – and minimize the disruptive effects of periods of relapse and illness.
- Some people have problems that are ever present, but this does not mean that recovery is impossible. The challenge is to help people to make the most of their abilities and work out ways of coping with the problems that remain.

*“Recovery is the process of developing a new sense of self, meaning and purpose in life. The journey of the individual and those close to them in rebuilding a satisfying, hopeful and contributing life with a diagnosis of mental health problems” (5)*

*“I would not be here if it were not for my family. I can always talk to my mum and she is great when I am really low. My Dad can sort things out in a crisis but he gets impatient with the way I live my life. It is my brother who really understands what I need when I'm feeling very bad” (6)*

*“I'm so proud of him. He was so ill and now look – he's out everyday working at the centre and he runs errands for me, I can't get up and down stairs very well you know” (7)*

*“I'd always expected him to get married and leave home, but as it is we're lucky to still have him around. We've always enjoyed bird watching together and now we can go whenever we like” (8)*



No matter how severe a person's difficulties, everyone can do things that they value and which give their life meaning. Everyone can contribute to their family and community. Although studies have traditionally focused on the 'burden' or negative impact of living with a person with mental health problems, more recently, the importance of reciprocity has been identified. This is the mutual support provided within families: the contributions made by everyone to both provide help and support for others.

The challenge is to find the support and adjustments that a person needs if they are to make the most of their life and the abilities they have. Although the challenges are very different, there are some parallels with the challenge facing people who develop physical disabilities and the people who are close to them.

- If a person breaks their spine then we think about the sorts of supports – like a wheelchair and a personal assistant – and adjustments – like ramps, lifts and lowered work surfaces – if they are to live as full a life as possible and do the things they value.
- If a person experiences the emotional problems and difficulties in thinking that sometimes accompany a diagnosis of mental health problems the challenge is to think about the mental health equivalent of the wheelchair, the personal assistant, the ramp and the lift.
- Whatever the nature of their disability, the person faces the challenge of recovering a new sense of meaning, purpose and value in order to make the most of their life.

Those who love and care about the person – parents, partners, children, siblings, other relatives and close friends – face a twin challenge of recovery.

- Helping the person they love in their journey – we must never forget that the majority of help and support that people with mental health problems receive comes not from services but from relatives.
- Keeping themselves well, rebuilding their own lives in

*"Tim would be the first to emphasise that he still has his demons to battle ...*

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

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

*The saying 'knowledge is power' is true, and in Tim we have been watching the filtering of knowledge into wisdom, insight and deep understanding of himself." (1)*

the changed circumstances they face, finding new sources of value and meaning their loved one and in their relationship with them.

## What helps people in their journey of recovery?

Everyone's recovery journey is different, but research suggests that three things are particularly important - **hope, control** and **opportunity** – both for you and the person you love and care about.

### Hope

*“Hope is an essential part of being able to care. It is hard to have hope after three relapses... You have lost all the hopes and dreams that you had for them” (15)*

It can be difficult to hold onto hope, and help your loved one to hold on to hope, in the face of what seem like overwhelming odds, but it is important that you try to. If you cannot see the possibility of a decent future for yourself and your loved one – if you can't believe that a decent life is possible - then it is not possible to rebuild your own life or to help them rebuild theirs. Just as people can, live well with profound physical impairments many people have shown us that it is possible to live well with mental health problems – even more serious ones.

Hope – the belief that things will get better, is linked to better mental and physical health, better relationships within families, and better outcomes. Hope and optimism can be inspired in many different ways:

- Finding out about others who have experienced similar challenges and have found ways of living fulfilling and rewarding lives together.
- Focusing on strengths, resources, all the things a person can do rather than all their problems, disabilities and deficits.

*“In the old days, David's life consisted of sitting and staring into space, chain smoking, walking a lot, listening to his beloved music and coming home once a week for dinner. Today he still smokes and walks a lot, but he also works at a restaurant an hour a day, gets himself to a clubhouse for lunch every day, and has learned to ride the buses so that he can get to his music and pottery lessons every week.*

*I do not believe these changes came about because of the tendency for schizophrenia to improve over the years. Nor do I believe that the newer medications played a role ...David's changes came about rather quickly when professionals and family members began to focus on his considerable strengths instead of his illness.*

*In the old days the emphasis on his treatment, aside from medication was put on helping with his abysmal 'daily living skills' – helping him learn to ride the buses, to take a shower, to make eye contact and so on. But where should he go on the bus? For whom should he have a shower? With whom should he make eye contact? ...*



- Working out how everyone can actively contribute to family life: we all have something to give to each other. Always being the one providing support and help can be tiring and frustrating. Always being on the receiving end of help is dispiriting and demeaning. We all have something we can give each other and finding it can make everyone feel more hopeful.<sup>i</sup>
- Understanding what has happened and accepting that you are not to blame for what has happened and neither is the person who you love. It is much easier to feel hopeful about the future when you have an explanation for what has happened that makes sense in the context of your life.

## Control

It often seems that mental health problems are completely beyond control: beyond your control and that of the person you care about. It can be tempting to look to professionals to fix all the person's problems. It is important that you have all the information you want and are fully involved in decisions about what treatments work best for you. But finding the best treatment is only part of the story.

Each person and the people who are important are the real experts in looking after themselves and the person who is important to them. Over time you can work out patterns:

- What are the things that keep you – and the person you care about – on an even keel?
  - Maybe it is important for you to have a bit of quiet time each day. Perhaps you can get this by taking a long hot bath, or having half an hour to yourself in the morning before the person you care about gets up.
  - Maybe the person you love likes to listen to loud music. Perhaps they can do this while you are out ... or maybe some headphones

*...This approach got nowhere. A few years ago ... the psychiatrist said "I don't want to hear all that again. That's his illness, and we have not been able to change that for years. Tell me about his strengths; we would do better to work on those..."*

*Once a conscious effort was put into his strengths, the turnabout was dramatic." (4)*

*"Over the years I have worked hard to become an expert in my own self-care. Over the years I have learned different ways of helping myself. Sometimes I use medications, therapy, self-help, mutual support groups, my relationship with God, work, exercise. Spending time in nature – all of these measures help me remain whole and healthy even though I have mental health problems." (9)*

*"it has been invaluable to have ... my husband with whom I can test 'reality'. I let him know my perceptions and he gives me feedback. I am then able to consider that my perceptions may not be accurate and I modify my response accordingly if I wish." (10)*

would help.

- What are the things that upset the person you care about – and what can you both do to stop these things getting to them too much?
  - Maybe the person finds it difficult to remember what they have to do and this frustrates both them and you. Perhaps writing a list together, or having a calendar on the wall with both of your activities on it might help.
- What are the things that upset you – and what can you both do to stop these getting to you too much?
  - Maybe you find it really irritating when she keeps asking you the same question over and over again. Perhaps writing encouraging her to write down the answers in a notebook might help.
- How can you tell when either of you are having an off day – not feeling 100% - and how can you look after yourselves (and each other) when this happens. Talking to each other about what you feel and what helps can be really important.
  - Maybe you know that things are getting too much for you when you starting getting short-tempered with your friends and family. Perhaps saying to the person you care about that you are not feeling so good and asking them if they would mind if you had a bit of a lie down, or going out for a walk might help.
  - Maybe you know that the person you care about is having a bad day because they don't greet you in the morning. Perhaps asking them if anything is wrong (and listening to their troubles) may help or you may agree that it is better to give them some space - maybe suggest they go out for a walk.

*"I have now learned to walk **alongside** my sister, instead of trying to tell her what to do or to push her in the direction I think she should go in. For years I did try to push and experienced feelings of frustration, annoyance and at times total despair for her chosen path or inability to see things from my point of view. I think it said more about me actually, and that this was my way of trying to control the seemingly sometimes uncontrollable.*

*At times of her despair, I felt it too and at her lowest ebb, I was with her too ... for my sister, my door remains open when it needs to be opened by her, and that is the most important thing."*(11)

*"... even though there was no tangible change we all began to entertain the possibility of improvement ... .. often tiny incremental improvements have combined to achieve remarkable progress. She now lives in a supported home, remains well-integrated with her family and leads a full and happy life."*(2)

*"I have gained much practical information, insight and support from my peer run support group, a very comfortable means of coming to accept and deal with mental illness." (10)*





- How can you both tell when ‘the wheels are about to fall off’ – the signs that the person you care about is heading for a crisis or when you really are at the end of your tether ... and what can you do to stop things getting worse or minimize the disruptive effect. It can be really important to talk about these things in advance – when the time comes it may be very difficult for either of you to see a way through.
  - Maybe you know that you are reaching the end of your tether when you start bursting into tears, or find yourself drinking more than usual.
  - Maybe the person you care about starts talking about things you don’t understand or flies off the handle at the slightest little thing.

At times like this there may be things that you can do to help yourselves or each other, but this maybe the time to ask for help from someone else – maybe from mental health services or from other family/friends. Don’t forget that, if you want help from other people you will need to discuss what they might be able to do. If you all develop a ‘joint crisis plan’ then it can make things run more smoothly during the difficult times.

## Opportunity

Recovery is not just about managing difficulties, it is about both you and the person you care about growing, and developing, doing the things that interest you and pursuing your ambitions. Mental health problems can be a water-shed – cause you and the person you care about to rethink what is important to you and what you want to do in the changed circumstances that you both face. Each of you must make your own decisions about what is important to you and what you want to do in your life.

Sometimes you will want to do things that the person you care about does not like. Maybe you value meeting up with your friends once a week and the person you care about does not want you to leave them alone. Perhaps you can explain how important it is for you and arrange

*“It’s hard to have a partner who is depressed. You do not know what to say to them just in case they get the wrong idea or that it starts up a major argument over nothing. Sometimes even you question your relationship and whether you are also strong enough to handle what is going on plus living an everyday life of your own.*

*Many questions circle in your head; is it my fault? Why, no matter what I say or do, nothing helps them? Why do I feel so useless?*

*The simple thing is, once all these things do go around in your head, you start to discard them all, and say, I loved them and I know they love me. I’m not giving up on this or on them. They need me right now and I’m going through every step with them no matter what. Because that is what it is all about. ‘For better, for worse. In sickness and in health.’*

*But also think about yourself as well, just because you decide to be there for them or not, you have a duty, not only to your decision, but to yourself. Your physical health can become worse if you allow it to eat away at you.”(12)*

*“The greater danger for most of us lies not in setting our aim too high and falling short, but in setting our aim too low and achieving our mark.” (13)*



for them to see their friends or spend time with another relative, or watch a DVD while you are out.

Sometimes the person you care about will want to do things that you do not feel are for the best. It is a normal part of growing up for children to do things of which their parents disapprove. It is a normal part of any relationship that partners want to do things of that the other dislikes. It is a normal part of any friendship that people disagree about what is best. It can be really hard to watch someone who also faces the challenge of mental health problems doing things that you believe will add to their burden ... but at some level we all have to make our own mistakes – it is part of growing and learning. At times like this maybe the best things you can do are to help to think of ways to minimize the chances of things going wrong – maximize their chances of success ... or simply be there to support them if things do not turn out as they had hoped.

Sometimes both you and the person you care about may feel rather lost and unable to think about your future, or see only bleak times ahead. At times like this ‘peer support’ can be helpful in enabling you to start thinking about your possibilities and help you to believe that a decent future is possible.

- Maybe you might find it helpful to talk to other relatives and friends of people who have mental health problems or read about their experiences. There are lots of local support groups and web-sites where you can find contacts and share experiences (16).
- Maybe the person you care about might benefit from meeting with people who face similar challenges – maybe people who are a little further down the road than they are. Again, there are lots of support groups, e-groups and places where people can read the stories of others (16).

Sometimes the person you care about may want to do things that you consider unrealistic. This may be difficult. We know that low expectations can be very destructive of

*“On very weary days there is always the temptation to hide behind the protective shield of illness where little is expected of the sufferer. Which brings me to an issue about which I feel very strongly: the business of expectation.*

*Our experience of the mental health world is that expectation falls quickly into the hole of ‘we mustn’t set him up to fail.’ ... which has the potential to keep everyone ‘safely’ in the world of the lowest common denominator.*

*We have worked with everything Tim is, in character, personality, potential, ability and inclination at every stage. ... We have no fear of ‘failure’ for two main reasons: firstly, we believe in Tim’s ability to filter out of all happenings whatever lesson there is for him to learn, and secondly, we are confident, willing and able to help him in any way we can.*

*So – in the past 5 years Tim has tried a number of jobs ... lived independently ... traveled abroad ... learned to drive his own car ... taken up a wide variety of study ... has been deeply involved in music ... enjoys hill walking, badminton.*

*There have been occasions where things haven’t ‘worked out’ – but that’s fine, and we have never sought to wrap Tim up in cotton wool ...*

hope and morale – stop people making the most of their talents and possibilities. If no-one around you believes that you will amount to very much then it is easy to give up and sink into apathy. Having a family, relatives and friends around who believe in your possibilities – people who believe in you when you cannot believe in yourself – is very important.

If someone's ambitions seem unrealistic to you it is often best to suspend your disbelief and help the person to think about where they can make a start. What small steps they can make right now to move in the direction of their dreams. No-one can tell what the future holds, everyone's life changes course from time to time, and can we say that any of us realize all our ambitions. But our dreams are what motivate us, give us a reason to get up in the morning ... and every journey starts with a single step!

- Maybe the person you care about wants to be a pop star – well maybe the first step is to look up local courses, learn to play a guitar, get some music, see if anyone you know is interested in forming a group.
- Maybe the person you care about wants to be a brain surgeon – maybe the first step is to look up what qualifications you need to do this on the internet, look at local return to study courses at the local college, get a voluntary job working in a hospital or nursing home...

## A journey of discovery

Everyone's journey of recovery is unique. You and the person you care for have to find your own way. You both have to discover what helps and what does not. You both have to discover what is important to you and discover how to pursue your interests and ambitions.

Your journey of discovery can feel like a risky business ... but 'nothing ventured, nothing gained'. Risks cannot be avoided if you are both to grow and rebuild your lives and

*... He learns from experiences, good and bad. He has probably gained a great deal more confidence and belief in himself through coping with the bad bits.*

*Today, as we look at Tim, we know he is all that he was meant to be – that the promise in the child is here in the man ... He has at his command all the tools and strategies he has forged from his difficult journey, and the knowledge and mastery of himself." (1)*

*"I have learned to understand and accept that her choices may not be my own and to respect the decisions she chooses to make. I suppose it is about knowing where to draw the line for my own personal well-being and to be aware of what I can and cannot take responsibility for. We have been through some hellish times in the last few years, but I sleep easier at night now knowing that I have told her how I feel and that my door is open when she needs me." (11)*

*"You have the wondrously terrifying task of becoming who you are called to be. Your life and dreams may have been shattered – but from such ruins you can build a new life full of value and purpose." (9)*

no course of action – including doing nothing – is risk free. If either of you are to that are important to you then risks must be taken. The challenge we face is to We too have to be prepared to take risks ... and support each other in taking risks. The challenge you face is to support each other in taking risks ... maybe taking small steps at first and then bigger ones as your confidence, and that of the person you care about – grows.

Maybe there is something that you want to do but you feel unable to leave the person you care about alone. Maybe you could start gradually – just popping to the shops. Maybe you could help him/her plan what they will do while you are out – perhaps there is somewhere they could go to? Perhaps a neighbour could keep an eye to start off with? Maybe you could call home from time to time to check how they are doing?

Rebuilding a satisfying life with mental health problems is not easy, but it really is possible. There will be ups and downs, set-backs along the way - times when you falter, slide back, have to re-group and get going again. Sometimes we will need help from others. It can be difficult to ask for help – both for ourselves and the person we care about. Hanging on to hope, working out ways of taking back control and pursuing your interests and ambitions are all important. But most of all, it is important to believe in your own possibilities and those of the person you care about.

It can sometimes feel a very lonely road – but always remember that you are not alone. The lives of many, many people are affected by mental health problems. And many, many people have found ways to live decent and satisfying lives with mental health problems.

### **Only A Person Who Risks Is Free**

*To laugh is to risk appearing the fool.*

*To weep is to risk appearing sentimental.*

*To reach for another is to risk involvement.*

*To expose your ideas, your dreams,*

*before a crowd is to risk their loss.*

*To love is to risk not being loved in return.*

*To live is to risk dying.*

*To believe is to risk despair.*

*To try is to risk failure.*

*But risks must be taken, because the*

*greatest hazard in life is to risk nothing.*

*The people who risk nothing, do nothing,*

*have nothing, are nothing.*

*They may avoid suffering and sorrow,*

*but they cannot learn, feel, change,*

*grow, love, live.*

*Chained by their attitudes they are slaves;*

*they have forfeited their freedom.*

*Only a person who risks is free.*

~~ Author Unknown ~~

## Feedback on

# Recovery: Rebuilding life with mental health problems

## A journey of discovery for family, friends and carers

This booklet has been developed by the ImROC project team to support the development of recovery focused services. It is for use with family, friends and carers of people who have mental health problems. It was developed with the relatives, friends and carers of people with mental health problems. We hope that you have found it helpful.

In order to improve it, we would like to find out about how it works in practice: what it does well and what could be improved. We would, therefore appreciate it if you - as a family member, person with mental health problems or mental health worker - could let write any comments you have about using it below and return it to:

**Dawn Fleming (carer booklet feedback),  
ImROC Project  
NHS Confederation  
29 Bressenden Place  
London  
SW1E 5DD**

or email your comments to [imroc@nhsconfed.org](mailto:imroc@nhsconfed.org)

Thank you

What aspects of this booklet did you like and/or find most helpful?	How could this booklet be improved? (e.g. content, presentation, layout, information provided)	
I am a: (please tick)	A relative, friend or carer of someone with a mental health condition	<input type="checkbox"/>
	Someone with a mental health condition	<input type="checkbox"/>
	A mental health worker	<input type="checkbox"/>

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