

Having captured the essence of personal recovery in animation and video, this resource looks to add further weight of opinion from service users and professional organisations, as well as referencing how to find much more depth of research and ideas about recovery and its need to be focussed on and with the individual..

PERSONAL RECOVERY

An E-Booklet Resource

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Welcome to the Recovery E-Booklet

We hope that you will find this brief e-booklet useful. We have produced it in order to share our perspective on personal recovery in bipolar disorder, which has been informed by a partnership between service users, clinicians and academic researchers. In addition to the e-booklet, there are other resources you might find interesting and useful. These are, an animation depicting key elements of personal recovery and a suite of videos of clinicians and service users talking about their experiences of supporting and living with personal recovery in bipolar disorder. These are:

- An animation briefly depicting key elements of personal recovery
- A suite of videos in which service users and a clinician talk about their experiences of personal recovery via:

Lancaster University | Spectrum Centre for Mental Health Research www.lancaster.ac.uk/fhm/research/spectrum

The Spectrum Centre has been working with service users to explore personal recovery for over a decade now. The impetus for this work came from our own frustration with the limitations of more symptom based approaches to mental health. This echoed concerns expressed by service users that their priorities were being missed in both research and clinical services. This work is consistent with proposals put forward by the mental health service user movements in the US and UK. The recovery agenda is noted as an important focus by Department of Health and reflected in re-structuring of mental health services to include recovery focused teams. © 2018 Lancaster University, All rights

Our approach is not to duplicate this, but to offer more detailed insights into how people living with bipolar disorder specifically experience personal recovery and to develop approaches that can help people enhance this. We think this is particularly crucial in bipolar disorder, because our research shows us that the individual is best placed to understand their motivations, goals, ambitions, and what is meaning full to them. Therapeutic interventions that concentrate on managing the condition alone, do not always focus on how the individual can formulate their own personal goals and work towards those. The need to achieve a meaningful life and feel valued means that a person should be able to see themselves contributing to, and being valued by, society. Whilst achieving a level of control over changes in mood does have its benefits in terms of stability, it is the social and economic factors of a person's life that gives them the sense of achievement and self esteem that are a crucial part of a balanced life, enabling longer term and resilient mental health. Although the more extreme mood experiences people can have may at times be very upsetting and disruptive, there is much evidence that with the right support people can live full, productive and contributing lives alongside their mood experiences. Our focus is to continue to learn more so that we can offer people information and support to live their lives well in the ways that they want to live them.

People with bipolar disorder at all stages from late adolescence to older adults have provided insights about their experience of personal recovery. There is much richness and diversity in their accounts but there are also important common threads. Key features of personal recovery that people described include:

- having a sense of autonomy including being able to exercise choice over what support they receive, from whom and when
- having a model or story to frame their experiences which makes sense to them and provides a context for understanding future experiences
- Seeing personal recovery as a journey rather than a destination so that challenges and set backs are all part of the process
- engaging in interests and activities that have personal meaning and value.

Our team have also developed and tested an individual approach to enhancing personal recovery. Recovery focused therapy was co-created with people with bipolar disorder to harness established psychological techniques to help people realise their own individual personal recovery goals. We have tested versions of this intervention with people with disorder in both early and later stages of their journey through bipolar disorder. The same approach has also been adapted for older adults. We have shown that this approach is valued by people who are offered it and that it helps improve personal recovery, even after therapy has finished. In practical terms, this means that this support can help people to live the lives they want to live, alongside their mood experiences. References and links to our research of these areas are listed in the final section of the e-booklet. (Page 11)

We believe that the work we have done has implications for service delivery. Importantly, we are working to provide tools that services can use to offer people support and information. This includes a questionnaire to help people measure their current level and pattern of personal recovery, as well as recovery focused therapy as a treatment option for implementation in services.

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In our work, we have identified that, whilst people with bipolar disorder value personal recovery they also have concerns about how approaches to recovery might be applied in practice. A particular issue is where they feel that the service they are being offered is essentially unchanged, but given a new recovery label. If services are to truly embrace personal recovery approaches to bipolar disorder, this will involve significant change. A personal recovery approach involves clinical teams genuinely seeing the service user as the manager of their own care and trusting them to make important decisions in relation to this. This does not mean that clinicians become blind to risk or to impeding mood episodes but it does influence the clinical relationship. Many clinicians are already very creative in their work and are aware that 'one size fits all' approaches are doomed to failure in bipolar disorder. Some of the research literature in bipolar disorder seems to emphasise that all people with these experiences must avoid excitement, stress, sleep disturbances and challenging activities. In practice however, for many people, not being able to engage in activities that interest or challenge them can be a substantial form of stress/trigger in its own right. There is therefore a balance between having a shared sense of the realistic vulnerabilities of each individual and an empowering approach to supporting each person to achieve their potential

Our experience of truly engaging with individual's own recovery goals is that this does lead people to challenge themselves but also to a readiness to plan for this and to develop strategies for any negative consequences of such efforts.

What do we really mean by 'Recovery'?

Here at the Spectrum Centre, we think....

Recovery in bipolar disorder is a **journey** not a fixed point. It is not about never experiencing mood symptoms or never being unwell again. It is not about avoiding all conflict with friends or family or about never experiencing frustrations at home or at work.

Personal recovery is about moving towards the things that matter to you in your life. It is about aiming to live your life in a way that is meaningful to you even as things try to knock you off course. So mood symptoms, conflicts and challenges can all be part of the journey of personal recovery.

Personal recovery is truly personal, it is a unique and idiosyncratic journey. Only you can decide what matters to you and this is an individual decision. Help to aid recovery therefore must be personally tailored to your **individual values and goals**. Recovery is a fluctuating process with many twists and turns. Steps back can be as much a part of the process as steps forward. Recovery focused therapy is therefore about offering tools and techniques that can be useful when required. It is not about curing or fixing someone. It is about recognising and building on an individual's strengths and respecting and **trusting** in their values and choices.

What do service users and clinicians say about Recovery?

Below we have brought together a wide range of views on what personal recovery means to people living with bipolar and clinical professional organisations trying to support them.

The next section offers perspectives on personal recovery from ourselves at the Spectrum Centre; clinical and third sector organisations working in the field of mental health; and very importantly by users of services and people with the lived experience of bipolar disorder. (People with lived experience of bipolar have discussed their views on the condition, and recovery, with us as part of the work to create this resource, and throughout the research work at the Spectrum Centre).

On Pages 7-10 we have broken down the definition of Recovery from page 5, and illustrated how key elements of this intersect with other perspectives. We hope this provides an easy reference for you to work with, in what ever capacity you are doing so. Ideally using the following section will facilitate conversations about recovery for all those involved; professionals, service users, friends and carers, service providers and researchers together.

On each page the use of colour is designed to highlight how Spectrum Centre's, Service User's and Clinical and Third Sector organisations thoughts and comments show similarities of opinion and how different experiences illustrate aspects of personal recovery as it has been considered in this resource.

..A JOURNEY.....

Recovery in Bipolar Disorder, is a journey, not a fixed point, it is not about never experiencing symptoms or never being unwell again, it is not about avoiding all conflict with friends or family or about never experiencing frustrations at home or at work.

Mental Health Service User Experience

- '...I was shown a graph....the line had ups and downs in it, but moved upwards anyway. I think recovery is like that. Over time we can make progress but have to accept there are ups and downs along the way....'
- in'the best advice I was given was that to make any long and difficult journey, we need to create and maintain some resilience.....'
- ☐ ...' being part of this project has shown me how lots of different people each have their own view of how to make progress...'
-'we can all see how we have created our own way forward through this project, and have become part of the community, like everyone else..
- …'knowing where I wanted to get to gave focus and stop me meandering through life...'

Other Organisations...

- Royal College of Psychiatrists
 'as a journey'....'Recovery
 does not necessarily mean
 'clinical recovery'.....'people
 often describe themselves as
 being in Recovery rather
 than Recovered'
- Mental Health
 Foundation....'is a journey
 rather than a
 destination'......'In Mental
 Health, recovery does not
 always refer to the process of
 complete recovery from a
 mental health problem in the
 way that we may recover
 from a physical health
 problem'
- MIND...'a journey'
- Mental Health
 Foundation....'recovery can be a voyage'

MEANINGFUL....

Personal Recovery is about moving towards the things that matter to you in your life. It is about aiming to live your life in a way that is meaningful to you even as things try to knock you off course.

Mental Health Service User Experience

- ☐ ...'the world had moved on a year, I could not get back to where I was.

 The future has not happened, the present is called the present because it is a gift.'
-'I find it essential to have a project, something to do, absolutely anything...'
- ☐'the therapy was good, but it is not the whole answer, it went hand in hand with meds. I also found my friendships offered and easy way of counselling....'
- □' I looked backwards and found some positives to focus on from in amongst all the dark memories...apparently that is known as reflection...'

Other Organisations...

- MIND...'For many people, recovery doesn't necessarily mean going back to how your life was before, but learning new ways to live your life the way you want to.'
- Mental Health
 Foundation...'the belief that it is possible for someone to regain a meaningful life...'
- Mental Health
 Foundation....'to look beyond mere survival and existence.
 It encourages us to move forward, set new goals and do things and develop relationships that give our lives meaning...'

INDIVIDUAL VALUES & GOALS

Recovery is truly personal, it is a unique and idiosyncratic journey. Only you can decide what matters to you..... help to aid recovery, therefore, must be personally tailored to your individual values and goals.

Mental Health Service User Experience

- ...'I agree that constant, elated happiness is impossible to achieve, but contentment, which is a different way of feeling can be and is ongoing, and is day to day...'
- '...permitted work helps a lot....'
- ☐ '....a real sense of independence is really good for my mental health..'
-' on your good days there's no better person to be around, its important to have hope and believe in recovery to achieve the lifestyle you desire.'
- ☐'Have a purpose to get up in the morning...'
- ☐' I agree with Jordan Peterson (University of Toronto)..Get your own house in order, take responsibility for your own life...'

Other Organisations.....

- Royal College
 Psychiatrists....Recovery means service users taking control over their own problems, the services they receive, and their lives. It is concerned with self-management, self-determination, choice and responsibility.
- Mental Health Foundation....Experiences of mental illness can provide opportunities for change, reflection and discovery of new values, skills and interests.
- Royal College of
 Psychiatrists...Recovery is about individualised approaches and,...it is about having a satisfying and fulfilling life, as defined by each person...'

TRUSTING STRENGTHS & CHOICES

Recovery focussed therapy is therefore about offering tools and techniques.. useful when required...building on individuals' strengths.. and trusting their choices and values.

Mental Health Service User Experience

- ☐ 'Having something to do at any level, scale, any activity, interest...making short, medium, and longer term plans...let them settle...'compost'...
- Geing able to design and create our own projects to help us back into mainstream activities was key to many of us. Within our project we could play to our own individual strengths.....'
- ☐ 'I gained a lot from the support I was given to create my own pathway of recovery...'
- When I was finally able to look back positively on my life, I found I had many of the skills I needed to move forward....'
- ☐ '...My choices were my own, and sticking with them, and working towards them kept me full of hope, and I have reached many of my own goals now....by not giving up..'

Other Organisations...

- Mind....What recovery means to you will be personal, but for most people, the most important thing is to find ways to live the kind of life that you want..
- Mental Health
 Foundation...'it is about
 seeing beyond a person's
 mental health problems,
 recognising and fostering
 their abilities, interests and
 dreams..'
- Mental Health
 Foundation...Recovery
 emphasises that, while
 people may not have full
 control over their symptoms,
 they can have full control
 over their lives...

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RECOVERY RESOURCES – SPECTRUM TEAM

- Beck, AK, Baker, A, Jones, SH, Lobban, AF, Kay-Lambkin, F, Attia, J & Banfield, M 2018,
 'Exploring the feasibility and acceptability of a recovery-focused group therapy intervention for adults with bipolar disorder: trial protocol' BMJ Open, vol 8, e019203.
 DOI: 10.1136/bmjopen-2017-019203
- Dodd, AL, Mezes, B, Lobban, AF & Jones, SH 2017, 'Psychological mechanisms and the ups and downs of personal recovery in bipolar disorder' British Journal of Clinical Psychology, vol 56, no. 3, pp. 310-328. DOI: 10.1111/bjc.12140
- Echezarraga, A, Las Hayas, C, González-Pinto, AM & Jones, S 2017, 'The Resilience Questionnaire for Bipolar Disorder: Development and validation' Archives of Psychiatric Nursing, vol 31, no. 4, pp. 376-385. DOI: 10.1016/j.apnu.2017.04.010
- Jones, S, Robinson, H, Riste, L, Roberts, C, Peters, S, Bateman, L, Weymouth, E & Barrowclough, C 2018, 'Integrated psychological therapy for people with bipolar disorder and co-morbid alcohol use: A feasibility and acceptability randomised controlled trial' Contemporary Clinical Trials Communications, vol 10, pp. 193-198.

DOI: <u>10.1016/j.conctc.2018.05.001</u>

- Jones, S, Jovanoska, J, Lobban, F, Wintermeyer, C, Vincent, H, Parker, R, Long, R, Calam, R, Wainwright, LD, Asar, O, Diggle, PJ & Sanders, M 2018, 'Web-based integrated bipolar parenting intervention (IBPI) for parents with bipolar disorder: intervention development and evaluation in a randomised controlled pilot trial' Bipolar Disorders, vol 20, no. S1, S56, pp. 31-31. DOI: 10.1111/bdi.18_12616
- Jones, SH, Smith, G, Mulligan, LD, Lobban, F, Law, H, Dunn, G, Welford, M, Kelly, J, Mulligan, J & Morrison, AP 2015, 'Recovery-focused cognitive-behavioural therapy for recent-onset bipolar disorder: randomised controlled pilot trial' British Journal of Psychiatry, vol 206, no. 1, pp. 58-66. DOI: 10.1192/bjp.bp.113.141259
- Jones, S, Dodd, A & Gruber, J 2014, '<u>Development and validation of a new multidimensional measure of inspiration: associations with risk for bipolar disorder</u>' *PLoS ONE*, vol 9, no. 3, e91669. DOI: <u>10.1371/journal.pone.0091669</u>
- Jones, S, Mulligan, L, Higginson, S, Dunn, G & Morrison, A 2013, '<u>The bipolar recovery</u> questionnaire: psychometric properties of a quantitative measure of recovery experiences in bipolar disorder' *Journal of Affective Disorders*, vol 147, no. 1-3, pp. 34-43.
 DOI: 10.1016/j.jad.2012.10.003

- Morrison, A, Law, H, Barrowclough, C, Bentall, R, Haddock, G, Jones, SH, Kilbride, M, Pitt, E, Shryane, N, Tarrier, N, Welford, M & Dunn, G 2016, 'Psychological approaches to understanding and promoting recovery in psychosis and bipolar disorder: a mixed-methods approach' Programme Grants for Applied Research, vol 4, no. 5, pp. 1-304. DOI: 10.3310/pgfar04050
- Murray, G, Leitan, ND, Thomas, N, Johnson SL, Michalak, EE <u>Jones, S</u>, Perich, T, Berk, L & Berk, M 2017, '<u>Towards recovery-oriented psychosocial interventions for bipolar disorder: quality of life outcomes, stage-sensitive treatments, and mindfulness mechanisms' Clinical Psychology Review, vol 52, pp. 148-163. DOI: <u>10.1016/j.cpr.2017.01.002</u></u>
- <u>Tyler, E, Lobban, AF</u>, Sutton, C, Depp, C, <u>Johnson, SL</u>, Laidlaw, K <u>& Jones, SH</u> 2016, <u>'Feasibility randomised controlled trial of Recovery-focused Cognitive Behavioural <u>Therapy for older adults with Bipolar disorder (RfCBT-OA): study protocol</u> *BMJ Open*, vol 6, no. 3, e010590. DOI: <u>10.1136/bmjopen-2015-010590</u></u>

RECOVERY SUPPORT SOURCES TO EXPLORE....

CREST.BD

New directions in bipolar disorder research, treatment and care

THE SPECTRUM
CENTRE FOR MENTAL
HEALTH RESEARCH

NSUN

National Survivor User Network

Time To Change | let's
end mental health
discrimination
Time to Talk Campaign

RECOVERY COLLEGES

Five things you might like to know about Recovery
Colleges

BIPOLAR UK

Supporting people affected by bipolar

RETHINK MENTAL ILLNESS

Mental health charity

THE UNIVERSITY OF NOTTINGHAM

Research into recovery and wellbeing

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