

Take Control

Self-management in care and treatment planning



Foreword

David Crepaz-Keay, Head of Empowerment and Social Inclusion



Self-management is nothing new and the idea is simple; give people with health problems or illnesses the skills and tools to look after themselves. It has been in common use for long-term medical conditions like diabetes and arthritis for many years. Even in the world of mental health, Bipolar UK (formerly the manic depression fellowship) has been running self-management courses for years.

So when I set out to develop and test self-management for people who experienced mental ill-health at its most disabling, I thought it would be straightforward... In my teens and early twenties, I collected six diagnoses and spent many months going in and out of psychiatric hospitals across England and Wales. After many years, and an awful lot of support, I think I've got things more or less under control and I wanted to see if I could formalise what I and many people I knew had achieved into something that could be tested and taught.

I had the very good fortune of meeting Ian Hayes, an expert in self-management from the world of HIV and AIDS and between us we turned the idea into a national programme funded by the

National Lottery (my second piece of good luck) and to date over six hundred people across Wales have been trained. The programme was entirely designed and each of the more than sixty courses were delivered by people who have experienced mental ill-health.

Good luck, they say, comes in threes, and my third piece came when the Welsh Government passed one of the most progressive pieces of mental health legislation to be seen. Holistic care and treatment planning is now the law and this means that the goals we set in our self-management should form part of our statutory care and treatment plans.

This booklet tells the stories of some of the people involved, our goals, the obstacles we have faced, and the ways we have overcome them. It is based on the eight life areas that form the heart of Wales's approach to mental health and I hope that it will help people who need care and treatment plans to ensure that those plans deliver a better life.

Terry Davies has been a passionate advocate of self-management for many years and has been a key part of this project. This is his story, supported by the testimony of many others, and the process of getting it all together was led by Mel Cook. My thanks to all of them and to the Big Lottery for putting their money where my mouth was.

My self-management story



Learning to manage your mental health effectively is a fundamental prerequisite to experiencing and sustaining long-term recovery from mental ill-health. Self-management is not rocket science, it is more about acquiring the necessary tools and techniques to empower individuals to take control of their lives, to put themselves back in the driving seat and regain the initiative.

In recent years there has been a great deal of discussion over what is meant by self-management and recovery within the context of mental health. There is still a great deal of confusion about the term recovery, but the key to recovery has to be around the realisation that the person with the mental ill-health must learn to help themselves. Allied to this is the fact that the individual needs to have appropriate help and support from those around them to achieve their goal of long-term recovery.

Recovery, if it is to be effective, is not something that can be imposed on the person no matter how well meaning, but must come from within. There are so many factors in life that can affect a person's mental health and an holistic approach must be taken to address the fundamental areas which can make a difference.

The Mental Health Measure, which came into effect in Wales on the 6th June 2012, identifies eight main areas that need to be addressed, particularly in writing the care and treatment plan for service users who find themselves in the secondary services.

These include:

- Finance and money
- Accommodation
- Personal care and physical wellbeing
- Education and training
- Work and occupation
- Parenting or caring relationships
- Social, cultural or spiritual
- Medical and other forms of treatment including psychological interventions

There needs to be an appreciation on both the part of mental health service providers, as well as the service users, that their needs must be addressed in this wider context.

When a person experiences long-term mental ill-health, their whole life can be seriously affected. The start of recovery is often the acceptance on the part of the individual that they do indeed have a problem. There then needs to be a willingness to engage with the relevant services to access appropriate help and treatment, which may or may not result in a formal diagnosis of mental ill-health.

The first intervention may well be to stabilise an individual on appropriate medication, but it is becoming

increasingly apparent in recent years that in order to sustain any sort of recovery all eight areas that have been mentioned need to be addressed. Once a person has engaged with the services, they need to be encouraged to realise that their lives are not over and that there is hope for the future.

The word recovery is widely used these days and denotes different things to different people. Recovery is very much a journey through which an individual learns to manage their problems or condition more effectively.

Recovery may take place over a longer period of time. Putting recovery at the heart of the new Mental Health Measure gives a clear indication that long-term

mental ill-health is not insurmountable but can be overcome.

The individual with the problem needs to appreciate that they must do everything in their power to help themselves. At the same time those that are tasked with helping the individual need to have in place the necessary tools and techniques to be able to help that person on their journey into recovery. Practicing self-management in an effective manner can be the key to a personal transformation in a person's health and life circumstances. Goals and the process of goal setting is an important part of self-management, enabling a person to look forward and focus on the future.

My goals

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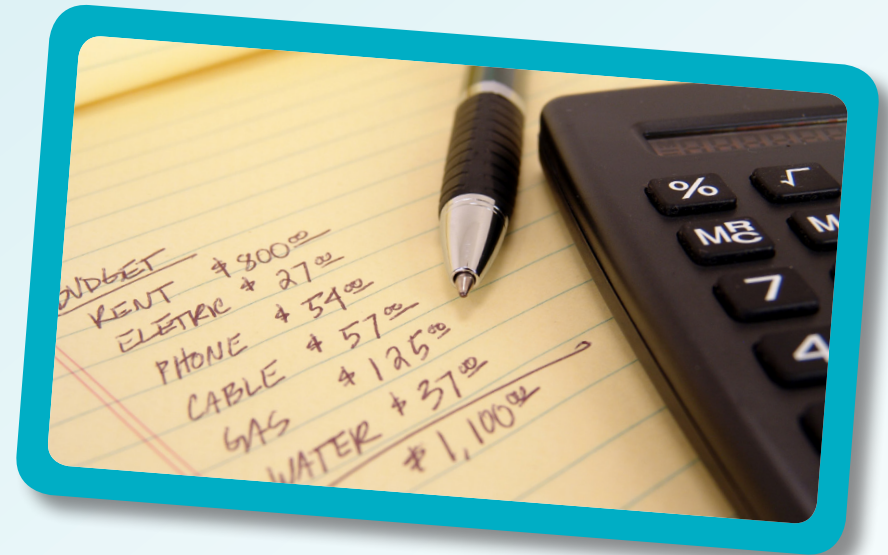
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Finance and money

Keeping control over finances is just so important, as losing control can often make it tougher to manage the other areas of life. This involves keeping track of day-to-day spending and if necessary drawing up a budget plan to ensure finances are kept on a sound footing. Crisis plans have proved a useful tool to enable sensible steps to be taken in the event of things going out of control and to ensure bills and standing orders are still paid when an individual's health fluctuates.



Terry's story

Terry, Swansea Aged 47

Life is challenging enough without having to learn how to manage your money and finances. But when you have a long-term mental health diagnosis such as bipolar, as in my case, then the ability to manage your money can go out of the window, especially when you are experiencing a 'High' episode.

I found it very easy to get credit for loans and credit cards, which was the most disturbing for me. I remember one occasion many years ago when I worked for a charity in Swansea. I went up to a store called Leekes, just for a coffee in my lunch break and I saw a sales assistant playing a Yamaha keyboard, and as I learnt to play the piano as a child I was drawn to watching him play. Before you knew it I have bought the £2000 keyboard there and then taken it home. At the time it seemed like a good thing to do. I was married with two young boys, we were struggling to keep our heads above water as it was, so for me to have bought this keyboard was an added strain on our financial situation and our family life.

My mother was the first to recognise that this wasn't right and contacted the Leekes store to see if I was able to receive a refund, but as this was a display model they couldn't do anything and we were stuck with it.



Fortunately I made contact with a gentleman who was interested in buying the keyboard off me, which he did for much less than I had originally paid for, but I was happy to sell it to be able to pay off some of the debt owed on it.

I've since had similar experiences regarding money and finance, but fortunately a friend of ours recommended us to contact a charity called 'Christians against Poverty'. We soon had a gentleman who visited us, sat us down and went through all our finances and helped us manage our money with less worry and with more structure. So with the help of this charity we signed up to a repayment plan where we paid back money on a monthly bases that we could afford and we could still survive on what was left if we budgeted our money properly.

The contact details for Christians against Poverty is www.capuk.org

Accommodation

Having somewhere safe and secure to live is of fundamental importance in sustaining wellness and ensuring lasting recovery. Many people who experience mental ill-health experience strong feelings of isolation, so supported housing schemes can play an important part in enabling individuals to manage their lives better on a day-to-day basis.

The actual physical environment people live in can have a significant impact on their health and feelings of wellbeing. Associated with appropriate accommodation needs is having a sense of belonging, where roots can be put down which can provide a bedrock of stability for future growth and self-development. Feeling part of a community where relationships can be

nurtured and developed is an essential part of longer term recovery and mood stability.

‘I especially thought the goal setting and problem solving was of great use to me, as it means I have something to plan and work towards’ Monica, Newtown



Barry's story

Barry, Cwmbran
Aged 44

I was homeless for 6 years living all over Great Britain. When you are on the streets it is hard to get accommodation because you haven't got a job and you can't get a job, because you have no accommodation, it was like a vicious circle. When I found my first accommodation I couldn't sleep on the bed as it was too comfortable. I now have a bedsit which I find too small for me, this isn't helping my mental health but I am very grateful for it.

During the self-management course I was taught how to deal with my situation and to accept the condition I am in. I deal with it in a better way and I don't think I would have had the skills and confidence to accept this if I hadn't attended the course.



Personal care and physical wellbeing

The Individual needs to be encouraged to care for themselves on a day-to-day basis, as their self-image may have been distorted and their self-esteem may be low, as well as their confidence. They may feel they have little to offer and may also be experiencing feelings of self-dislike.

It is so important that the individual is encouraged to care for themselves and look after not just their emotional needs, but also their general physical health as well. Self-management is all about the individual taking responsibility for themselves. This can be as fundamental as ensuring their sleep patterns are

back in order and they are aware of the importance of sleep. It also means trying to establish some sort of routine, which may have been severely compromised by episodes of ill-health. Personal hygiene is important. It is so fundamental to learn to love oneself.

The practice of self-management can encompass an awareness of the importance of healthy eating and of regular exercise. It also emphasises that people grow healthily through nurturing healthy relationships and these can be found in connecting with people through peer support groups.

Melvyn and David's stories

Melvyn, Newtown Aged 65

The self-management course has helped me to find my voice again, especially when visiting my GP or Dentist; I even make my own appointments, which I would never be able to do before.

I am using the goal setting exercises to help me start swimming again. I have also gained the confidence to help teach my wife to swim, she becomes very nervous and fears the water, but I have been able to ease my fear to help her gain her confidence.

David, Cardiff Aged 48



My health and mental health are completely intertwined. When I left hospital I was unfit, unhealthy and not very good at looking after myself. For me, managing my mental health started with managing my physical health. I learned to cook and soon found I could create food far more appetising than the hospital! I've even picked up a few recipes from people on the self-management courses. I joined a community gym and they helped me set targets for exercising and strength building.

All this has made a big improvement to my life and also helped me cope better when things get tough.

Education and training

Francis Bacon wrote that ‘Knowledge is power.’ This applies particularly to individuals who live with mental ill-health. Self-management is all about empowerment, and education is a key component in this. The more an individual becomes self-aware, the more they will be able to manage their health and wellbeing effectively. It is important to learn about individual triggers and early and late warning signs, which may precede an episode of illness and act at an early stage to stop things going from bad to worse. The key is for the individual themselves to take control and not rely on other people to sort challenges and difficulties out.

It is fashionable these days to speak of lifelong learning and this involves a willingness to keep an open mind and continue to pursue opportunities around education and training which can enhance self-development, help regain confidence and raise self-esteem. The experience of education and training can bring an

individual into contact with others where opportunities for friendship are increased, thereby helping to alleviate feelings of isolation and strengthen social skills.

It is important to build structure and routine into life and pursue meaningful activities. Having goals around education and training can help greatly in recovery. Often the process of learning can be as important as the actual outcome. The pursuit of education and training can open up further doors of opportunity which in themselves will enhance recovery in the long-term; bringing new focus away from previous problems and adverse circumstances, which may have contributed to significant fluctuations in an individual’s mental health.

Ian's story

Ian, Newtown Aged 52

I was very sceptical about attending the course. I really didn't want to go, but after much consideration I went, and it was the best decision I have made in recent times. I met some lovely, like-minded people which was both refreshing and comforting as they too had the same fears and doubts as I did.

In my younger youth I was a self-employed builder, but found it too much of a strain. It is still quite raw in my mind, but with the skills I have learnt I am hoping I can learn to accept this and not to feel guilty, and that one day I may be able to get back out there and do some voluntary work.

The self-management course has changed my thought process, especially when dealing with professionals; it has given me the confidence to change my Community Psychiatric Nurse (CPN) and to build a new relationship with them.

I wish that I had the opportunity to attend one of these courses back when I was first diagnosed, because 'Fear' is the key, all the information and help would have helped me immensely.

The course in all has taught me not to be so hard on myself and it taught me that I 'DO' matter. I used to ask myself 'Am I ill, or am I making a big deal over things?', but thanks to the tools I have gained from the course I have been able to accept my illness and to be who I am.

Work and occupation

Another important aspect of self-management is re-establishing and sustaining worthwhile activities and occupations. That may not mean, depending on the degree of severity of illness that a person has gone through, paid employment, but may well mean participating in voluntary work. Research has shown that meaningful work can be therapeutic.



Once a routine is established, where both physical and emotional needs are being met on a regular basis, there is much more opportunity for stability to be realised in a person's mental health. In addition, that all-important sense of health and wellbeing is reinforced, as well as that sense of self-worth which is so vital in giving meaning, hope and purpose in a person's life.

'The course gave me the confidence to obtain a part-time job, which I am very grateful for, as I have been out of work for some time. I am so proud of what I have achieved' Monica, Newtown

'I am now confident to travel alone and to different places' Gemma, Swansea

Monica and Terry's stories

Monica, Newtown Aged 57

I thought the self-management course was really good. I especially thought the goal setting and problem solving was of great use to me, as it means I have something to plan and work towards.

It also gave me the confidence to obtain a part-time job, which am very grateful for, as I have been out of work for some time, I am so proud of what I have achieved and I don't think I would have achieved all that I have, if I hadn't attended a self-management course.

I have also become a facilitator, which I think is amazing as I can now teach other people with a mental health diagnosis to gain and enjoy all the new skills I have learnt.

Terry Davies, Swansea Aged 47



There was a position that became available to work for Bipolar UK, as a self-management co-ordinator for Wales, to which I applied and successfully obtained the position. I maintained this position for 2 1/2 years rolling out courses throughout Wales, it was on the job that I learnt the skills to self-manage.

I didn't know what the role was all about or how I was going to achieve this role, all I knew was that I wanted to be back in work, back in society. Having been at home for some time, signed off on ill health, with my wife working full time and two small children, I needed to be earning a wage and gain the confidence to work again.

I learnt that my life wasn't over just because I have a heavy diagnosis hanging over me. The fact that I had to take responsibility for my own health and I had to learn how to speak up and become my own advocate was revolutionary to me, and hopefully to the others attending the self-management course.

I've been working for the last 12 years doing similar things that involve helping others manage their mental health and their recovery if possible, and I have been relaying all the information and proof that self-management does work.

Parenting or caring relationships

With effective self-management comes the realisation that life is not all about an individual's needs but also about seeking to meet, as best as possible, the needs of others, of sharing and taking as full a part as possible in family life. Getting back in the driving seat enables people who live with mental ill-health to achieve a measure of stability rather than being in a state of perpetual crisis, and play a more active role in caring responsibilities. Recovery can lead back into paid employment opportunities which can help with the family finances.



Terry's story

Terry, Swansea
Aged 47

Being married for nearly 20 years, my wife, according to the doctors, was classed as my 'carer'. She made it very clear that she wasn't just my carer but also my wife. If she hadn't, it would have destroyed the dynamics of our marriage relationship, because when one person is heavily reliant upon another person for their personal care and wellbeing it could have serious implications on their marriage relationship.

I have since learnt to self-manage. I have learnt that I must take responsibility for myself and that I also have to take responsibility for our marriage relationship. When we were first married, my wife really did support me, as I wasn't managing my condition very well and was finding myself in and out of hospital all the time. If one person doesn't take responsibility for themselves it is dependent on the other person, and my wife was very strict in her caring for me, she would not be easy on me because we were married.



She once told me that I was only allowed to leave the bedroom in the middle of the night if needs be, to use the bathroom and I was to come straight back to bed. Previously I would get up to use the bathroom and then go downstairs until it was morning, causing a lack of sleep not only to myself but her also.

I have since managed to self-manage my daily routine and daily life with the help of the self-management training and the help and guidance of my wife.

Social, cultural or spiritual

The 18th-century metaphysical poet, John Donne, wrote that ‘No man is an island’. The key to good mental health is the ability to nurture and sustain healthy relationships with others, because humans are not equipped to travel on the journey of life in isolation from one another.

People need people, and people who experience long-term mental ill-health often find themselves isolated from others, but also isolated from themselves. This can lead to more profound experiences of being cut-off and the service provider’s role is to help people reconnect, both with themselves and the wider community within which they live. This involves addressing the

eight key areas. When self-management is encouraged and put into practice, in time, feelings and emotions can stabilise and this in turn can lead to greater opportunities to cultivate healthier and more meaningful relationships.

‘I really enjoyed meeting different people and found it gave me confidence to interact with them with great ease’

Monica, Newtown

‘I am looking forward to the peer support group meeting to start so I can continue improving my skills and confidence with people whom I trust and feel at ease with’ Melvyn, Newtown

Barry and Melvyn's story

Melvyn, Newton Aged 65

The self-management course has boosted my self-confidence. I found it easy and helpful to be able to talk to somebody else who is of similar circumstances as me and to be able to discuss it freely, knowing it will be treated with great sensitivity and of great confidentiality.

I also have a great fear of talking to people over the telephone, which would limit my access to the outside world. Since attending the course my confidence has improved slightly and I have now started to talk to people over the phone, mostly people I know I might add, as I have a routine in place where 'they ring 3 times, hang up and ring back'. That way I know it's someone I know calling so I am happy to answer.

My social skills have improved, I have learnt to say 'No' which has helped stop people making me have things I don't want or need.

I am looking forward to the peer support group meeting to start so I can continue improving my skills and confidence with people whom I trust and feel at ease with.

Barry, Cwmbran Aged 44

3 years ago the self-management project started, and I gave a talk and I felt good about myself. Before attending a course I was very quiet and reserved, but since attending the course I have gained confidence in talking. I've been asked by many organisations to give talks in men's groups, women's groups and I'm doing a talk next week with a youth group. It hasn't only helped me with my condition, it made other people aware of illnesses, especially schizophrenia. Because there has been such bad publicity surrounding schizophrenia, to actually hear someone talk about it who actually suffers with it is an eye-opener for them.

I've benefited from the course as it helped me talk to people. I could talk to people before, but not very well as I found it difficult to talk out loud in front of a group of people.

The course made me more confident in myself, made me more outgoing, it made me talk to more people I wouldn't normally speak to. I've been more open about my illness which has made me realise I'm not the only one with the problem and I'm not on my own.

The course also helped me respect other people and their illnesses and to understand their illnesses. Before I attended the course I had only really heard of my illness, schizophrenia. Since attending the course I've met and continue meeting people with other illnesses such as bipolar, anxiety issues and I now know more about these other illnesses.

Medical and other forms of treatment including psychological interventions

Self-management is not about throwing away the tablets, because it is clear that appropriate medication can play a large part in the effective management of long-term mental ill-health for some people.

Not only does this diminish the adverse effects of fluctuations in a person's mental health from day-to-day, but also in terms of diminishing the likelihood of further episodes which would disrupt and set back the individual on their journey into recovery. Many journeys in life can be arduous, depending on the paths that need to be taken to reach an eventual destination.

There may be very real obstacles, barriers and diversions along the way.

There may well be a whole host of distractions to draw someone away from where they want to get to. If a person is serious about learning how to manage long-term mental ill-health, a focused and resilient approach is essential. Sir Winston Churchill, the wartime Prime Minister who provided inspired leadership to Great Britain during the dark days of May 1940 when the country stood alone against an implacable foe, urged people, 'Never to give up' and to fight on until eventual victory, choosing to ignore the counsel of others who urged otherwise.

If one is to experience real and sustained degrees of recovery from long-term mental ill-health, one must be similarly determined and resolute not to give up on the journey.

Tabitha and David's stories

Tabitha, Cardiff
Aged 34



I am currently taking antipsychotic tablets, and they calm me down and stop me thinking bad thoughts that come into my head when I'm ill. When I attended the self-management course I think it helped me to learn about my illness and it helped to learn about other people's illnesses too. It helped me to realise I'm not on my own. It also taught me that I can look after my illness without it interfering with my life, and I can achieve educational goals and achievements in work and family commitments and that I 'can' balance my medication with all of these things and try to stay well on my medication.

The support of the peer support group has taught me that people who are on medication are not alone and there are others out there that are on the same medication that I can talk to and relate to and help and support them if needs be.

On the whole I found the course was a real help to me and I learnt a lot from it and others that attended the course. I think that medication is not the only key, I think a good attitude and personality also helps when dealing with my illness. I think it's important that I take control of my life and medication and not my medication taking control of my life. I also think its key to balance who you are, what your illness is, and to recognise that your goals are achievable in life and not let your illness hold you back.

David, Cardiff
Aged 38

I've been hearing and seeing things for over thirty years now. Psychiatrists call them hallucinations and delusions, symptoms of my illness. None of the drugs I was given stopped me hearing things, and most of them just made it more difficult to cope; I gave them up years ago and haven't looked back. What I really needed was to be able to manage the voices effectively and control my responses to the things I heard and saw to minimise the damage. Different people find different ways of managing - for some it's medication, for others it's talking treatments, sometimes both, sometimes something else entirely. I'm not sure there's a right or wrong answer but people need to be given the chance to find what works for them.



Summary

A key principle of self-management is that of hope, that experiencing mental ill-health need not be the end of meaningful life. The individual can themselves take necessary steps to still move forward and enjoy life, in spite of the problems which they might be experiencing. There is a need to treat people as individuals and not to think that individuals who share similar labels or diagnoses behave the same. Therefore the journey into recovery can be similar in some respects for certain people, but then very different for other people and that the interplay of the needs as expressed in the eight areas may influence one person far more greatly than another.

For myself I have found that the journey to recovery has involved very much finding meaning and purpose through work. Although at times it has been very challenging to find appropriate work, I have

found it has been really important not to give up on that ambition of re-engaging in the world of work.

I find that having something to do gives me something to get out of bed for in the morning and that my mood fluctuated far more greatly when I was at home, just signed off on sickness benefits, with very little to do with my time. I have really benefitted in recent years from those service providers who were able to encourage me back into the workplace by providing job placements, advice and support around what work I could pursue.

I found that having others to talk to when I was experiencing difficulty was very important, especially when I thought some sort of crisis was brewing. I also have acknowledged the relevance of training opportunities in terms of not only

enhancing my abilities to work, but also to enable me to grow as an individual. As I have already mentioned, a key aspect of self-management is establishing a routine and that can come through both work and educational or training opportunities.

Coupled with this is the opportunity for relationship building that comes through both interaction in training and work. This can again overcome feelings of isolation and also restore feelings of normalcy, especially as building friendships with people can help to ensure feelings of acceptance. When an individual is interacting well with others around them, those feelings of being different and feeling worthless can be dissipated.

‘I have found my voice again, especially when visiting my GP or dentist’

Melvyn, Newtown

‘The self-management course has changed my thought process, especially when dealing with professionals; it has given me the confidence to change my CPN and to build a new relationship with them’

Ian, Newton

Self-management of long-term mental ill-health is therefore a means of encouraging an individual to help themselves, with the relevant support, to work towards establishing a good routine of self-care. It involves setting goals to achieve personal hygiene; regular sleeping patterns; healthy eating plans; building relationships both on a personal and professional level; taking regular exercise; establishing voluntary or paid employment; gaining an understanding of how to deal with money and finances and having a say in their medical and associated treatment, and in doing so, bringing stability, a sense of self-worth and hope for the future with quality of life and ultimate recovery.

Partner contact details

About The Mental Health Foundation

We are the UK's leading mental health research, policy and service improvement charity.

We are committed to reducing the suffering caused by mental ill health and to help everyone lead mentally healthier lives. We help people to survive, recover from and prevent mental health problems by carrying out research; developing practical solutions for better mental health services; campaigning to reduce stigma and discrimination and promoting better mental health for us all.

We work across all age ranges and all aspects of mental health. We are the charity for everyone's mental wellbeing.

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About Hafal

Hafal is the principle organisation in Wales working with people recovering from serious mental illness, their families and carers. Everyday our 150 staff and 100 volunteers provide help to over 1,000 people affected by serious mental illness across all the 22 counties of Wales.

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About Bipolar UK

Bipolar UK is a user-led mental health charity which works to enable people affected by bipolar disorder (manic depression) to take control of their lives. The organisation began life in 1983 as the result of an advert in the personal column of a national newspaper. The organisation's expertise is rooted in the personal experience of our members: people with the diagnosis and their families and friends.

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