



Staying well with bipolar.

Your guide to dealing with the ups and downs.

Who we are

Rethink Mental Illness is a charity that believes a better life is possible for millions of people affected by mental illness. For 40 years we have brought people together to support each other. We run services and support groups across England that change people's lives and we challenge attitudes about mental illness.

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7 Key Things

What's the best way to stay well when you have a diagnosis of bipolar disorder? Based on our research, we found 7 key things:

- Spotting **early warning signs**
- Looking after your **wellbeing**
- Being in **control**
- Doing what works for **you**
- Making **decisions about medication**
- Talking to people **who really listen**
- Getting support from **family and friends**

More for you online

If you're reading this online, click **here** to watch the full 17min film and shorter clips on YouTube.

The videos were made by Alice and Roger, who both have personal experience of bipolar. Or you can type this into a browser –

bit.ly/upsanddownsstudy

And stay in touch with all our *Ups and Downs* resources in one place

www.rethink.org/upsanddowns



Ups and Downs used evidence from 27 people with direct and indirect experience of bipolar disorder.

Research study: *Ups and Downs*

Does the support people need when they are ‘up’ differ to the support needed when they are ‘down’?

What we did

We interviewed 16 people with bipolar disorder and 11 other people who have an informal supportive role (carers, family and friends).

We asked:

- What was helpful and unhelpful when ‘up’ or ‘down’?
- What support was received?
- Who gave the support?
- What support would be ideal in either situation?

About the researchers

Five researchers who had personal experience of mental illness, and three academically trained researchers, worked together to develop tools, collect and analyse data, and report findings.

The researchers with personal experience conducted all of the face-to-face interviews with people with experience of bipolar disorder, as well as the carers, friends and family.

We used an approach which made **active use of the researchers’ personal experiences and insights** in developing and analysing the findings.

In this research paper we have described the method and our findings in detail: Billsborough, J. et al. (in press) ‘Listen, empower us and take action now!’: Reflexive-collaborative exploration of support needs in bipolar disorder when “going up” and “going down”, paper accepted for publication in *Journal of Mental Health*.



Spot early warning signs



Click [here](#) to watch the ‘Spot early warning signs’ video.

Early warning signs are **actions, thoughts and feelings** that show you may be becoming unwell.

For some it is smoking many cigarettes or being more intensely absorbed in religious ideas – but they are different for each person. If you learn to be aware of your own warning signs you can more easily prevent a crisis and use self-management and coping strategies to make yourself feel better.

Being able to identify your early warning signs can help you experience your life as more ordered rather than chaotic, and more meaningful rather than nonsensical. This makes it easier for you to be in control, which is linked to better mental health.

Spotting the early warning signs means that you can take action yourself, or seek help early on. This leaves more support, treatment and care options open to you and could prevent a crisis or a hospital admission.

Your own personal warning signs

Every person has their own unique mix of early warning signs. There is no one warning sign that has the same meaning for everyone. You can learn to become aware of your warning signs by **reflecting on the times you became unwell in the past** – did anything happen or did you feel or behave in certain ways that may have warned you that you were starting to become unwell?

Others can help

To find out about your personal warning signs you can talk to **people who know you well** and ask if there is anything that they noticed before you became unwell in the past. Carers, friends and family can often help to detect early warning signs, and act to prevent crises.

One mother described how she helped her daughter notice if she was becoming high:

“We’ll say to her, ‘you’re gabbling, you’re overexcited, can you try and bring it down a little bit for us?’”

It can also be helpful if for example friends notice you are becoming socially withdrawn and that can be a warning sign. For example, in the research we heard about friends noticing that a person had withdrawn from online activities (such as Facebook and email) and pointed this out to the family to help them take action.

You can ask mental health professionals if they perhaps can help you to find out about early warning signs and which signs you might have. Timing is crucial. **There may be only a short window of opportunity to do something** to prevent a developing high or low becoming a crisis.

Read more information about bipolar disorder on our website at www.rethink.org/bipolar



Up vs. down

Many people learn over time to identify their early warning signs, but it can often be more difficult to recognise and acknowledge signs of becoming manic (up or high). Some people are not aware of going up because when they feel 'high', they do not experience this as being 'unwell'.

While you may not personally feel unwell, others may notice the change and experience it as a problem. Among the people that we spoke to for the research, all of the 11 people in a 'support role' we interviewed described manic episodes as being problematic; however, 5 out of 16 people with bipolar disorder did not:

“It’s like a fix... you feel much better, it makes you feel in control... you can do anything you want to do.”

On the other hand, early intervention can be crucial, and one man pointed out the need for health services to step in to situations when he is becoming manic:

“I need a psychiatrist who’s going to spot the early warning signs before things get too bad, because I find that once[...] I go deep into an episode its very, very difficult to get out.”

If you miss the signs...

It is very important to learn about your personal warning signs as it will make it easier to take action before becoming acutely unwell. Although in the beginning it may feel like a positive 'high' some may lose touch with reality and this can be very dangerous, as they may do risky things that they would not do under normal circumstances.

If you act too late, you may not have so much control over what happens, for example, when reaching a crisis and needing to be hospitalised.

Look after your wellbeing



Click [here](#) to watch the **‘Look after your wellbeing’** video.

The most important thing you can do to avoid becoming manic or depressed is to look after **your wellbeing in your everyday life**. If you can remain well and prevent a crisis it is much better than finding ways to respond to a crisis that is already developing.

Many people with bipolar disorder have learnt to take an active role in managing their own wellbeing. This involves developing different **coping strategies** including:

- Ensuring healthy daily living routines
- Keeping mood diaries
- Developing wellness plans
- An action plan to be followed if they begin to move towards an up or down state

Such coping strategies help people to keep well and prevent or minimise the effects of extreme mood states and crisis situations.

“[I] have to exercise, I have to eat well, I have to monitor my sleep. I actually have quite a lot of control over my medication, so I have a set amount of sleeping pills that I take because if I suffer with insomnia for too long, then it triggers a bit of an episode. So, I have to monitor my sleep, which my doctor and my psychiatrist let me do, and try and be very conscious of spending time doing [...] self-care.”

‘Going up’ self-management techniques:

- Avoid too much stimulation
- Pause, take time out
- ‘Stop and think’ (be aware of your own situation)
- Keep a journal (describe and reflect on what’s happening to you)
- Avoid too much social contact
- Talk to someone who will listen to you
- Eat healthily and have regular meals
- Exercise (to ‘burn off’ excess energy)
- Have quick access to a prescriber to change medication as needed

‘Going down’ self-management techniques:

- Use mindfulness or meditation
- Have a routine
- Avoid pressure
- Relax
- Keep active and busy
- Be involved in enjoyable activities
- Exercise (to lift your mood)
- Have a goal – future orientation
- Talk to someone who will listen to you
- Seek affirmation you are cared about and valued
- Receive gentle encouragement to engage in positive activities

These are examples from our interviewees – you may have other techniques that work for you.

Environment is important

Surroundings and environment have an effect on your mood. This is the case in respect to the **physical environment**, for example buildings, decoration, light, noise, furnishings, acoustics, colours, materials, cleanliness, etc. Also the **social environment** is important, such as who is around you: carers, family, friends, professionals, and/or strangers; and the **type of communication**: expressed emotions or not, communication styles, friendliness/unfriendliness, etc. In general, calmer surroundings and environment are likely to lead to calmer moods.

Your environment can make a big difference to your wellbeing. Having a 'home', a place to call your own, gives a feeling of being independent, and many find that it supports their wellbeing and helps them to manage their moods better. In our research people spoke about the importance of 'fresh air' and outdoor based activities. Some talked about wanting a calmer, less stressful environment, and the importance of having their own space away from other people both when they were down and when they were up.

"I like my own space and I like everything to be quiet around me when I'm a bit low."

"When I began to get things back on the straight and narrow, I took on an allotment, so I was getting out in the fresh air and getting exercise far more."

Hospitals can help a person when they are in crisis, but people we spoke to in the research described the hospital environment as unpleasant, traumatic and not therapeutic. In hospital you are in an unfamiliar place and with unfamiliar people, and it can be difficult for you to feel at ease and do the things that you usually do. Some of the people we spoke to mentioned **crisis or recovery houses** as offering an alternative and possibly more therapeutic environment than a hospital.

This being said, there are of course examples of people benefiting from informal **peer support in hospital**.

FIND OUT
MORE

Get more resources about
having a supportive environment
and physical activity at
www.rethink.org/upsanddowns

Physical activity and keeping busy

Different types of self-management and coping strategies may be useful when up or down. If you are feeling down you may feel better if you take part in positive activity. If you are up it can be helpful to **avoid triggers** such as stressful situations and too much stimulation. Physical exercise can be useful both when you are down or up: when down to help to lift mood, and when up to burn off excess energy.

A good balance between activity and relaxing is helpful for general wellbeing and controlling moods. Having a routine and keeping to it, in spite of changing moods, can help to reduce the 'pull' of an up or a down.

Start with something simple

It is useful to **start with something simple** when you begin to develop your personal coping strategies and get control over your wellbeing. One of the people we spoke to in the research explained how he started on his personal recovery the day he decided to tidy up his sock drawer. This was something that he felt he could manage at the time, and the success of having done this made him confident that he could take on other things in his life.

Be in control



Click [here](#) to watch the 'Be in control' video.

Self-management techniques and coping strategies can help you to be more in control. Feeling more in control over your life and your mental health in itself helps your mental wellbeing.

Ways of taking control

There are different ways in which you can learn to take more control over your own life. Some find it helpful to keep a '**mood diary**' where they write about their mood and what helps them. This can help you to better understand your mood and how it is influenced by things in your life.

Here is a resource that can help you to keep your own personal 'mood diary':

www.aware.ie/help/information/mood-diary/

Knowing your early warning signs, having effective coping and self-management strategies and having real choice over your own treatment and support are all ways in which you can be in control.

Here is a resource that can help you to develop your own personal 'strategies for living': **Strategies for Living** from Mental Health Foundation.

Learning from the past

A good way to develop a greater sense of control in your life and over your mood swings is to learn from what happened in the past. Things that triggered a crisis for you in the past are likely also to influence you in the future, so knowing about these will help you to learn how best to avoid future ups and downs.

Support and encouragement

Other people can help you to feel more in control. They may help you to find out about triggers in the past or they can point out to you if you start doing things which may mean that you are becoming unwell. Sometimes it is not easy to spot the early warning signs yourself.

It can be useful to have someone who gives you encouragement to do things if you feel low and unmotivated – for example seeing people or joining activities. Receiving and acting on such encouragement can mean that you feel more active and alive, and in control of things happening in your life.

There is guidance available on how to offer support and encouragement to someone with mental illness.

Supporting someone with a mental illness from Rethink Mental Illness.

Do what works for you



Click [here](#) to watch the ‘Do what works’ video.

Everyone is different, whilst you can learn through the experience and knowledge of others you need to find out what works for you to keep well.

Finding your own way

It can take time to find out what works for you and how you can take an active role to keep well. Discovering and using your self-management techniques can provide you with a greater sense of self-worth. Health professionals can advise you on possible coping strategies and help you to discover what works for you.

Search our list of factsheets and other online resources www.rethink.org/resources

Stay in touch

However you are feeling it is important to stay in touch with your carers, friends, family and healthcare professionals. These are people who can listen to, support, and help you. There are of course situations where ways of relating and communicating in certain relationships can make you feel worse, and you may need to protect yourself from these. However, try to develop positive relationships. Isolating yourself can put you at greater risk of crisis and mean that you are not able to draw on your social support when you need it.

If you have relationships with friends or family that you feel are difficult to engage with when you are becoming unwell, this guidance may be helpful for them to maintain and develop a supportive relationship with you.

Guidance on ***Dealing with unusual thoughts and behaviours.***

Peer support

Some of the people that we spoke to found that having support from other people with experiences of bipolar disorder can be very helpful in maintaining their wellbeing. People with similar experiences can provide you with a sense that you are not alone in how you are feeling and what you are thinking. They can share strategies of how they cope and maintain their wellbeing, and they can point you in the direction of useful knowledge and local resources.

“There’s help there, there’s people to talk to, have a coffee, and I can think, I haven’t got two heads anymore.”

Your own knowledge, strengths and experiences can also benefit others in similar situations, which can provide you with a sense of achievement and greater self-worth.

Peer support can be accessed through local peer support groups, online communities like **RethinkTalk** or by joining bipolar associations. It can be challenging to go to a face-to-face support group for the first time and you can perhaps get support from a carer, friend, family member or healthcare professional who can go with you the first few times.

Make decisions about medication



Click [here](#) to watch the ‘Decisions about medication’ video.

Medication often plays an important role as one way of managing the ups and downs. It is important to consider how you can have choice and control in respect to medication, rather than feeling controlled by the medication prescribed by your doctor.

Value of choice

People in our research highlighted the importance and value of being involved in choosing their medication. Having an understanding of the effects (and ‘side effects’) can allow people to make a choice as to which medication might benefit them the most. Having choice over medication allows people to take ownership and be more in control; it can raise self-esteem.

For choice to be meaningful you need to have access to relevant information, and sometimes a second opinion from a professional can be useful.

Being in control

Your medication needs are likely to change over time, and the medication currently prescribed may or may not be the best option for you. It may be the case that you need different types of medication to take depending on how you feel, and if so, you may need advice about how to manage this.

Having a conversation with your prescribing healthcare professional (GP, psychiatrist or nurse) about the effects of medication that you are taking can be useful for you and them to help make decisions about medication.

In our research people recognised the difficulty in finding the ‘right’ medication and dosage, and described the importance of being able to contact their prescribing healthcare professional quickly to be able to make changes to medication to maintain their wellbeing and prevent a crisis.

For many people taking medication was a key part of maintaining their wellbeing but for some people being free of taking medication was a key goal, because they wanted to remove side effects and wanted to take back control of their own lives. One person said:

“Well I was on this one for about 15 years, the same milligrams as well. And they weaned me off it and I’ve been 10 times better.”

But do remember that suddenly stopping taking some forms of medication can lead to worse symptoms. Gradual withdrawal with the support of other people may enable someone to remain well during withdrawal.

Always speak to your prescribing healthcare professional about medication changes.



Talk to people who really listen



Click [here](#) to watch the ‘People who really listen’ video.

It is extremely important to have someone who is able to really listen to you. It can be different people: carers, family, friends or professionals.

Professionals who listen

One of our key findings was that people valued professionals who actively listened to them and made them feel heard. One person that we spoke to was very happy with his care team who had listened, taken him seriously and given him choices. Another person said that he could not be ‘talked out’ of a crisis but could be ‘listened out’ of a crisis.

Mental health professionals who do actively listen are better able to understand a person and their particular concerns, and they are better able to decide what action or advice might be needed to prevent crisis.

We found that when people felt listened to by a healthcare professional they were more likely to follow the recommended action. It may be useful to tell healthcare professionals who work with you whether you feel as though you have been heard or not.

Coaching is an approach to working with and listening to people, putting their concerns at the centre. The booklet ***Empowering People*** describes this approach, and you may wish to mention it to your mental health professional.

Sharing things with different people

You may find that it can be useful to have different people to talk to about different things. Some things you perhaps feel more comfortable sharing with a friend, others with a parent, or a sibling, or a professional. It can also be useful to benefit from the different perspectives that different people can bring.

Sharing your thoughts and feelings with carers, family, friends, peers and healthcare professionals can allow the other person to gain a better understanding of your life. This will make them better able to provide feedback and advice and affirm that they value and believe in you.

“I think [what helped me] was being able to talk to somebody on their own, at a very, very, deeply personal level.”

Simply talking to another person who is actively listening can be therapeutic in itself. It can make you better understand how you are thinking and feeling, and this will make it easier for you to make decisions and take actions in your life.

Get support from family and friends



Click [here](#) to watch the **‘Support from family and friends’** video.

People who are close to you can play an important role in preventing ups and downs.

Spotting changes in mood

Carers, friends and family often spend a lot of time with you, and their knowledge of you can be very useful.

They can spot subtle changes in your mood or behaviour and let you know if they are concerned. In our research people described the importance of having people who were there for them, could demonstrate love for them, who were non-judgemental and provided emotional support.

If carers, family and friends are aware of your early warning signs they can provide you with feedback so that you can use relevant coping strategies and seek help if needed.

Encouraging (and discouraging)

When you are down it can be helpful if carers, family and friends offer encouragement to do activities they know you enjoy and find helpful. It is important that such encouragement is given in a sensitive way. As one person stated it can be useful to have things: “to get up for – things to focus on.”

Discussing with your carers, family and friends what sorts of encouragement may work is useful and can provide agreed starting points. In our research, carers, friends and family told us about how they provided positive encouragement:

“(I’d give) encouragement to get out of bed, helping her to focus on things, that she will get through it, keeping her going so she doesn’t get too low.”

“I’d run baths for him, and [...] then he’d feel a bit better after he was clean, because you do. Or, and I would try and make sure that he came out for a walk with me, even if it was only for 10 minutes.”

Some people explained that when they were ‘up’ they needed to be discouraged from engaging in activities which were too stimulating and that they needed to be encouraged to engage in activities that induced feelings of calm.

Support for families and friends

Your carers, friends and family may need their own support. This can be crucial to help them maintain their wellbeing and to continue to provide effective support for you. They may have questions and be unsure what to do to help. They may also benefit from considering things they need to do in their own lives not to feel too burdened by their supportive or caring role.

If you feel they are not getting the information, advice and support they need then you can direct them to this website where there is information, advice and signposts to support: www.rethink.org/carers

Stepping back sometimes

While it is useful to have carers, family and friends who can help monitoring your wellbeing and offer encouragement, guidance and advice, it can also at times be felt as ‘smothering’. Sometimes being allowed to take more responsibility can make you feel more in control of your life.

Also, providing support for you can be stressful and it can be beneficial for the person providing support to take a step back, giving you both breathing space and allowing time for reflection. Having a break or taking a holiday maintains wellbeing and puts challenges into perspective.



**Leading the way to a better
quality of life for everyone
affected by severe mental illness.**

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