



Bipolar Information for Family and Friends

Introduction

Bipolar UK has many members diagnosed with bipolar disorder who have become experts in managing their condition and who live independent fulfilled lives caring for themselves and others. We recognise that support from a network of family members and friends can play an important role in this process.

The purpose of this leaflet is to provide information on the nature of bipolar and, hopefully, answer many of the questions you will want addressing. A question and answer format is used which covers the issues we most frequently encounter when speaking with family and friends.

Living with a mood disorder can make it difficult to maintain friendships and relationships. The more information family and friends have, the better able they are to cope with mood and behavioural changes and to provide support in managing the illness.

Frequently Asked Questions

It is worth stating right up front that there are no clear answers to some of the questions that we get asked. We neither want to give the impression of certainty where none exists, nor to suggest that the answers are the same for everyone.

It can be very frustrating for family and friends to realise how little is understood about bipolar. Health care professionals can have quite different ideas about causes and treatment and there may also be a degree of trial and error in identifying the treatments that work best for a particular person. These factors can lead to confusion and frustration for those trying to offer support. It is difficult, but important, to accept that there are more uncertainties than there are facts about bipolar.

What is bipolar?

Bipolar disorder (also known as manic depression) is basically a mood disorder involving extreme swings of mood from depression to mania (highs and lows). We can think of 'mood' as how we are feeling at any

given point (happy, sad, frustrated, optimistic, etc.). It has been described as our 'emotional temperature'.

Generally, we feel a particular way because of what is happening in our lives at that time. With mood disorders, however, mood becomes disconnected from our environment and appears to be outside of our direct control. With bipolar there is a problem around the regulation of mood. The brain mechanisms that normally regulate mood do not always function as they should.

Of course, there can also be long periods of stability when we feel as we did prior to the onset of bipolar. During these times our emotions are within the usual range of experiences that anyone could identify with. Similarly, our behaviour also returns to that which friends recognise as reflecting our 'usual self'.

Having said that, however, it is important to realise that everyone's experience of bipolar is different. Some people have more depressive episodes; others have more manic ones. Some have long periods of stability between episodes; others experience them more frequently. The duration of an episode of mania or depression also differs from one person to the next, as does the severity of an episode.

What do the different categories of bipolar mean?

You are likely to come across diagnoses such as bipolar I, bipolar II, or cyclothymia. People with bipolar II have depressive episodes of a similar severity to those with bipolar I, but experience a less severe form of mania, which is referred to as 'hypomania'. People with cyclothymia experience less severe mood swings at each end of the spectrum.

You may also hear the term 'rapid cycling', which is used to describe a situation where a person experiences four or more 'highs' or 'lows' in a year. In extreme cases, people can cycle between mania and depression many times in a single day.

What causes bipolar?

Perhaps the most important, if obvious, thing to be said is that no-one causes him- or herself to have bipolar and that it cannot be overcome with willpower alone. In fact, bipolar appears to have no simple cause. There is strong evidence that it is associated with changes in various transmitter substances in the brain, but the precise mechanisms are not yet known.

The illness can also be influenced by the stresses and strains of everyday life, or a traumatic event, but it is likely that some people have a predisposition to developing it. In rare instances the onset of bipolar follows a physical trauma such as a head injury. There is no test that can be given to determine if someone has bipolar, and this can mean a long delay in getting an accurate diagnosis.

How might bipolar affect my friend's/ family member's behaviour?

During a manic episode you may witness any or all of the following behaviours:

- Expansiveness
- Grandiosity
- Overconfidence
- Euphoria
- Increased sexual preoccupations
- Increased interest in religion
- Inappropriate spending
- Intolerance
- Increased smoking, drinking or drug use
- Increased telephone use or letter writing
- Reduced need for sleep
- Irritability and much more rapid speech

It is not possible to be prescriptive because everyone's behaviour will differ, but this list should give you an idea of the most common behaviours. Do not assume that they will all necessarily apply to your friend or family member.

Sometimes a severe manic episode can also involve a mixture of depressive features (this is known as a mixed episode). During a mixed episode, both manic and depressive symptoms are experienced daily for at least one week. The person usually feels very anxious and disorganised and commonly will develop insomnia, psychosis, and lack of appetite. (A lay person's definition of psychosis might be those times when an individual appears 'out of touch with reality').

A mixed episode can last from a week to several months and is usually followed by a depressive episode. They occur more often in people (especially men) under 25 or over 60 years of age, and particularly in teenagers who have experienced major depression.

During a depressive episode the person may complain of physical symptoms such as pains (for example stomach ache or headaches), they may appear to move more slowly, to lack concentration and to feel that even the simplest of tasks require monumental effort. Their thinking can be dominated by thoughts of sadness, guilt, pointlessness and loss. Anxiety and panic can also be a feature of a depressive episode for some people. (N.B. It is also important for the health care provider to ensure that any physical symptoms are properly investigated and not dismissed as manifestations of bipolar without sound evidence).

Does bipolar run in families?

This is a very difficult area, both in terms of the concerns it may raise for family members, and because our understanding of the genetic component is very limited. We can talk about the family incidence of

bipolar disorder in only a very general way. Whilst we know that children of people who have bipolar disorder have an increased risk of developing the condition themselves, this needs to be put in context. Overall, the risk that a child with a parent who has the diagnosis will develop it him or herself is put at about 10-15%. The risk is somewhat higher where both parents have the diagnosis, but risks differ depending on different circumstances and, once again, it is difficult to generalise. The risk that siblings of the person with the diagnosis will themselves have children with the condition is very small indeed. Your GP can refer you to a genetic counsellor if you wish to discuss your concerns.

How can I better understand what my friend/family member is going through?

The behaviours exhibited by people with the diagnosis can have a profound effect on those closest to them, who can suffer the consequences of the disorder as well. It is not always easy to offer sympathetic support to someone who may have been behaving erratically, angrily, recklessly or thoughtlessly. It is difficult not to take such behaviour personally and to react to it, particularly when it creates disruption or has negative repercussions. Family and friends often express the opinion that they feel they have been rejected by the individual concerned, and are unsure how to respond. The more you understand about the illness, the more you will be able to empathise and to offer useful support.

One of the best ways of acquiring this insight is to read about the experiences of those who have the diagnosis. One of the books from Bipolar UK which we recommend is written by a clinical psychologist who has the diagnosis herself. *An Unquiet Mind* by Kay Redfield Jamison is an extremely well-written and enlightening memoir of her struggles with bipolar. In her book *Touched with Fire: Manic Depression and the Artistic Temperament*, she vividly describes the experiences of many well-known and accomplished people who have the diagnosis. She drives home the point that even the most strong-willed, popular and gifted individuals can be brought to the point of despair by this illness.

Talking to people who have bipolar disorder and their families and friends can also be very useful in helping to understand the condition. Bipolar UK runs support groups which are open to family and friends of people with bipolar as well as people with the condition themselves. You can find out where your nearest group is on our website, or by calling us on 020 7931 6480. We also run an eCommunity on our website which has a wealth of information and advice from people affected by bipolar.

Can bipolar be cured?

There is no clear answer here – certainly there is no one cure. There are some people who will never experience another episode of mania or depression again even without further treatment, but this is rare. Usually

there will be periods when the individual remains well for a given period of time, only to find the symptoms reappear.

Having said that, much can be done to reduce the severity or duration of an episode, or even the number of episodes experienced. Once the diagnosis is made, steps can be taken to minimise the extent of the mood swings and thereby reduce the disruption that they can have on our lives and the lives of those around us.

The best treatment is usually a combination of medication, counselling and self-management, but obtaining counselling via the NHS can mean a lengthy wait, depending upon where you live. The importance of early diagnosis and treatment cannot be overstated.

What is self-management?

Self-management is built on the principle that people with bipolar can become experts on their own mental health. Research shows that if we are able to recognise the triggers and early warning signs of an impending episode, and implement appropriate 'coping strategies', then we can gain greater control over our mood swings. Examples of coping strategies would be: reducing stressful activities, relaxation exercises, maintaining a regular sleeping pattern (for mania), or exercise and cognitive therapy techniques (for depression).

We know that circadian rhythms, especially the sleep/wake cycle, are very important in bipolar. Lifestyle regularity is important in controlling the symptoms of both mania and depression. Another useful tool is keeping a 'mood diary' which can provide an early warning of a mood swing and can also help to identify any patterns to the episodes (a mood scale and diary are available on our website).

People who self-manage often write an 'action plan' which lists coping strategies which can be put into effect if the triggers and warning signs should appear. Some examples of coping strategies are listed above, but it is not possible to be prescriptive; different strategies work for different people.

Is there any support I can offer someone who is self managing?

You can do a great deal to support this process. Have you noticed early warning signs? Are there any particular triggers which seem to make a mood swing more likely? Working together, you can often identify emotions, behaviours and events which could be early indications of a mood swing. Common early warning signs of mania, for example, are increased energy, a need for less sleep, and spending more money than usual.

Each person's symptoms are unique and by learning to distinguish between characteristic behaviours and non-characteristic behaviours

associated with episodes of mania or depression, you may be able to alert them to early warning signs. Identifying an episode right at the start means that one has a far greater chance of preventing it or reducing its impact. You may also be able to offer support in drawing up the action plan, helping in the identification of coping strategies and agreeing what help you could give if the early warning signs of an episode should appear.

But what if I am thought to be interfering or trying to take over?

This can be the cause of a great deal of tension. It is important to recognise how difficult it can be to manage the situation sensitively. You will want to take early action to prevent a mood swing, but no-one wants to feel that they are being continually observed for signs of an impending episode, nor lectured about how best they should live their life. On the other hand, it can be a mistake to wait too long to take action. Finding the right balance requires ongoing communication and acceptance of each other's feelings.

It is not uncommon for people with the diagnosis to experience overly controlling and critical behaviour from family and friends who believe they are acting in that person's best interest. Negotiation is required during periods of wellness, to ensure that any actions you take have been agreed ahead of time and address both your needs. Open communication and joint problem solving are required, but this takes practice and trust; family therapy may well be an option you wish to consider.

What types of medication are likely to be offered and what side effects do they cause?

There are a number of medications which can help in reducing mood swings. These fall into three broad categories:

Mood stabilisers (e.g. lithium, carbamazepine, sodium valproate, lamotrigine) can be described as maintenance treatments. They are taken long-term to prevent manic and depressive episodes.

Anti-depressants (e.g. Prozac, Efexor, Imipramine) are used to treat and control depressive episodes.

Major tranquillisers (sometimes called 'anti-psychotics') which are used to treat and control manic episodes. (Examples of the older drugs are chlorpromazine and Haloperidol; the newer 'atypicals' generally have less unpleasant side effects (e.g. Olanzapine and Risperidone).

Different medications, and combinations of medications, suit different people and the side effects experienced also differ. Determining if a particular medication is suitable is a question of balancing the benefits against the side effects experienced. If side effects outweigh the benefits then alternative medications should be sought.

Do not assume that the doctor will have prescribed the correct tablets and the correct dosage; there is often a great deal of trial and error involved before an acceptable medication regime is identified. Be an active gatherer of knowledge about bipolar so that you may be empowered to engage in discussions with health professionals from an informed position.

Further information on medical treatments for bipolar can be found online at <https://www.bipolaruk.org/FAQs/introduction-to-medical-treatment>.

My relative/friend has stopped taking their prescribed medication, what should I do?

The first and often the most difficult milestone in gaining control of lives affected by bipolar is to have the courage to accept the diagnosis. Particularly difficult is accepting one's vulnerability to another episode. Once an individual's mood has stabilised it is tempting to believe that the illness has disappeared rather than that it is in remission. A person may then decide to discontinue medication. It may also be the case that experiencing a high has led the person to believe that the medication is unnecessary.

Whatever the circumstances, it is important that the decision to stop is made in conjunction with the doctor. If a person is well at the time, then this poses fewer problems. If they are aware of the possible risks, and can make an informed decision, then, of course, it is everyone's right to decide what medication they will, or will not, take. During a manic or depressive episode, however, it may be necessary for you to alert their healthcare provider on their behalf.

Again, it is best to agree ahead of time what action you will take, and to have a shared, clear and reliable record of current medications. This will prevent a possible deterioration in your relationship should your actions be misinterpreted as controlling or interfering.

What should I do if I am concerned about my friend's/ family member's safety as a result of a manic or depressive episode?

You should contact their healthcare provider. Be very clear about your concerns, and ask for a home visit. If the person is attending an outpatient department, the best procedure is to contact their psychiatrist by phone. The Community Psychiatric Nurse can also be a good contact if he or she visits sufficiently frequently. Many of the Primary Care Trusts (PCTs) have 'crisis cards' that list telephone numbers where mental health services can be reached at all times. Get this information ahead of time. Not everyone will experience episodes which require this type of intervention, but it is best to prepare ahead of time.

Planning Ahead (available from Bipolar UK) is another valuable booklet, giving strategies for coping when unwell. You will find it has a centre-fold

blank 'Advance Statement' and some notes on how to complete it. The Advance Statement (or Agreement) expresses in writing what the person's wishes are in the event of an episode of mania or depression: who to inform, which medications are preferred, which medications to avoid, looking after the home, looking after the family, looking after money, where medical records can be located and so on. The Advance Statement can give considerable peace of mind. You will know that you are taking account of all eventualities and that you are behaving in a way that has the prior agreement of the person for whom you are caring. It is not always possible to prevent a mood swing, but this does not mean that there has been a failure on anyone's part.

Looking after yourself

Do not neglect your own needs. Having your own interests and leading your own life can prevent you from being perceived as too intrusive and will enable you to deal with difficulties more calmly and with tolerance. Consider what social support you need for yourself, and what practical and/or emotional support you have available. Do not feel guilty about putting your own needs first. It is important that you remain well if you are to offer support to others.

How can Bipolar UK help?

The organisation works to enable people affected by bipolar to take control of their lives. It has 4500 members in the UK, Eire and overseas. Founded in 1983, we have a store of expert knowledge to offer.

We produce a range of leaflets and information sheets. Our vibrant eCommunity provides members with a forum to express and share their views and experiences. We also provide a variety of services for individuals with bipolar, their carers and their families, including: over 100 self-help groups up and down the country; self-management training courses; our newly-launched Link Mentoring scheme; and our quarterly magazine, *Pendulum*.

For more information please call us on 0333 323 3880 or look at our website at www.bipolaruk.org.

Further resources

Carers UK

20 Great Dover Street
London
SE1 4LX
Tel: 020 7378 4999
www.carersuk.org

Young Carers

Include Programme
Ground Floor, Unit 4
Wessex Business Park
Wessex Way
SO21 1WP
Tel: 01962 711511
www.youngcarer.com

Bipolar Significant Others

www.bpsso.org

Saneline

0845 767 8000

Bipolar UK

11 Belgrave Rd
London
SW1V 1RB
Tel: 0333 323 4008
info@bipolaruk.org
www.bipolaruk.org