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talking about bipolar affective disorders

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This booklet reflects many discussions, suggestions and comments made by health professionals, professional bodies, lay and voluntary organisations, people with bipolar affective disorders and their friends and family.

NHS Health Scotland would like to thank all of those who contributed in any way to the development of this booklet, for so willingly giving their time, and sharing their expertise and experience.

All the quotes in this booklet are from real people.

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introduction

Bipolar affective disorder, or manic depression as it is sometimes known, is a medical term to describe a form of mental distress that affects someone's mood or behaviour. It can mean that those affected experience mood swings – periods when we feel terribly low and depressed, and periods when we feel high and elated. The length of any one of these periods can vary between an hour and several weeks or longer. How often and how severe the mood swings are varies from person to person.

These changes of mood are not like the general ups and downs of everyday life. They are much more extreme and can be alarming and frightening. They can affect how we behave, how we get on with other people, and how we manage our lives.

This booklet is written for people who have been advised by their doctors that what they are experiencing is bipolar affective disorder, and for their families and friends. It provides information on bipolar affective disorder, its causes and help available. The booklet also lists organisations that can provide further information.

what is bipolar disorder?

Bipolar affective disorder is a mental illness that can affect men and women from all walks of life and of all ages, from early childhood onwards. The word 'bipolar' means two opposite poles, and the poles of bipolar affective disorder are depression and mania. The disorder can involve repeated changes in mood, with periods of elation when we seem to have endless energy, and other periods of depression and despondency when we are barely able to cope with even the simplest tasks. But there are also periods of feeling well.

The spells of highs and lows may occur one after another, or some elements of both may be experienced at the same time. Some people find their mood tends to veer more in one direction, so that they are more prone to becoming either depressed or manic.

Some elements of both highs and lows can be experienced at the same time. This is known as a 'mixed state' and can make us feel very anxious. Some people experience 'rapid cycling', which is where the highs and lows quickly follow over a period of a month or less. In some cases, this can happen in the course of one day. In addition a milder version of bipolar disorder is called 'cyclothymia' where highs and lows are experienced but not as severely.

A number of people have only one bout or episode of bipolar affective disorder but the majority do have some recurrence. However, there are often very long periods of stability between bouts.

Some people's lives are more affected than others, but there are many common elements. During times of mania, we may find we:

> 'I always know when I'm going off the rails because I start to dash around the city in taxis when I can't afford taxis and normally walk everywhere.'

- Are excited and elated and our thoughts seem to race.
- May talk quickly and rather incoherently.
- Have boundless energy and come up with all kinds of apparently fantastic schemes and ideas that other people have doubts about.

> 'One time I was getting up at two or three in the morning and decorating the house while everyone else was asleep.'

- Experience difficulty sleeping or need much less sleep than usual.
- Have difficulty concentrating.
- Lose our sense of proportion in dealing with other people and handling our day-to-day business. We may spend money with unusual extravagance and beyond our means, or we may become less inhibited in our behaviour towards other people.
- Are easily irritated and frustrated – especially at times of higher moods when we have all sorts of plans but find that these are not always supported by others.

While we are going through that phase, we will probably not be aware that anything is wrong or that we are acting at all out of the ordinary.

Sometimes our experience of elation may not be so extreme. There is a milder form of mania – hypomania – which makes people overly active and excited, and possibly irritable and angry. This can lead to a full-blown high.

Mania can get people into difficult situations and they may lose touch with reality. Some people may have psychotic thoughts, may hear or see things that aren't there or suddenly develop strong beliefs. Their thoughts reflect their current mood, so they may believe they have committed a terrible crime or are homeless when depressed but that they are extremely wealthy and successful during times of mania. It is important to get a correct diagnosis as psychotic thoughts can also be the result of schizophrenia, another mental health condition.

'When I reach a certain stage, all I can do is just go to bed and stay there until it passes. I can't cope with anything else.'

If we are going through a low period when we feel very depressed, we may find that we:

'It was as if I was suddenly put into a dark room, on my own. I couldn't make contact with other people. I was trapped and alone.'

- Feel tired and exhausted all the time.
- Become irritable and frustrated.
- Find ourselves struggling to cope with even the simplest demands upon us.

- Are unable to concentrate or make decisions of any kind.
- Lose interest in sex.
- Feel overwhelmed by feelings of utter helplessness and despair.
- Find our sleeping patterns becoming disturbed so that it is hard to go to sleep, we cannot sleep long enough or we may want to sleep all the time.
- Have difficulty with food, either wanting to eat large amounts or totally losing interest in eating.
- Have thoughts of suicide.

Having bipolar affective disorder can touch our lives in all sorts of ways.

But there are many positive steps we can take to help ourselves as well as seeking treatment and support elsewhere. We can learn to recognise the earliest signs of onset of an episode, manage our symptoms and limit their impact on our lives.

'I found it very hard to pick up my career again. I had been working in catering, it was just too stressful so I had to have a rethink and change my expectations.'

'At first I couldn't understand what was going on – I felt too well! It took me and the doctor a while to fathom out what was wrong.'

'I've come to view it as a big achievement, learning to fight my bipolar disorder and to carry on in spite of it.'

understanding bipolar affective disorder

There is no agreement on what causes bipolar affective disorder. There may be a combination of factors involved.

Possible causes include:

- Early childhood experiences that may have left us emotionally fragile and vulnerable.
- Stressful events or major changes in our life, such as the death of a loved one.
- Possible hormonal changes – sometimes bipolar affective disorder occurs in women after childbirth or during the menopause.
- Biochemical imbalances in the body which then influence how we feel and think.
- Genetic factors, which would mean that a tendency to develop bipolar affective disorder could be passed from one generation to the next. This does not mean that the condition will definitely be passed to you if one or both of your parents have it, or that you will definitely pass it on to a child of yours. It merely increases the chances of this happening.

What may have caused us to develop bipolar affective disorder in the first place, and what might trigger a recurrence of symptoms subsequently, may be different.

For instance, our genetic or biochemical makeup may mean that we are more susceptible to developing bipolar affective disorder if we face traumatic events in later life.

However, while it may be helpful to highlight possible causes, it is important to note that while certain factors may put some people at risk, the same factors may have no affect on others and in many cases the cause is not known and more research is needed.

People with bipolar affective disorder may also struggle with alcohol or substance abuse. Such self-support approaches are unlikely to help and may make matters worse.

getting help from others

It may be that as time goes on, the type of help we need changes. Although there are no quick or easy remedies to cure bipolar affective disorder, there is a great deal we can do with the help of professionals and by other means to make it much more manageable, and to ensure that we can achieve as much as possible out of life.

counselling and psychotherapy

'I've found my counsellor has helped me greatly in recognising what made me stressed and in working out with me what I can do about it.'

Counselling and psychotherapy give us the chance to talk through our difficulties. Both focus on present day feelings and difficulties, take a longer-term view and help us to cope better and take more control of our lives.

With either, it is important to find someone we can relate to and trust. Your doctor will be able to help you find a qualified therapist or counsellor in your area.

'It was so good to find someone I could talk to who was detached from my situation. My family were all so concerned about me, I couldn't really be open with them. I felt really guilty about the distress I was giving them.'

Cognitive behaviour therapy (CBT) helps people to address how thoughts influence feelings and behaviour. It can be useful in helping us overcome negative ways of thinking and planning ways to become more active. CBT has been shown to be especially useful for treating low mood and helping us to stay well. We may not necessarily feel we have to find out what caused us to become depressed or manic, but may want to use counselling and therapy to help us bear the pain. It is important to go back to your doctor if counselling or psychotherapy doesn't work for you.

self help

A lot can be gained from meeting other people who have experienced bipolar affective disorder themselves. It can be valuable to find out how others cope with similar sorts of difficulties and to realise that we are not alone.

Self help groups can be accepting and welcoming. Members know first-hand what we are going through, whereas even those closest to us may be at a loss about how to react towards us. The direct experiences of others in the group can be an important influence on how we learn to adapt to living with bipolar affective disorder.

> 'Hearing things that other people had been through and seeing how they had got by had a powerful effect. To me it was much more effective than hearing the same advice from a professional.'

Groups can also offer a lot of practical advice and information about other facilities in the area. The organisations listed later in this booklet should be able to advise you of your nearest self-help group.

> 'The only other people I'd met with bipolar affective disorder before I came to the group were ones I knew when I was in hospital. They seemed really ill. It has been very encouraging to see that people can get by and be part of the community.'

It is possible to learn to recognise the warning signs of a manic or depressive episode. Though this will not stop the episode, it will mean that we can get help in time and reduce the severity of the episode.

Self Management Training helps people diagnosed with bipolar affective disorder to understand what triggers a mood swing, and to take action to prevent a period of illness.

Learning to self-manage bipolar affective disorder has proven to be an invaluable part of stabilising the condition. It has been shown to help significantly improve a person's self-esteem and reduce suicidal thoughts.

Self Management Training also improves communication with doctors and other health care workers, and has been shown to reduce our chances of needing time in hospital for treatment.

Further information on Self Management Training can be obtained from Bipolar Scotland. Contact details can be found at the end of this booklet.

medical treatment

Help is available from various different sources. Talking to your doctor is a good first step.

Often the doctor will refer someone with bipolar affective disorder to a psychiatrist for expert advice and help. This usually involves an initial assessment interview lasting up to an hour. Support may be offered by the local mental health team with ongoing contact to check how you are from a community psychiatric nurse. They act as a point of contact with local mental health teams for both the patient and the family. Because they are working with you in the community, they can observe how you are doing and they are often the first to notice if you are becoming unwell again, and can let your doctor know. They will also know about sources of information both locally and on the web or through appropriate publications.

Most people find that most of their treatment can usually be offered as an outpatient. If a time in hospital is required this is usually jointly agreed with you and your family. Sometimes admission under a section of the Mental Health Act requires you to be in hospital because your symptoms are very severe and extreme and there are concerns that you or others may be harmed. You or a family member can also appeal against this decision and there are various rights and safeguards that you have by law.

You have the right to make advance statements enabling you to appoint a representative and set out how you would wish to be treated in the event of becoming unwell and being unable to express your views at some point in the future.

Many non-profit organisations run local user and advocacy groups, drop-in centres and resource centres. Sometimes it can seem that decisions are being made by other people but user and advocacy groups can help give those with bipolar affective disorder and their friends and family the confidence, support and encouragement they need to have a say in matters that directly affect them. Advocacy now has a much stronger role, and legislation is in place to make sure that independent advocacy support is available to anyone who wants it.

The drug most commonly used to treat bipolar affective disorder is lithium. Many people find it helpful both in reducing symptoms and in preventing a further recurrence of mood swings. It is, however, not a cure.

People taking lithium need to have regular tests to ensure the level of lithium in their blood is high enough for effective treatment but not too high so that it causes unwanted side effects. As with all drugs, lithium can have unpleasant side effects. These may be minor and may not last. Many people decide to put up with the side effects because lithium helps control symptoms.

A small number of people react more severely to lithium. If you experience severe nausea, vomiting, confusion, or persistent diarrhoea, you should contact your doctor immediately as your lithium level may have risen too high.

Carbamazepine or valproate are sometimes used alongside lithium, or as an alternative. They help curb swings in mood and have a mild tranquillising effect. Both are often used as an antiepileptic medication – but in treating bipolar affective disorder they are being used because of their mood stabilising effects rather than as an anticonvulsant. Although the doctor has prescribed carbamazepine or valproate, it does not mean that you have epilepsy.

You may be advised to continue taking these drugs even when the symptoms have subsided, as they can help prevent a relapse.

Other types of drugs, which may be prescribed for particular symptoms, include antidepressants, major tranquilisers and very occasionally short courses of benzodiazepines. Antipsychotics such as olanzapine are used to treat symptoms of mania and in the long term to stabilise mood. As each person is affected in a particular way by bipolar affective disorder, the medication that suits best varies from person to person.

It is important that you ask your doctor to explain the treatment recommended. You are entitled to information about the likely benefits and disadvantages of each drug prescribed for you. If you are to keep taking medication for some time, it is important that it is reviewed regularly to ensure the dosage continues to be correct and to check for unpleasant side effects. You may want to discuss with your doctor what immediate steps you might take if you realise that you are becoming high or low.

Some people may decide that they do not want to continue on medication in the longer term, perhaps because of the side effects. It is not advisable to stop taking medication suddenly and without first consulting your doctor and other advisers about what is best for you.

No matter how effective medication proves to be, you may well find other forms of support useful to help you find your feet again.

what you can do

Bipolar affective disorder can be very distressing. We may feel frightened by being told that we have bipolar affective disorder and by its symptoms. Or we may find it hard to accept that other people think there is something wrong – particularly if we are high and feel better than ever before.

We may take important decisions and do something that later seems misguided and may have unfortunate consequences. Looking back on it later can all be extremely bewildering and unnerving as our lives appear to be out of control. With help though, we can begin to set about putting our lives in order again.

It is important to remember that if we have done anything unwise during a bout of illness, it was because we were ill. For example, when high we might buy inappropriate things, start all sorts of wild plans, say things or act towards people in ways we later regret. Those people around us who are likely to have been most affected, like our close friends and family members, may well understand that.

They may know it is part of the illness, and want to help us work out ways to make some adjustments to our lives so that we are in a better position to take more control rather than letting bipolar affective disorder control us. It can be really useful at this time to talk things over with professional helpers and those who have been through similar experiences.

What helps may be different for each of us, but here are some general suggestions which other people have found helpful. We should:

- Try to seek help early rather than waiting until we are very distressed or unwell.
- Avoid situations that may be stressful as far as we can.
- Learn to recognise the early warning signs that may mean symptoms are likely to come back.

However, we should try to keep this in proportion, and not let it rule our lives. For example, it is only to be expected that stressful situations like moving house make everybody tense and anxious. It certainly does not automatically mean that we will become unwell again.

When we are feeling depressed or down, we should:

- Take care of ourselves, pamper ourselves, give ourselves small treats.
- Try to get enough rest. Get into a routine at bedtime to help us unwind.
- Do some exercise to help us relax. It does not have to be anything strenuous – a short walk or a swim.
- Try to eat regular meals. If we have no appetite, we should try telling ourselves that food is medicine. In time, our appetite will return.
- Take one day or even part of a day at a time. We should try to pay attention to the good times and good feelings, rare as they might seem just now. They will become more frequent.
- Make an effort to keep in touch with people if we can.
- Seek the support of family, friends and self-help groups. Ask them to let us know if we need more help.
- See our doctor. Our medication may need adjusting.

'I make myself busy. If I'm sitting at home on my own, I'm at my worst.'

'I plan what I'm going to do that day and then try to stick to it. That helps me get through the day.'

If we allow ourselves time, the dark spell will gradually pass. But it is not easy and it is not quick.

When we feel we are getting high, we should:

- Remember to take care of ourselves, eating and resting regularly, even though we may not feel we need to.
- Maintain a normal sleep pattern as this can make a great difference.
- Find constructive ways of using all that energy – perhaps by writing or exercising.
- Avoid taking decisions of any importance.
- Write down ideas and plans as they come to us, to look at later when we are calmer.
- Steer clear of situations that could be difficult or stressful – meetings, social events, work situations.
- Listen to the advice of those close to us, and try to remember how things went when we were high before.
- See our doctor. Our medication may need adjusting.

Bipolar Scotland has produced a booklet that provides more detailed information and advice on how to handle periods of depression and elation. The contact information is given later in this booklet.

Like everyone else, people experiencing bipolar affective disorder need to look after themselves. That means eating healthily, drinking in moderation, if at all, and being physically active. The 'feel good' factor can also be helped by learning new skills, taking time to relax, enjoying different creative activities and keeping in touch with friends or making new ones by joining a club or volunteering.

'My husband takes away my credit cards and my car keys when there are signs I am getting high. It's something we agreed upon after a few near disasters.'

We may find that after a high period we feel guilty, embarrassed or ashamed of how we have behaved towards other people. We should try to talk this through with them and try not to blame ourselves. We may be able to work out what we can do together should such a situation happen again.

Again the support of others who have themselves had similar experiences can be invaluable.

the role of partners, family and friends

Being close to someone who is experiencing bipolar affective disorder can be emotionally draining. It can also cause a great deal of disruption and put an enormous strain on family and friends. The person you thought you knew may be behaving in unexpected ways that are hard to understand. You may be angry or embarrassed at how your friend or relative is acting. You may feel exhausted at trying to keep up with their apparent boundless energy.

You may feel deeply worried or guilty that in some way you have contributed to their feelings of misery.

When your friend, partner or relative is high, he or she may not realise that anything untoward is happening. Your attempts to help and calm them down are likely to be rebuffed in no uncertain terms. When he or she is depressed, it can feel as though they are out of your reach. Try not to feel hurt or discouraged.

There are ways in which you can help the person you care about and even though they may not show it at first, it is very important for them to know there is someone there to support and encourage them as they struggle to cope. You can let them know that you will be there for them when they are depressed or high, even though it can be hard to understand or tolerate their mood. When they are calm you can discuss how you might handle things in the future if they show signs of becoming unwell again.

Try to respect their wishes as far as possible. However, there may be times when you have to seek help whether they consent or not, because of your concern for their wellbeing. If they are becoming seriously unwell again, you should encourage them to get in touch with their doctor, community psychiatric nurse or other professional helpers and organisations, some of which are listed later in this booklet. If they fail to seek help, you should do so on their behalf.

There are practical ways in which you may be able to help, like doing some of the daily chores, encouraging them to keep a doctor's appointment or finding out about self-help groups in the area. Try not to be over-protective though. Your friend, partner or relative needs to be able to regain control of his or her life when well again. Part of that may be working out for themselves how much stress they can cope with.

Your encouragement and support will be important in helping them rebuild their self-confidence. It will not help if you are overly anxious about the possibility of another spell of depression or a high recurring.

It is upsetting to see someone you love experience such distress. Sometimes you can struggle to know what to say and how best to offer support. If difficulties persist for some time, you may find that you also struggle to cope yourself. This is especially the case when someone you are close to finds it difficult to venture out or if they begin to push you away or become very reassurance-seeking or dependent.

It is important that you look after yourself and consider your needs too. Take regular breaks if you can manage to. Keep up with your own friends and interests. Make sure you find time to do the things you enjoy, including some things outside the home.

If you are doing a lot to help out practically, you may feel resentful and become increasingly worn out by the burden of it. If you notice symptoms of depression or find that you are no longer enjoying life as you used to, you may

be experiencing symptoms of a depressive illness. If this is the case, please discuss these issues with your doctor or healthcare practitioner who can advise you how best to seek help.

Find an outlet for your feelings, someone you can talk to about your concerns. It might be your doctor, a close friend or another member of a support group for people in situations like your own. Community psychiatric nurses can be very helpful and supportive, and there are also many care groups attached to hospitals. One of their roles is to help families and friends cope.

looking ahead

Being given a diagnosis of bipolar affective disorder can feel like our world is crumbling around us. Yet there are many ways in which we can help ourselves and get help from other sources. If we continue to experience symptoms from time to time there are steps we can take to limit the impact on our lives.

Some people say that in time they get a sense of achievement out of learning to contend with bipolar affective disorder. Many creative people – artists, writers and so on – are now known to have had the condition. There are many individuals today with bipolar affective disorder who lead full lives and pursue successful careers. Although not everyone is able to do so, it is possible for each person to work out for him or herself how best to cope, and make adjustments so that he or she can lead as fulfilling a life as possible.

useful addresses

The national organisations listed below can put you in touch with local sources of help in your area.

Bipolar Scotland (formerly Bipolar Disorder Fellowship)
Studio 1015
Mile End Mill
Abbeymill Business Centre
Seedhill Road
Paisley PA1 1TJ
Tel: 0141 560 2050
www.bipolarscotland.org.uk

British Association for Behavioural and Cognitive Psychotherapies (BABCP)
11 Alva Street
Edinburgh EH2 4PH
Tel: 0845 123 2320
www.dascot.org

Depression Alliance Scotland
3 Grosvenor Gardens
Edinburgh EH12 5JU
Tel: 0131 467 3050
Email: info@dascot.org
www.depressionalliancescotland.org

NHS24
Caledonia House
Fifty Pitches Road
Cardonald Park
Glasgow G51 4EB
www.nhs24.com

NHS 24 is a 24-hour health service for Scotland.

SANE
1st Floor, Cityside House
40 Adler Street
London, E1 1EE
Tel: 0845 767 8000
www.sane.org.uk

Scottish Association for Mental Health (SAMH)
Cumbrae House
15 Carlton Court
Glasgow G5 9JP
Tel: 0141 568 7000
(information service 2-4.30pm Monday to Friday)
Email: enquire@samh.org.uk
www.samh.org.uk

The Scottish Association for Mental Health is a major voluntary organisation in Scotland working to promote mental health.

useful websites

www.bipolarscotland.org.uk
Bipolar Scotland

www.livinglifetothefull.com
Living Life to the Full contains free modules on improving sleep, healthy living, challenging negative thinking and staying well.

http://moodgym.anu.edu.au
The Mood Gym Training Programme
Information on cognitive behaviour therapy skills for preventing and coping with depression.

www.seemescotland.org
'see me' is the national campaign to end the stigma of mental ill health.

suggestions for reading

There are many publications about bipolar affective disorder and your GP or local library will be able to suggest some help for you. Here are a few that might help.

An Unquiet Mind
by Kay Redfield Jamison.
Published by Picador, 1997.
ISBN 033-034651-2

Balancing Act: Getting and Keeping Your Life in Balance
by Paul Heneks.
Published by Fraser Publishing Company, 1995.
ISBN 087-034119-7

The Bipolar Disorder Survival Guide: What You and Your Family Need to Know
by David Miklowitz.
Published by Guilford Press, 2002.
ISBN 157-230525-8

Coping with Bipolar Disorder
by Steven Jones, Peter Haywood and Dominic Lam.
Published by Oneworld Publications, 2002.
ISBN 185-168299-6

The Depression Workbook: A Guide for Living with Depression and Bipolar disorder
by Mary Ellen Copeland and Matthew McKay.
Published by New Harbinger Publications, 2002.
ISBN 157-224268-X

Diary of a Young Bipolar
by Alexander Scott.
Published by iUniverse.com, 2004.
ISBN 059-530663-2

Loving Someone with Bipolar Disorder: Understanding and Helping Your Partner
by Julie A Fast and John Preston.
Published by New Harbinger Publications, 2004.
ISBN 157-224342-2

The Naked Birdwatcher
by Suzy Johnston.
Published by The Cairn, August 2004.
Available from The Cairn (go to www.thecairn.com for full contact details).

Overcoming Mood Swings
edited by Jan Scott.
Published by Constable and Robinson, 2001.
ISBN 184-119017-9

To Walk on Eggshells
by Jean Johnston
Published by The Cairn, 2005.
ISBN 095-480921-1

The Naked Birdwatcher is Suzy Johnston's candid and honest account of living with bipolar disorder. Whilst *To Walk on Eggshells* is written by her mother from the carer's perspective.

Other topics covered by the *Talking about...* series are:

- Anxiety
- Attention deficit hyperactivity disorder (ADHD)
- Bereavement
- Depression
- Eating disorders
- Panic attacks
- Personality disorders
- Phobias
- Postnatal depression
- Self-harm
- Schizophrenia
- Stress

These publications are available online at www.healthscotland.com/publications or telephone 0131 536 5500.

Disclaimer

Every effort has been made to ensure that this publication is as up-to-date and accurate as possible. However, new research can sometimes mean that information and recommendations change very quickly. Changes and alterations will be made at the next reprint to reflect any new information.

While the booklet represents the consensus of good practice, please remember that different circumstances and clinical judgement may mean that you have slightly different experiences.

If you have any doubts, worries or fears, then do not hesitate to contact your doctor for reassurance and further explanations.

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