Division of
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Understanding Bipolar Disorder

*Why some people experience extreme mood states
and what can help*

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Foreword

This report was written by a working party of clinical psychologists drawn from universities and the NHS and brought together by their professional body, the British Psychological Society Division of Clinical Psychology. Contributors were chosen because of their particular expertise on the subject of bipolar disorder. Experts by experience – people who have themselves received a diagnosis of bipolar disorder – were also members of the working party and contributed substantially to the report. A number of the contributors were also involved in writing a previous Division of Clinical Psychology report, *Recent advances in understanding mental illness and psychotic experience*, published in 2000. The present report has been informed by many of the elements of this earlier work, which has proved influential amongst clinicians, academics and service users. In particular, both reports provide psychological perspectives which are typically neglected in the wider literature on both psychosis and bipolar disorder.

The purpose of the report is to provide an overview of the current state of knowledge about why some people tend to experience periods of extreme mood, and what can help – in traditional medical language, the 'causes and treatment of bipolar disorder'. There have been significant developments in recent years, particularly in our understanding of psychological aspects of what has traditionally been thought of as a largely biological or medical problem. Much has been written about the biological aspects: this report aims to redress the balance by concentrating on the psychological aspects, both in terms of how we understand the problems and also approaches to help and treatment. We would like to think that this report will influence the way in which services are delivered, so that more people have access to psychological treatments. Perhaps even more importantly, we would expect that, as a result of this report, services will no longer insist that service users accept one particular view of their problem – for example that they have an illness which always needs to be treated primarily by medication. We hope that the report will be a resource for front-line workers and service users, ensuring that their conversations are as well-informed and useful as possible. We ask that those responsible for commissioning and designing both services and training will read this report, especially since the recent NICE guideline said little about psychological approaches. Professional training courses will need to be changed to take account of the information presented in this report. We also hope that it will be read by journalists and other opinion-formers, and will help to change the way that we as a society think about not only bipolar disorder but also all the other kinds of distress and confusion that might attract a label of 'mental illness'.

> *'I have often asked myself whether, given the choice, I would choose to have manic depressive illness … Strangely enough I think I would choose to have it. It's complicated. Depression is awful beyond words or sounds or images … So why would I want anything to do with this illness? Because I honestly believe that as a result of it I have felt more things, more deeply; had more experiences, more intensely; loved more, and been loved; laughed more often for having cried more often; appreciated more the springs, for all the winters; worn death 'as close as dungarees', appreciated it – and life – more; seen the finest and the most terrible in people, and slowly learned the values of caring, loyalty and seeing things through.*

Kay Redfield Jamison (Jamison, 1996)

Executive summary

This report describes recent developments in our understanding of bipolar disorder. It is written for people who have received the diagnosis, people who feel it might apply to them, friends and relatives, mental health professionals and anyone else with an interest in this issue. The report is divided into five parts, covering the nature of the problem, causes, sources of help and treatment, recovery and how mental health services need to change.

Key points:

■ This report is about those problems that are traditionally thought of as arising from a mental illness called 'bipolar disorder' (formerly called 'manic depression').

■ Many people experience periods of depression and also periods of elation and overactivity. Mood can affect how we feel about ourselves. For example, at times we may feel extremely positive or even grandiose about our own abilities, whereas at other times we may feel that we are a complete failure.

■ For some people, episodes of extreme mood are frequent and severe enough to lead them, or those around them to seek help. Within mental health services the problems are currently likely to be seen as a 'disorder' – bipolar disorder. It is only people who come into contact with mental health services who are likely to receive a diagnosis and be seen as having a mental illness.

■ However, not all mental health professionals accept the idea that these experiences are caused by an underlying illness.

■ There is increasing evidence that it may be more helpful to conceptualise these problems as being on a continuum: we are all subject to mood variation, but within this, people range from those who experience relatively few highs or lows to those who tend to experience more extreme mood states. There are both positives and negatives associated with both ends of the continuum. For example, individuals who experience extreme mood states tend to be very creative, at times have a great deal of energy and often can be high achievers. But they can also experience problems – for example, during periods of elation people sometimes do things that they later regret, such as spending too much money.

■ Each individual's experiences are unique – no one person's problems, or ways of coping with them, are exactly the same as anyone else's.

■ Some people who experience extreme mood states find it useful to think of themselves as having an illness. Others prefer to think of their problems as, for example, an aspect of their personality which sometimes gets them into trouble but which they would not want to be without.

■ Mental health services have traditionally tended to assume that once someone experiences problems with unstable mood severe enough to bring them into contact with services, the problems are likely to recur. In fact this appears to be the case for fewer than half of those people.

■ Traditionally, medication has often been the only type of help offered. Some people, but not all, find it helpful. For those considering using medication, a 'try it and see' approach is needed in order to find which medication, if any, is helpful and in what dose. There is increasing evidence that talking treatments (particularly cognitive behaviour therapy), and self-help (especially supported by a worker or self-help group) can also be very useful.

Part 1: Understanding the bipolar disorders

Section 1: What is bipolar disorder?

- Many people experience periods of depression and also periods of elation and overactivity. For some people, these episodes are frequent and severe enough to be seen as a 'disorder' – bipolar disorder. The word 'bipolar' refers to the two extremes or 'poles' of mood: depression and 'mania'. Until recently the term 'manic depression' was also used.

- Each person's experience is unique and there is a continuum between the extreme mood states described in this report and the normal mood swings that everyone experiences.

- Some people, but not all, find it helpful to think of themselves as having an illness.

Section 2: How common are these experiences?

- These experiences are quite common – about 1 to 1.5 per cent of the population are likely to receive a diagnosis of bipolar disorder at some point in their life.

- Elation and overactivity ('hypomania') are very common but only lead to problems – and therefore a diagnosis – in certain circumstances, for example if they alternate or co-exist with depression or if they lead the person to behave in a destructive way (for example, overspending). People can also experience problems if, when feeling elated, they temporarily develop unrealistic beliefs (for example, that they are a great leader), or start to perceive reality differently (for example hearing voices when there is no-one there), become exhausted, feel out of control or are admitted to hospital.

Section 3: Development impact and course of bipolar

- Problems often start in late adolescence or early adulthood, and can affect a person's development.

- In addition to episodes of extreme mood, some people experience ongoing mood difficulties.

- Research tends to focus on people who have ongoing problems and are in contact with services. This may have led to an overly negative view of how problems affect people, i.e. that they tend to recur.

- Despite the negative bias, the research still shows that overall 60 per cent of people do not experience 'relapse' and nearly half are able to return to their previous lifestyle in terms of job, social life, etc., over a two-year period.

- There are positive as well as negative aspects to these experiences. Many people with a diagnosis of bipolar – and people with similar experiences who have not received a diagnosis – have huge amounts of energy and are extremely creative and productive.

Section 4: Problems with 'diagnosis' in mental health

- There is a debate about whether 'diagnosis' is useful in mental health.
- Mental health diagnoses are defined by lists of 'symptoms' (experiences and behaviours) and do not indicate anything about cause.
- There is a large overlap between diagnoses.
- People may meet criteria for different diagnoses at different times in their lives.
- Among people with a diagnosis of bipolar disorder, there is much variation in how frequently they experience problems and in what treatments are helpful. This suggests that the diagnostic category fails to capture some important differences between individuals.

■ Clinicians often disagree about whether someone fits the criteria for a diagnosis of bipolar disorder.

Part 2: Causes

Section 5: Life/social circumstances and bipolar

■ People in difficult life circumstances are much more likely to experience all kinds of mental health problems.

■ The same applies to people who have had a difficult childhood.

■ Having a supportive network of family and friends can make it less likely that mood problems will return. Conversely, people are more likely to experience ongoing problems if their family members are either highly critical or overprotective towards them.

■ Therapists should therefore consider family as well as individual therapy work in bipolar disorder. In either case it is important to pay attention to life circumstances as well as what the individual themselves might be able to do differently.

Section 6: Psychological factors in bipolar experiences

■ When people are depressed, they tend to see the negative in everything, including themselves and this can lead to a vicious cycle keeping the depression going. Conversely when people are very active and experiencing elation, there is a natural desire to see this as 'the real me' and to want to do even more. There is evidence that these 'thinking styles' are particularly pronounced for people whose moods are extreme enough to attract a diagnosis of bipolar disorder.

■ There is evidence that some people with a diagnosis of bipolar disorder show these more extreme thinking styles even at times when they are not experiencing very high or low mood.

■ People can learn to 'catch' this kind of thinking as it develops and take action, for example making themselves rest when their thoughts begin to race.

Section 7: Biological factors in bipolar disorders

■ Someone with a sibling or parent with a diagnosis of bipolar disorder is over ten times more likely to receive the diagnosis themselves compared to someone from an unaffected family. Whilst there may be a number of reasons for this, it does suggest that people's genetic makeup may play a role. However, attempts to isolate contributing genes have, as yet, proved unsuccessful.

■ There is evidence that certain neurotransmitters (brain chemicals) – for example serotonin and dopamine – may play a role. However, all thoughts and emotions involve chemical changes in the brain and cause-and-effect relationships are unclear.

■ Some people with a diagnosis of bipolar disorder appear to have slight differences in brain structure and function. However, again, cause-and-effect relationships are unclear: for example, some differences could be the result of prolonged use of certain medication.

■ The varying nature of people's experiences, both within and between individuals, indicates that they are likely to be the result of a combination of factors that interact across time.

Part 3: Help and treatment

Section 8: Assessment

■ The person experiencing mood changes, or their family and friends, are usually the first to notice problems with mood and typically visit their GP. Elation and overactivity may initially not be seen as a problem and therefore not reported.

■ If the GP thinks that the person's experiences may fit the criteria for a diagnosis of bipolar disorder, they are likely to be referred for assessment by secondary care services.

■ It is important that this is an in-depth assessment and covers the person's life circumstances, their view of the problem, and likely triggers as well as coping strategies, strengths and sources of support.

■ It is common for assessment to be an ongoing process and for people to be given various diagnoses and therapies before an agreed diagnosis is made. On average, this process lasts five years.

Section 9: Self management

■ Over time, many people learn to recognise the 'warning signs' that their mood may be going up or down, and what they can do to prevent things worsening.

■ The opportunity to talk things through with a mental health worker or in a self-help group can aid this process greatly.

Section 10: Psychological therapies for bipolar experiences

■ Psychological therapies which can help include educational groups, cognitive behavioural therapy, interpersonal and social rhythm therapy and family focused therapy. This report describes these forms of help, which are usually offered over several months or longer and can greatly assist the person in developing skills to reduce the risk of further episodes.

■ All these therapies give the person the opportunity to discuss their experiences in a calm and nonjudgmental atmosphere, help them to work out what causes their problems and keeps them going, and assist the person to develop strategies for preventing the problems returning.

■ It is important to tailor therapies to fit the individual and reassess and revise the approach as circumstances change and develop.

■ Despite the popularity of psychological therapies and the evidence for their effectiveness, only a minority of mental health service users are currently able to access them. This needs to change.

Section 11: Medication

■ Medication offered to people with a diagnosis of bipolar disorder can be separated into three categories: mood stabilisers, anti-depressants (for depression), and neuroleptics (also called major tranquillisers – for mania). Doctors usually recommend that people take medication every day, even when they feel well and sometimes for years after an episode.

■ Medication is helpful for many, but not all people with a diagnosis of bipolar disorder.

■ Each person has to weigh up the advantages and disadvantages, for them, of taking medication. For example it may help prevent the problems returning but can also

have unwanted ('side') effects, may have a negative effect on things that are valued by the individual, such as periods of creativity, and can raise questions about the person's self-identity.

■ It is important for medication to be reviewed regularly in the context of a collaborative partnership between the prescriber and the individual. There is evidence that this does not always happen.

Section 12: Risk and bipolar experience

■ People with a diagnosis of bipolar disorder are at higher risk of suicide. It is estimated that 10 to 15 per cent of people admitted to hospital with the diagnosis will eventually die by suicide.

■ A kind of talking therapy, known as mindfulness based cognitive therapy (MBCT), is a promising new approach for people who have thoughts of suicide. Participants are encouraged to focus on self-acceptance and compassion as opposed to self judgment and criticism, and learn to recognize warning signs such as certain thoughts and feelings.

Part 4: Recovery

Section 13: Recovery and staying well with bipolar disorder

■ Recovery is defined in a variety of ways. Some people think of recovery as no longer using services or taking medication, whereas others see recovery as gaining back control of one's life and achieving valued goals whilst perhaps continuing to draw on support.

■ People use a variety of strategies for recovery. The most common involve learning to notice early warning signs of mood changes and knowing what is likely to help at that point.

■ Recovery is an ongoing journey that is unique to each individual.

Part 5: Wider implications

Section 14: Implications for mental health services

■ Services should not insist that all service users see their problems as an 'illness' and take medication.

■ There is increasing evidence that talking treatments can be very effective and they should be much more widely available.

■ Trusting, collaborative relationships between workers and service users are a prerequisite of, and arguably as important as, any specific treatment.

■ People should be offered information and choice about all aspects of the help offered by services.

■ Service users are experts by experience and services should draw on their expertise to help improve services and train staff.

■ Sources of funding are needed for research that is not based uncritically on a medical model of 'bipolar disorder'.

Section 15: Social inclusion

- People diagnosed with bipolar disorder may encounter difficulties with practicalities such as obtaining a driving licence or a travel visa.

- There are both advantages and disadvantages in choosing to disclose mental health difficulties to existing or potential employers. Whilst there is no legal obligation to inform employers of diagnoses, people can be protected under the Disability Discrimination Act (1995) and some employers actively seek people recovering from mental health difficulties.

- Some aspects of our culture are arguably unhelpful to anyone at risk of mania or depression, for example long working hours and valuing of excess work over a balanced life.

- Mood problems can both cause and be caused by relationship problems. It is important to maintain good levels of social support and share difficulties with those around you.

- The information in this report should be used as part of public information campaigns in order to reduce stigma and discrimination and promote social inclusion.

Note on terminology

There is considerable debate about the most helpful way of referring to the experiences described in this report. The different terms used by different people reflect the more general debate about the nature and causes of these experiences. That means that care must be taken to ensure that the terms used do not carry implications that are not intended.

Traditionally, extreme mood states have been thought of as symptoms of a mental illness known as bipolar disorder (previously called manic depression), and people who experience them have been referred to as 'patients' or ' sufferers'. Extreme elation accompanied by overactivity is sometimes known as 'mania' or, when less severe, 'hypomania'. However, as outlined above, not everyone finds this the most helpful way of thinking about these experiences, and many people do not see themselves as having an illness or 'disorder'.

Throughout this report we have attempted to use terms which are as neutral as possible and do not imply a particular 'framework of understanding' (e.g. a medical one).We refer to the experiences in question as 'experiences' or 'mood states' rather than as symptoms of an illness. We have used the term 'bipolar disorder' within the report because it is the term in common use within our society to describe the tendency to experience periods of extreme mood. We wanted to be sure that readers understand that it is these experiences that are the subject of this report. However, we use the term 'people diagnosed with bipolar disorder' rather than 'people with bipolar disorder'. This is because we do not wish to give the impression that everyone agrees that there is an underlying illness, when in fact this assumption is debated. Finally, we refer to people as 'people', rather than as 'patients'. An additional term used in the report is 'service user'. We recognise that this term has its critics but it was decided to include it as the primary focus of the document is on people with personal experiences of using mental health services.

Of course, much of what has been written in this area previously has used a medical framework and therefore used medical terminology. When describing this work we have used quotation marks round these terms.

PART 1: Understanding the bipolar disorders

Section 1: What is bipolar bisorder?

> **Key points**
> - Many people experience periods of depression and also periods of elation and overactivity. For some people, these episodes are frequent and severe enough to be seen as a 'disorder' – bipolar disorder. The word 'bipolar' refers to the two extremes or 'poles' of mood: depression and 'mania'. Until recently the term 'manic depression' was also used.
> - Each person's experience is unique and there is a continuum between the extreme mood states described in this report and the normal mood swings that everyone experiences.
> - Some people, but not all, find it helpful to think of themselves as having an illness.

1.1 Definition

The term 'bipolar disorder' (previously manic depression) is used by mental health professionals to describe a pattern of extreme disruptions to mood, behaviour and thought.

As with all psychological problems, each person's experience of bipolar disorder is unique and, at the same time, there is overlap between the experiences of someone who receives a formal diagnosis and the normal mood swings of ordinary life. When people's problems with mood swings are serious enough to significantly disrupt their lives, then a formal diagnosis of 'bipolar disorder' may be appropriate – it is important to remember that all formal textbooks of diagnosis stress that one of the criteria for formal diagnosis is that the person's psychological difficulties are causing significant problems in their personal or family life.

Bipolar disorder describes a pattern of episodes of severe depression, mania or hypomania, in addition to periods of relatively stable mood. People do not necessarily swing from one extreme to another, but instead typically experience maybe one, two or three periods of significant mood problems over a two or three year period. Episodes may last several weeks and usually follow no particular predictable course – depression is not necessarily followed by a 'high'; it isn't inevitable that a period of mania will crash into low mood. Also, even during periods of so-called 'remission', people who experience bipolar disorder often find that their lives are seriously affected by mood swings and difficulties in personal and family life.

1.2 Diagnosis

There are two main diagnostic manuals used by mental health professionals. The World Health Organisation's *International Classification of Diseases* (10th edition) or 'ICD-10' (WHO, 1992) and the American Psychiatric Association's *Diagnostic and Statistical Manual* (4th edition) or 'DSM-IV' (APA, 2000). The two definitions of bipolar disorder are generally very similar. However, one difference worth noting is that a diagnosis of bipolar

disorder can be obtained after a single manic or mixed affective episode under the DSM-IV criteria whereas under ICD-10 both mania and depression or two mixed affective episodes are required. Because of the episodic nature of bipolar disorder, the diagnosis can be complex.

People may experience episodes of either mania or hypomania. Mania is a very intense episode often associated with increased well-being, energy and optimism. People in a manic episode can feel very happy and excited and find their thoughts full of new and exciting ideas. When a 19-year-old with mania was advised that he was indeed ill, he replied, 'If I'm ill, this is the most wonderful illness I've ever had.' (Campbell, 1953)

Although sometimes subjectively enjoyable, other aspects of mania may prove problematic for the individual. People in a manic episode can easily become irritated with other people who don't share their optimistic outlook or when other people find it hard to understand what they are talking about. People may also make plans that are grandiose and unrealistic, make odd decisions on the spur of the moment, sometimes with disastrous consequences such as recklessly spending money or getting involved in unwise sexual adventures. A period of mania can affect both relationships and work (and remember that such a threshold is an important part of the formal diagnostic criteria). When these experiences are intense – so intense that a person's life is very seriously affected, if a person loses touch with reality or needs admission to hospital, for example – then this is called mania. Less extreme episodes (where a person's personal life is clearly affected, but not so seriously) this is called 'hypomania' (hypo means 'under' in Greek).

> *'My early warning signs are that colours seem very bright, particularly reds and yellows, they take on neon characteristics and I believe they have magical properties, I also start to talk much faster and more than is usual for me. If I do nothing about these signs, within a day or two I am highly excited, very active, wanting to run, dance and climb things. At this stage everything seems wonderful and I feel like I am a genius! The next stage is more worrying (though not to me at the time) I become disinhibited and take off all my clothes in public. Also, I believe I can fly and try to get to high places so that I can launch myself into the air. What seems such a wonderful feeling quickly becomes very dangerous!'*
>
> Debbie Mayes – service user

Some people experience so-called 'mixed episodes', during which they experience some of the aspects of mania (for example, excitement and a rush of new and exciting ideas) with some of the aspects of depression (perhaps restlessness, agitation, anxiety, irritability or even suicidal thoughts). This can happen in parallel with, for instance, depressed mood accompanied by pressured speech and agitation. Alternatively people may alternate between symptoms of mania and depression within or across days. This combination of symptoms is often reported to be particularly difficult to cope with by many people. If a person is experiencing a manic, hypomanic or mixed affective episode, or has done recently, then a diagnosis of bipolar disorder often follows. When the person has experienced manic episodes, then commonly the label 'bipolar disorder – type I' is used. When the person has experienced hypomanic episodes, then the label is usually 'bipolar disorder – type II' is used. Bipolar II (with hypomanic episodes) is more common (Angst, 1998; Angst et al., 2003). Of course, people receiving this diagnosis typically also

experience episodes of depression. In fact, most people who receive the diagnosis of bipolar disorder spend significantly more time depressed as opposed to manic (Post, 2003). The criteria for identifying an episode of depression in bipolar disorder are no different from identifying episodes of depression in 'unipolar depression' ('unipolar' referring to cases when people experience episodes of depression but without the 'highs'). Most people experiencing depression do not have the highs associated with bipolar disorder. What that means is that if a person experiences their first episode of mania, they will be given a diagnosis of bipolar disorder, but if they experience a first episode of depression, they will be diagnosed with 'major depressive episode' or 'unipolar depression'. If, at a later time, they then have an episode of mania or hypomania, then a diagnosis of bipolar disorder will be used.

> *'My experience of depression tends to follow the same pattern each time. It comes on quite quickly, the first sign is that my sleep gets interrupted, I wake early in the morning and can't get back to sleep, then my appetite goes, I no longer feel hungry. Alongside these things are a worsening of my mood, I feel bleak and lonely, even when I am around people who I love and am loved by. I feel an intense ache deep inside my chest and a sense that I am a horrible person that no-one can possibly like. I feel useless and guilty and as though I have done something dreadful and it is only a matter of time before I am found out. As time goes by I start to feel suicidal, that the world and especially those close to me would be better off without me.'*

<div align="right">Debbie Mayes – service user</div>

1.3 Continuum

The use of medical terms such as 'diagnosis', 'episode', etc., tends to give the impression that bipolar disorder is a discrete disorder that is clearly distinguishable from 'normal' aspects of human life and from other kinds of psychological problem. It also tends to imply, in the case of bipolar disorder, that the different episodes (manic, hypomanic, depressed, mixed) can all be distinguished from each other and from so-called 'normal' mood.

We now know that this picture is too simplistic, however. There is now a huge body of evidence which would suggest that these experiences are both very complex and overlapping and also range on a spectrum or continuum with normal experiences (Jones & Bentall, 2006).

There is also a great deal of overlap between the different types of episode – manic episodes are characterised by many conventional aspects of depression (irritability and even low mood) and of course there are explicitly 'mixed' episodes. On the other hand, people experiencing conventional (i.e. not 'bipolar') episodes of unipolar depression report aspects of hypomania during those episodes. The idea of episodes itself tends also to become problematic. Cyclothymia is a diagnostic term referring to recurrent episodes of mild (but clearly problematic) mood disturbances between hypomania and a mild form of depression referred to as 'dysthymic mood'. The existence of this term indicates how the experiences of bipolar disorder overlap considerably with less severe problems.

Finally, there is very considerable overlap between the problems diagnosed as 'bipolar disorder' and problems that have been given other labels (by mental health professionals who are quite appropriately applying diagnostic rules). Around half of people diagnosed with borderline personality disorder have 'co-morbid' diagnoses of bipolar disorder (Barbato & Hafner, 1998), and there is considerable overlap between bipolar disorder and schizophrenia, anxiety disorders and disorders of substance use (Moller, 2003; Freeman et al., 2002; Regier et al., 1990).

These observations have led very many psychologists and psychiatrists to conclude first that diagnostic approaches have weaknesses – while they try to 'carve nature at the joints' (Plato in *Phaedrus*, 265d-266a), that runs into difficulty when there are no clear 'joints' between what is 'normal' and what constitutes a 'problem'.

Secondly, many psychologists and psychiatrists have stressed the overlap between bipolar experiences and normal life. That is, while it's clear that problems that severely disrupt a person's life need to be addressed, it makes more sense to discuss the degree to which a person is able to regulate their moods and behaviour (on a continuum) rather than to diagnose people in an all-or-nothing sense as being unable to regulate their moods (as opposed to being 'normal').

That means that sensible definitions of depressed mood recognise both the wisdom of identifying problems and of recognising that depression lies on a continuum from healthy well-being to serious problems, and sensible definitions of mania recognise both the wisdom of identifying a person's real problems and of recognising that mania lies on a continuum from healthy well-being, through hypomania to serious problems.

This 'continuum' approach is not a new idea – for decades, mental health professionals and researchers have talked about the idea that both depressive and hypomanic traits are seen on a spectrum across the general population(Jones & Bentall, 2006). This includes discussion of ideas such as hypomanic personality traits, but also a serious discussion of the links between such hypomanic traits and artistic or creative personalities (Simeonova et al., 2005; Andreasen, 1987, Santosa et al., 2007; Jamison, 1993). In a similar vein, psychologists have studied the phenomenon of *'peak experiences'* – when people experience mystical or ecstatic states, sometimes drug-induced, sometimes part of religious or mystical experience or sometimes part of everyday lives. These states, for many, seem similar to 'normal' hypomania (Maslow, 1972).

Section 2: How common are these experiences?

> **Key points**
> - These experiences are quite common - about 1 to 1.5 per cent of the population are likely to receive a diagnosis of bipolar disorder at some point in their life.
> - Elation and overactivity ('hypomania') are very common but only lead to problems – and therefore a diagnosis – in certain circumstances, for example if they alternate or co-exist with depression or if they lead the person to behave in a destructive way (for example, overspending). People can also experience problems if, when feeling elated, they temporarily develop unrealistic beliefs (for example, that they are a great leader), or start to perceive reality differently (for example, hearing voices when there is no-one there), become exhausted, feel out of control or are admitted to hospital.

2.1 Prevalence

About 1–1.5 per cent of the general population in the US and UK meet the criteria for a diagnosis of bipolar disorder (Weissman et al., 1996). Usually people receive the diagnosis in their early 20's, but there is some evidence that younger people, even a very few children, may experience these kinds of problems. Bipolar disorder is usually described as a lifelong mental health problem, because most people experience repeated episodes of mania or depression with most research studies reporting around 50–60 per cent of people relapsing within one year of recovery from a mood episode (Kessing et al., 2004; Gitlin et al., 1995; Soloman et al., 1995).

2.2 Mood swings

As noted in Section 1, highs and lows in mood are a feature of being human. But what about when people get changes in their mood and energy levels that are to such an extreme that they no longer feel like their normal selves? These kinds of mood swings are common in people who do not have bipolar disorder and who are not seeking help for them. For example, in a Swiss study of young adults who experienced highs in mood and energy that would be considered to be 'hypomanic' over half had no history of depression and therefore did not have bipolar disorder (Wiki & Angst, 1991). Similarly, in a study of undergraduate psychology students in the UK, a quarter of the sample reported a period of time when they were not their normal selves and had a cluster of experiences such as euphoric or irritable mood, reduced need for sleep and racing thoughts (Udachina & Mansell, 2007). High energy states and mood swings have also been reported in a wide range of individuals who do not have formal diagnoses of depression such as: naturally short sleepers (Monk et al., 2001), creative individuals (Furnham et al., 2008), and people with an anxiety disorder (Bowen et al., 2004).

There may be a good reason why these 'hypomanic' experiences are so prevalent – many people who experience them want to have them because they see them positively. For example, high moods can help them to perform at work and deal with other people (Seal et al., 2008). Here is one example from a female professional who has had four hypomanic episodes but has never had depression nor sought psychological treatment:

'I enjoy that feeling of being able to give out more – it's almost like a special offer at the supermarket, 10 per cent extra with your washing powder! I feel bigger and better. I think my husband finds it quite a positive thing really because I'm much easier to be with and I am I think probably entertaining and interesting too.'

<div align="right">Quoted in Seal et al., 2008</div>

2.3 Mood swings becoming a problem

This section explores the reasons why mania and hypomania can become problematic in bipolar disorder. Several studies have investigated the experiences reported by people in mania and found the most common symptom pattern is not euphoria/high mood but rather dysphoria (an unpleasant combination of depressed mood, anxiety and guilt) (Mansell & Pedley, 2008). When individuals experience a mixed state in which high and low moods combine there is particularly high risk of self-harming and suicidal ideation (Mansell & Pedley, 2008). For other people, the experience of the depression following on from periods of mania or hypomania can be the primary problem.

Even when mania is perceived positively by the individual it can have a negative impact on relationships with others. This can be at more subtle levels such as becoming more dominant in conversation but can also include getting into unnecessary arguments with others and even being physically confrontational. People can also act out of character in other ways during mania such as being sexually promiscuous, spending excessively or using large amounts of drugs or alcohol. This can be very challenging for other people and can lead to separation or divorce (Dore & Romans, 2001). Often when the person's mood drops again, they may experience feelings of shame for what they have said or done that was out of character (Lam et al., 1999). Some people may have unusual experiences (psychotic symptoms) during their highs such as hearing voices or they may develop strong beliefs that are not accepted by other people. For example, they may believe that they are a religious prophet or that they are fighting with the devil. These experiences can be very distressing and lead the person to worry that they will go 'crazy'. When the experience has passed it takes time to try to make sense of more unusual experiences (Lam et al., 1999; Lam et al., 2000; Bonney & Stickley, 2008).

One of the most common problems people with bipolar disorder experience is sleep disturbance. During periods of hypomania and mania, people are much more active and typically sleep less. At the end of this period, they may feel exhausted and low in energy, which can herald a period of low mood. A change in sleep may be one of the early warning signs of the beginning of an episode of mania or depression Wehr et al., 1987; Hudson et al., 1992).

'I can't sleep too much or too little, there has to be a balance. If I sleep too much it is an indication of low mood, and if I sleep too little it is an indication of high mood or mixed state. I have learnt to not ignore sleeping problems and force myself to follow a strict routine, hard as it may be. If I can't sleep I go to the doctor who gives me a short-term prescription for sleeping tablets.'

<div align="right">Karin Falk – service user</div>

Sleep disturbances also affect people's ability to concentrate and deal normally with day-to-day problems. This can leave individuals more vulnerable to the development of mood episodes even when trigger events seem relatively mild.

People who report more problems with their high moods often report that they feel that their moods are outside their own control (Mansell et al., 2008). This feeling can be compounded by the experience of psychotic symptoms in mania or depression. Understandably, feeling that one's own thoughts and feelings are out of control can be very frightening and lead to worry about what one might do as a result. This can be especially concerning for people if mood changes have led to risky behaviours in the past. Conversely, people who manage to have hypomanic experiences and do not develop bipolar disorder report greater awareness of and control over their high moods (Seal et al., 2008).

Many people with bipolar disorder are admitted to hospital at the peak of their high moods. Although the admission is usually designed to minimise risk and provide a place for effective treatment, many people find this a distressing experience. For example, some people are admitted against their wishes ('sectioned' which means being compulsorily admitted to hospital under a section of the Mental Health Act) because clinicians see them as being at risk. Whether people enter hospital voluntarily or against their wishes, many report that some hospital staff treat them in ways that feel patronising or belittling. This quote illustrates some of the stressors of going into hospital:

> *'The experience of being sectioned felt like social control rather than treatment for illness. My aim was to convince the staff that I was fine so that I could get out of hospital. It was nothing to do with getting better.*

> *'The staff just would not listen. I found it so frustrating to be in a situation where I was suddenly so patronised. I was being spoken to by nurses in the way I might address a two-year-old. This increasingly fed my frustration. How do you make yourself heard when no-one will listen and you have been put in hospital against your will? You may or may not have any time to pack. You may or may not have a comb- toothbrush, shampoo, never mind the collection of cosmetics you may be used to which help you feel "right" to face the world. What would you do if faced with that sort of loss of dignity? How would you make yourself heard? I'm not that proud of the ways I tried but through the experience of depot (injected medication against one's will), I felt like they broke my will if not my spirit. Depot was one of my most humiliating experiences of my life – and they wonder why people are depressed after a spell in hospital? Might it be post-traumatic stress?'*

> Joanne Hemmingfield – service user

Many people experience both the negative side of hypomania and some of its positive qualities. This understandably leads people to have ambivalent feelings about their highs, often wanting to find a way to retain them but to avoid the negative consequences. The above quote also reveals that some of the negative features are made more pronounced by other peoples' reactions. An important feature of therapy for bipolar disorder therefore involves helping to weigh up the pros and cons of hypomania for themselves to provide the opportunity to address ambivalent feelings about controlling periods of elevated mood.

Section 3: Development impact and course of bipolar

Key points

- Problems often start in late adolescence or early adulthood, and can affect people's development.
- In addition to episodes of extreme mood, some people experience ongoing mood difficulties.
- Research tends to focus on people who have ongoing problems and are in contact with services. This may have led to an overly negative view of how problems affect people, i.e. that they tend to recur.
- Despite the negative bias, the research still shows that overall 60 per cent of people who have problems do not experience 'relapse' and nearly half are able to return to their previous lifestyle in terms of job, social life, etc., over a two-year period.
- There are positive as well as negative aspects to these experiences. Many people with a diagnosis of bipolar – and people with similar experiences who have not received a diagnosis – have huge amounts of energy and are extremely creative and productive.

3.1 Onset of bipolar disorder

Problems with extreme mood states usually start in late adolescence or early adulthood – between the ages of 15 and 24. Younger adolescents can also sometimes experience problems, although their mood swings tend to be less extreme. These milder mood swings are sometimes referred to as 'cyclothymia' (Akiskal et al., 1977; Depue et all, 1998).

Late adolescence and early adulthood are, of course, crucial periods in our development. Adolescence is also the developmental stage where we develop key skills such as problem solving and decision making, and the ability to manage our own mood and feelings. During this period we also often make key life choices that shape our adult lives. Early signs of problems which might lead to bipolar disorder include mood instability, changes in behaviour such as taking more risks and impulsive acts, and periods of low mood and social withdrawal. These disturbances can interfere with the development of a person's identity, their friendships, and their career. Getting help early is important but can be difficult as sometimes it is hard to distinguish early signs of mood disturbance from normal adolescent behaviour.

3.2 What tends to happen over time

Many people experience ongoing problems often with episodes of mania and depression interspersed with periods of relative stability. However, this varies substantially between individuals and some people only experience a single episode of mania (Kessler, 1997). Even within one individual, the pattern can vary considerably over time, for example the length of time between episodes. Also, many people experience mood symptoms between mood episodes which can also be associated with significant distress and difficulties in day-to-day functioning (Judd et al., 2002; Judd et al., 2003).

3.3 Limitations of Research

Our understanding of what influences the course of bipolar disorder is hampered by the limitations of research studies. One important problem is that participants in research studies are often people who are in contact with mental health services over a number of years. Such studies therefore do not report on the many people with bipolar experiences who have never had contact with services or who leave services. It is likely that these people are experiencing very different challenges and consequences from their mood swings. Furthermore, the majority of large-scale studies are funded by pharmaceutical companies which have a vested interest in maintaining a view of people with a diagnosis of bipolar disorder as consistently reliant on medication. Yet this perspective underplays the achievements of people who manage their moods well and cope with little reliance on clinical services. Bearing these limitations in mind, research across a number of studies suggests that for many people adherence to prescribed medication helps to delay relapse (Geddes et al., 2004). Across studies, within two years after a mood episode, around 60 per cent do not relapse and around 40 per cent achieve a functional recovery (e.g. restore most social and work commitments (Goldberg et al., 1995; Tohen et al., 2003). The rates of recurrence increase over longer follow-up periods, yet in studies spanning 15 years or more, around a third of people followed up achieved a good level of functioning (Coryell et al., 1998). Consistently, symptoms of depression are closely linked to poorer functioning whether or not these reach the criteria for a depressive episode. Concurrent problems such as severe anxiety (Boylan et al., 2004) and drug and alcohol addiction (Levin & Hennessy, 2004) are associated with poorer recovery and so deserve attention (Kessler et al., 1997). Generally, the better a person's functioning before a mood episode, the better they recover (Gitlin et al., 1995).

3.4 Positive impact

Many individuals also describe positive aspects of their bipolar experiences, including increased sense of autonomy, social connectedness, and creativity (Jamison et al., 1980). In this context it is frequently quoted that many famous and distinguished people suffer from bipolar disorder (Pendulum, 2009) and that many would not like to exchange the relative distress caused by their mood difficulties for a life without the positive aspects (Jamison, 1996).

'It is true that I detest my depressions. I cannot make my thoughts work – it is like thinking through treacle. When my depression is at its worst I cannot make even the simplest choices about things like what to wear. I cannot follow conversations, I cannot drive, I cannot work, I am totally unrewarding to be with … At these times I don't feel miserable or unhappy in the colloquial use of the term 'depressed'. I know I am useless and worthless, but I don't feel anything very much at all … However, I would also contend that my manic depression is responsible for a great deal of the positive energy and creativity in my life. For a great deal of the time I am blessed with buckets of energy – more than most people. I love to work hard. My thoughts work like liquid crystal. I can see what things mean quickly and clearly. Ideas – generally good ideas – come to me with little or no effort. I know my surfeit of energy can be irritating to others, but my brain does all the things I want it to very efficiently and I am proud of it. I feel extremely engaged with, and part of, life.'

Rachel Perkins (Perkins, 1999)

3.5 Alternative labels

Many people who have been given a diagnosis of bipolar disorder have also been given other diagnoses at some point. The most common are anxiety, depression and psychosis (Hilty et al., 1999). Personality disorders are also commonly diagnosed. This array of labels can be very confusing and contribute to the difficulties people have in making sense of their experiences. It can also lead to changes in the suggested course of treatment, especially medication. However, the use of multiple labels is simply due to the wide range of emotional difficulties that often accompany mood swings, and the fact that people's problems don't come in neat categories. Anxiety is especially common, and psychotic experiences are also common – especially during mania. In some individuals experiences of paranoia can develop during periods of grandiosity, for instance from a fear that others wish to harm or hurt you because they are jealous of your special powers.

Section 4: Problems with 'diagnosis' in mental health

> **Key points**
> - There is a debate about whether 'diagnosis' is useful in mental health.
> - Mental health diagnoses are defined by lists of 'symptoms' (experiences and behaviours) and do not indicate anything about cause.
> - There is a large overlap between diagnoses.
> - People may meet criteria for different diagnoses at different times in their lives.
> - Among people with a diagnosis of bipolar disorder, there is much variation in how frequently they experience problems and in what treatments are helpful. This suggests that the diagnostic category fails to capture some important differences between individuals.
> - Clinicians often disagree about whether someone fits the criteria for a diagnosis of bipolar disorder.

4.1 Diagnoses

'When I was diagnosed it was like a light going on – it meant I wasn't just a mad horrible person.'

Amy Sanderson Diedra

'It was quite distressing really cause I knew … that bipolar disorder was a long-term, chronic, incurable condition, so it's like being given a diagnosis of diabetes or something like that really … because I'm not going to get rid of it you know.'

Service user

Diagnostic approaches to understanding psychological difficulties are widely used as a basis for research and for making decisions about treatment. Physiological, emotional, behavioural and mental experiences seen to be part of a disorder are termed symptoms, and diagnostic decisions are made on the basis of the pattern of symptoms observed in a particular individual.

Diagnoses are helpful when they can accurately predict what is likely to happen to someone with the diagnosis, and what is likely to make their symptoms better or worse. A diagnostic label can also be an efficient way of communicating a great deal of information about what an individual is experiencing. Some people also find it helpful to have a diagnosis. However, this relies upon diagnoses being reliable, in that we should be able to agree upon who does and does not 'fit' a given diagnosis. It should also be valid in that it relates to a real phenomenon in everyday life.

4.1.1 Reliability of psychiatric diagnoses

One way to investigate the reliability of a diagnostic category is to look at whether clinicians tend to agree on that which best applies to a given person's experiences. Historically, low rates of clinician agreement for psychiatric diagnoses led to calls for improved diagnostic systems (Beck et al., 1962; Spitzer & Fleiss, 1974). Nevertheless, levels of diagnostic

agreement in clinical practice remain highly variable with respect to bipolar disorder (Carta & Angst, 2005; Dubicka et al., 2008; Zimmerman et al., 2008).

4.1.2 Validity of psychiatric diagnoses

For a diagnosis to be considered valid it should help clinicians to specify which treatments will be helpful. However, there is no overwhelming consensus about the treatment implications of a bipolar diagnosis. For instance, many individuals with a diagnosis of bipolar disorder find the use of medications beneficial, but vary widely in the combination of medications that works for them. Additionally, a significant proportion of individuals report finding that medication is not helpful in managing their bipolar disorder. The consistent failure to find treatments that work for everyone with a diagnosis of bipolar disorder suggests that this diagnostic category fails to capture some important differences between individuals.

For a diagnosis to be valid it should also tell us what the individual can expect in terms of the symptoms they will experience in future. For instance, a diagnosis of bipolar disorder suggests a vulnerability to more episodes occurring in the future. Yet looking at individual differences in patterns of symptoms across the lifespan, not everyone with a diagnosis of bipolar disorder is equally vulnerable to further episodes. This raises the question of whether, once a person receives a diagnosis of bipolar disorder, this diagnosis remains equally valid and informative across his or her lifetime.

A key criticism that is often levelled at the diagnostic system is that it makes artificial divisions between sets of experiences that are actually more continuous in reality. For example, most people experience ups and downs in mood to a greater or lesser extent, and there is ongoing debate about which patterns of mood cycling fall within the bounds of the diagnostic category of bipolar disorder. People often talk of a Bipolar Spectrum encompassing many different patterns of mood cycling (Akiskal et al., 2000; Phelps et al., 2008), yet this raises fresh questions about where the 'ends' of this spectrum should lie.

Many 'bipolar symptoms' also occur within a number of different psychiatric diagnoses. A good example is what are thought of as 'psychotic' experiences. Examples of these might be seeing everything in very bright colours, hearing voices or developing beliefs that others do not share – for example, that the person is the Messiah. Whilst these often occur within the context of the diagnostic category of schizophrenia, it has been estimated that over half of people with a diagnosis of bipolar disorder experience symptoms of psychosis within their lifetime (Dunayevich & Keck, 2000). Indeed, the overlap between bipolar disorder and schizophrenia causes some difficulties for diagnosis. The category of schizoaffective disorder was intended to account for individuals whose experiences seemed to sit between the two conditions. However, the reliability of this diagnosis is relatively poor (Vollmer-Larsen et al., 2006), suggesting that clinicians find it difficult to determine which sets or combinations of symptoms belong more to one category than another, particularly when symptoms typical of both bipolar disorder and schizophrenia are present. The distinctions between these categories seem even more blurred when we consider that many individuals meet criteria for different conditions at different times in their lives, and this appears to be the case for individuals who have been diagnosed with bipolar disorder (Chen et al., 1998).

Finally, it is often incorrectly assumed that a diagnosis tells us about the cause of a disorder. In fact standard systems of psychiatric diagnosis were deliberately designed without reference to the underlying causes of the symptoms (APA, 2000). Therefore it would be a mistake to assume that the symptoms within a single diagnostic category are the result of a common cause. For example it has been argued that different factors lead to vulnerability for mania and vulnerability for depression, yet the two co-occur in some individuals, leading them to be diagnosed with bipolar disorder (Johnson et al., 2006). Thus it may be the case that the diagnostic category of bipolar disorder does not relate to something 'real' in nature, namely a single, discrete condition.

Part 2: Causes

As with other human characteristics, there is an ongoing debate about what causes the tendency to extreme mood states that can lead to a diagnosis of bipolar disorder. Inherited tendencies, life experiences and the way we see the world and interpret events can all play a role. No-one can ever know for sure exactly what elements combined together to cause problems for a particular individual. Similarly, people who have themselves received the diagnosis hold a wide variety of views about the nature and causes of their difficulties (Van der Gucht, 2009).

Section 5: Life/social circumstances and bipolar experiences

Key points
- People in difficult life circumstances are much more likely to experience all kinds of mental health problems.
- The same applies to people who have had a difficult childhood.
- Having a supportive network of family and friends can make it less likely that mood problems will return. Conversely people are more likely to experience ongoing problems if their family members are either highly critical or overprotective towards them.
- Therapists should therefore consider family as well as individual therapy work in bipolar disorder. In either case it is important to pay attention to life circumstances as well as what the individual themselves might be able to do differently.

5.1 Family characteristics

Life circumstances and family characteristics can influence not only whether or not someone experiences the problems which can lead to a diagnosis of bipolar disorder but also how the problems develop over time. It can of course also work the other way round: having a member who experiences mood problems can affect family and social relationships. Two main areas are particularly important. Firstly, people in families with overly protective or critical patterns of family communication (known as high expressed emotion; Miklowitz et al., 1988) are at increased risk for future mood episodes. These patterns of communication can be addressed using family based psychological help (Ryan et al., 2005; Weinstock et al., 2006). Secondly, the range of genuine friendships and other sources of informal support that the person has access to (social support and social networks; Johnson et al., 1999; 2003) can be crucially important.

5.2 Family functioning

Expressed emotion research began with work in families of people diagnosed with schizophrenia. This showed that when families were critical or overprotective towards their relative (high levels of expressed emotion: high EE) episodes of acute schizophrenia were more common. Essentially the same findings have been reported in relation to bipolar disorder with people having more relapses of mania or depression and gaining fewer benefits from drug treatment if they live in high EE environments (Honig et al., 1997; Miklowitz et al., 1988; Priebe et al., 1989).

It is not necessarily easy for either the individual or their families to deal with bipolar experiences. It is therefore not surprising that there are sometimes problems in families. In many cases the protectiveness or criticisms of family members represent their efforts to cope with day-to-day life. It is also important to note that these patterns can be changed through family therapy which also helps improve outcomes for the individual with a bipolar diagnosis including reducing risk of requiring hospital admissions and improving day to day functioning (Clarkin et al., 1998; Miklowitz & Goldstein, 1990; Miklowitz et al., 2000; Rea et al., 2003).

5.3 Friendships and social support

Another key aspect related to family functioning is that of general social integration and the ability to make best use of social networks. People's definition of adequate social support varies from individual to individual (Johnson et al., 1999, 2003; Morriss et al., 2007; Romans, 1992). So for some people a small number of close friends or family members can be regarded as all that is necessary, whereas for others a broad ranging network of family, friends, colleagues and acquaintances are needed. In either case people typically benefit from believing that they can access both practical and emotional support when it is required (Harris et al., 1999).

Several studies have examined the relationship between social support and outcomes in bipolar disorder. Overall, these reports show that higher levels of social support are associated with better outcomes including fewer relapses of mania or depression and better recovery if mood episodes do happen (O'Connell et al., 1991; Johnson et al., 2003; Stefos et al., 1996). Good social relationships are also associated with greater likelihood of the person with a bipolar diagnosis gaining employment and functioning better in the work environment (Hammen et al., 2000; Wilkins, 2004).

5.4 Life events

Individuals who have had more stressful life experiences seem to be at more risk for the development of bipolar disorder. Stressful life experiences seem to be particularly important in triggering earlier episodes of mania or depression (Ambelas, 1987). There is also evidence that individuals with a bipolar diagnosis who had greater problems in their childhood have more frequent problems with mood episodes as adults (Dienes et al., 2006). Also, people with a vulnerability to extreme mood states sometimes find day-to-day problems more stressful than do individuals with no bipolar diagnosis (McPherson et al., 1993; Myin-Germeys et al., 2003). The impact of stressful life experiences is likely to also be linked to how people think about their situations and also to having access to social support.

In addition to general life events there is increasing evidence that a proportion of people with a diagnosis of bipolar disorder have experienced traumatic events in childhood. Helping individuals overcome the psychological consequences of such events can therefore form an important part of psychological therapies for some people. Stressful life events also influence people's outcomes after bipolar disorder has been diagnosed. So, research has shown that higher levels of life stress are linked to higher rates of relapse and slower recovery from mood episodes in individuals with a bipolar diagnosis (Ellicott et al., 1990; Johnson & Miller, 1997).

Section 6: Psychological factors in bipolar experiences

> **Key points**
> - When people are depressed, they tend to see the negative in everything, including themselves, and this can lead to a vicious cycle keeping the depression going. Conversely when people are very active and experiencing elation, there is a natural desire to see this as 'the real me' and to want to do even more. There is evidence that these 'thinking styles' are particularly pronounced for people whose moods are extreme enough to attract a diagnosis of bipolar disorder.
> - There is evidence that some people with a diagnosis of bipolar disorder show these more extreme thinking styles even at times when they are not experiencing very high or low mood.
> - People can learn to 'catch' this kind of thinking developing and take action, for example making themselves rest when their thoughts begin to race.

6.1 Psychological perspective

There is sometimes a false separation made between biological and psychological explanations of bipolar disorder. It is important to remember that biological changes can affect psychological states and psychological states can affect biological states. Every thought or emotion also involves chemical changes in the brain. So both levels of explanation are relevant. A great deal has been written about biological aspects of bipolar disorder, for example about brain chemistry and medication. This section aims to provide a psychological perspective.

6.2 Positive and negative thinking styles

Some people with a diagnosis of bipolar disorder appear to show certain characteristic patterns of thinking. These have been termed 'thinking styles' by psychologists and include both positive and negative styles.

Negative thinking styles can include a tendency to self blame when things go wrong and to see the self, other people and the wider world in a negative light (Alloy et al., 1999; Jones et al., 2005). Another factor is a tendency to ruminate when feeling low, which can make the person feel even worse. These styles are most prominent during periods of low mood and are often similar to thinking styles that are characteristic of people who experience depression alone. A contrast with individuals who experience only depression is that some people with a diagnosis of bipolar disorder also tend to engage in risk taking behaviour in response to low mood. This may include risky sexual behaviour, use of alcohol, street drugs or taking other health risks (Thomas et al., 2007).

Positive thinking styles are also often prominent in people diagnosed with bipolar disorder. However, just as negative styles are clearest when mood is low, positive styles are clearest when mood is higher. For instance, when an individual experiences increases in alertness or activity or reduced need to sleep, some people with bipolar disorder are more likely to interpret these as reflecting their true self rather than as being caused by external events. This positive appraisal style is likely to cause individuals to engage in more behaviours (such as taking on new challenges, working harder, taking less rest) when their mood starts going up. This can increase the likelihood of mania or hypomania in the first instance and

can lead subsequently to depression for some people if they cannot meet the commitments they have taken on in elevated mood (Jones et al., 2006).

Some people appear to have these 'thinking styles' even between episodes, and this can leave them somewhat vulnerable to further episodes of extreme mood when faced with significant challenges or difficulties. It is likely that therapeutic work which addresses these styles serves to reduce risk of experiencing future mood episodes.

Another feature of thinking styles is their tendency to fluctuate. Specifically, the way the person thinks about themselves can change substantially across mood episodes (Bentall et al., 2005). Even between episodes people often experience rapid changes in self esteem and mood. People can also experience contrasting thinking styles at the same time. So when experiencing an elevation of mood someone might on the one hand feel this is a marvellous opportunity to get on with all the tasks they wanted to do before they became ill, but on the other hand feel fearful that their mood might escalate into an episode requiring hospitalisation. The tension between these possibilities can clearly be a source of stress in its own right (Jones, 2006).

There is also evidence that some people with a diagnosis of bipolar disorder have difficulties with decision making and planning. These people are more likely than others to make more impulsive decisions and less likely to take into account future consequences of decision making. These tendencies can sometimes interact with the thinking styles noted above and increase risk for mood episodes (Clark et al., 2002; Murphy et al., 2001, 1999; Swann et al., 2004).

6.3 Psychological benefits

It is important to note that not all psychological factors in 'bipolar disorder' involve a deficit or cost. There are many positive psychological factors associated with a bipolar diagnosis, for example increased creativity, sparks of inspiration, feelings of optimism, increased motivation and productivity. Many people with a diagnosis of bipolar disorder are very creative and high achievers(Jamison et al., 1980; Johnson, 2005).

Bipolar experiences involve a mix of positive and negative psychological factors. The extent to which these factors dominate or can be harnessed depends on the coping styles used. Although some individuals with the diagnosis appear to adopt unhelpful coping styles at times, at other times they appear to use more helpful coping approaches as well. Effective coping styles may involve learning to recognise triggers or early warning signs such as sleep changes or increased agitation. Psychological therapies can help individuals enhance their use of these helpful approaches and reduce the dominance of the ruminative or risk taking styles discussed earlier.

A person's experience and behaviour is never influenced purely by one factor. Any experience involves an interaction of biological, psychological and social factors. There is a reciprocal relationship between each of these factors and the exact nature of these relationships will be unique to each individual.

Section 7: Biological factors in bipolar disorders

> **Key points**
> - Someone with a sibling or parent with a diagnosis of bipolar disorder is over ten times more likely to receive the diagnosis themselves compared to someone from an unaffected family. Whilst there may be a number of reasons for this, it does suggest that people's genetic make-up may play a role. However, attempts to isolate contributing genes have, as yet, proved unsuccessful.
> - There is evidence that certain neurotransmitters (brain chemicals) – for example serotonin and dopamine – may play a role. However, all thoughts and emotions involve chemical changes in the brain and cause-and-effect relationships are unclear.
> - Some people with a diagnosis of bipolar disorder appear to have slight differences in brain structure and function. However, again, cause-and-effect relationships are unclear: for example, some differences could be the result of prolonged use of certain medication.
> - The varying nature of people's experiences, both within and between individuals, indicates that they are likely to be the result of a combination of factors that interact across time.

7.1 Genetic factors

Bipolar disorder does seem to run in families, in so much as individuals with a sibling or parent who has this diagnosis are over ten times more likely to be given this diagnosis themselves than someone from an unaffected family (Mortensen, 2003). Although it is often argued that this increased likelihood may be due the presence of genetic factors it is likely to also reflect other factors that family members might share, such as the occurrence of stressful life events, the quality of their physical environment and learned ways of managing difficult experiences and feelings.

To discover the extent of the genetic influence, studies try to separate biological from environmental influences. One way to do this is to study individuals with bipolar disorder who have been adopted, and to compare rates of bipolar disorder of their biological versus their adopted relatives. Another way is to study the identical or non-identical twins of people with bipolar disorder. Although researchers reporting such studies have argued for an important genetic contribution to bipolar disorder (McGuffin et al., 2003) there is an ongoing debate about the significance of genetic factors. For instance attempts to make links between particular genes and bipolar disorder are not straightforward. Section 4 outlined some of the problems with taking a diagnostic approach to bipolar disorder, and these issues have an impact on our understanding of genetic studies. If bipolar disorder is not a single entity but a number of symptoms that are related but distinct, then even if genetic factors are important there may be multiple genes that predispose to overlapping but separable symptoms or experiences that are commonly seen as part of bipolar disorder (Hayden & Nurnberger, 2006). Additionally, a number of genetic markers reported for bipolar disorder have also been identified in relation to schizophrenia suggesting a lack of specificity, consistent with problems of diagnosis considered earlier (Berrettini, 2004; Blackwood et al., 2007). It is generally accepted that both genetic and environmental factors contribute to a person's likelihood of developing bipolar disorder, yet in some ways

this is a misleading statement as it implies that the two work separately. Instead it seems that our genes and our environment interact to shape the overall outcome. For example, a gene may express its effects only if the individual experiences certain events in life. Likewise, our genetic make-up might lead us seek out particular experiences or environments.

In summary genetic factors appear to play an important role in determining whether someone will experience aspects of bipolar disorder in his or her lifetime. However, by no means do they provide the full picture, and it is likely that our experiences and the settings in which we live also make an important contribution. This report does not attempt to resolve this debate but highlights the importance of psychological factors in bipolar disorder which are often neglected in the wider literature.

7.2 Neurochemical changes

Given the wide range of drugs that can impact on mania and depression it would appear unlikely that a single neurochemical (brain chemical) holds the key to understanding their cause. Neurotransmitters (brain chemicals) targeted by medications that are frequently prescribed to people diagnosed with bipolar disorder include serotonin, norepinephrine and dopamine. However, neurochemicals interact with one another in complex ways, thus we cannot assume that just because an effective medication is thought to target a particular neurotransmitter, this brain chemical must play a key role in causing or maintaining the symptoms of mania or depression. Despite the advances that have been made in this field of science it remains the case that we have no way of directly and unambiguously measuring the sequence of neurochemical events that leads up to periods of depression or mania. Even if we did have such a technique, this would not allow us to say with certainty that this sequence of events actually causes the emergence of depressive or manic symptoms, rather than merely accompanying it.

7.3 Brain structure

It does appear that some people with a diagnosis of bipolar disorder show some slight differences in brain structure (Kempton et al., 2008). There is also evidence that some brain areas may function differently in people with a diagnosis of bipolar disorder when performing specific tasks, for example tasks involving sustained attention (Strakowski et al., 2004).

Alternative explanations for findings of differences in brain structure are that changes to brain structure occur as a direct or indirect consequence of experiencing bipolar episodes, or that both vulnerability to such episodes and differences in brain structure are the result of a third, underlying factor. Some studies have looked at whether differences in brain structure or functioning are apparent early on, for example in young people who have been diagnosed with bipolar disorder. Whilst such studies can give us an idea of which differences in brain structure and function seem to be present earlier versus later in the lives of people diagnosed with bipolar disorder they cannot conclusively rule out the alternative explanations described previously. Neither can they exclude the possibility that there may be subtle differences between people whose mood problems start early on in their lives compared to those whose difficulties start later (DelBello et al., 2006).

7.4 Combination of causes

A great deal of research has investigated possible biological causes of bipolar disorder. Whilst significant advances have been made in our understanding of how vulnerability to bipolar disorder might be increased, for example by inheriting particular genes, our knowledge of biological factors cannot tell us with certainty who will or will not develop bipolar disorder, and the chain of events by which this occurs.

Therefore to think in terms of a single cause is probably incorrect. Instead it is likely that the experiences labelled as being part of bipolar disorder are the result of a combination of factors that interact with each other across time.

Part 3: Help and treatment

Section 8: Assessment

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Key points
- The person experiencing mood changes, or their family and friends, are usually the first to notice problems with mood and typically visit their GP. Elation and overactivity may initially not be seen as a problem and therefore not reported.
- If the GP thinks that the person's experiences may fit the criteria for a diagnosis of bipolar disorder, they are likely to be referred for assessment by secondary care services.
- It is important that this is an in-depth assessment and covers the person's life circumstances, their view of the problem, and likely triggers as well as coping strategies, strengths and sources of support.
- It is common for assessment to be an ongoing process and for people to be given various diagnoses and psychological therapies before an agreed diagnosis is made. On average, this process lasts five years.

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8.1 Self assessment

The aim of assessment is to understand the nature of a problem and develop a plan to address the problem. For people experiencing bipolar disorder, assessment may occur in different ways.

Many people identify themselves as having problems with their moods and may even identify their experiences as bipolar disorder. There is increasingly more information about mental health problems available through the media and internet, including sites which provide checklist-style assessments to help people find out if they are likely to meet diagnostic criteria for a mood disorder. Common triggers for searching for such information are prolonged periods of depression or anxiety or sleep disturbance. Friends and family may be the first to identify and begin to assess a problem. Their concern may be raised by more observable behaviour changes such as reduced activity associated with depression, or increased activity or unusual behaviour linked to hypomania.

8.2 Primary care

The GP is often the first point for individuals seeking help. The GP is able to carry out a routine assessment of mood, but often the focus is on depression and it is common for experiences of hypomania to be missed. This is possibly because many people do not experience hypomania as a problem and therefore don't report it. This omission can lead to inappropriate treatment, such as a prescription of antidepressants for depressed mood, which can act as a trigger for mania in people with bipolar disorder. In some instances, the GP will provide support and mood stabilising medication; however, once a bipolar presentation is identified, the majority of people are referred to secondary care services where they are assessed by a team of clinicians including a psychiatrist and mental health worker.

8.3 Secondary care

Assessment should always be a collaborative process in which the person with bipolar experiences and the clinician work together to build a clear picture. Although it can feel repetitive to have a second assessment, this is often in much greater detail and should include the following:

- Goals and aims: identification of what the individual hopes to work on.
- Current difficulties.
- Triggers and early warning signs for changes in mood.
- A review of all previous mood episodes and symptoms in between.
- Current and past sources of stress.
- Individual strengths.
- Coping strategies – including alcohol/substance use.
- Individual's own understanding or model of their difficulties and why they have occurred.
- Support networks.
- Family history – particularly of mental health problems.
- General physical and mental health and well-being – current and historical.
- Risk issues.

Given the breadth of assessment this can take some time to complete. The information is very personal so it is important for the clinicians to take some time to build up trust and to provide a safe and confidential context to the assessment. Where appropriate, it can help to involve a friend/relative to provide additional detail and support. Most of the information is collected through informal clinical interviews. However, in some instances standardised questionnaires may be used. These allow particular experiences to be measured on a continuum and compared either to the general population, or more often, used as a measure of change over time.

8.4 Diagnosis

The aim of assessment should be to help build a coherent understanding of experiences and to devise effective strategies to reduce distress or risk. Part of this may involve making a clinical diagnosis, but this should not be the sole purpose of the assessment. There is no definitive objective test for whether or not someone has bipolar disorder. The diagnosis is a 'functional diagnosis', i.e. it is given if a list of criteria are met (see Section 1).

For some people this diagnosis can be very helpful:

> *'I think I prefer my illness having a name (bipolar) because it makes me feel less lonely, and I know that there are other people experiencing my kind of misery. And that people live through my illness and make a meaningful existence with it. But I also have to be careful not to adopt the sick role, since I know I would just give up if I did that.'*

> Karin Falk – service user

Others experience diagnosis as stigmatising and unhelpful, and feel that it does not help them understand their difficulties or how to manage them.

'It is more mental illness per se than bipolar itself that is stigmatising. Public understanding of mental illness is very poor. I know that I contribute positively to society and that I am a good parent. I always allow people to get to know me well before I tell them my mental health history so that I can then provide a model of recovery to them and hopefully one that is different from that portrayed in much of the media.'

<div align="right">Service user</div>

8.5 Risk assessment

Specific kinds of assessment are carried out to identify risk. Risk may take the form of deliberate harm, neglect or vulnerability and may apply to self or others. Clinicians have a legal responsibility to act to prevent harm where possible. Therefore they have to ask questions and explore any thoughts or behaviours that may be associated with harm. Common examples include asking about thoughts of harming yourself or suicide. This kind of assessment should lead to an agreed plan to reduce any risk identified, which may include increased clinical support or respite care. For people who are responsible for looking after others, e.g. children or elderly relatives, the assessment should also cover any difficulties in carrying out this role and agree a plan of support where difficulties are identified.

8.5.1 Difficulties in assessment

The assessment of bipolar experiences can be complicated by a number of factors. Firstly, bipolar experiences are often initially misidentified as unipolar, i.e. the depression is recognised, but the (hypo)manic mood states are missed. Depression is commonly experienced by people as a problem and something for which they seek help, in contrast to hypomania which may be experienced as very positive and therefore not raised in the clinical assessment. The initial mood episode in bipolar disorder is most commonly depression. Clinicians have more difficulty in assessing hypomania than depression, sometimes because it is inadequately explored in the interview, and other times because it can be difficult to differentiate from normal behaviour of peers, e.g. adolescent populations. Secondly, there are some problems which can look very like bipolar experiences, but have different underlying causes including: head injury/trauma/tumor/ diabetes/thyroid disorders/AIDS/MS/PD/alcohol/substance use, etc. Consequently, it is common for assessment to be an ongoing process and for people to be given various diagnoses, explanations and therapies for their difficulties. The average time from onset to a correct diagnosis is approximately 5–10 years (Evands, 2000; NAMI, 2008). The average time to effective treatment is not known.

8.5.2 The importance cultural context

People vary in the extent to which expressions of distress are regarded as appropriate. If cultural aspects of these differences are ignored there is a risk that such expressions might be interpreted as mental illness. This is also a danger with religious and spiritual beliefs and beliefs about spirit possession. There is evidence that such misunderstandings are common (Jarvis, 1998; McKenzie, 1999). Part of the reason for this is that few mental health workers currently receive much training in cultural sensitivity, and there is an urgent need for such training. Mainstream services should also make links with local voluntary sector groups that have more expertise in this area. It is also well documented

that the effects of racism are likely to increase vulnerability to developing mental health problems (Jarvis, 1998).

The importance of taking cultural factors into account:

> *'I don't think they treat black people the same as they treat white people.… We have a different culture from white people, and because we talk loud and we laugh out loud – our behaviour is more loud than white people – they think it is mental illness.'*

<div align="right">Media, 1987.</div>

Section 9: Self management

<div style="border:1px solid purple">

Key points
- Over time, many people learn to recognise the 'warning signs' that their mood may be going up or down, and what they can do to prevent things worsening.
- The opportunity to talk things through with a mental health worker or in a self-help group can aid this process greatly.

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9.1 Taking charge of your health

Self management can take many forms. However, a key defining principle is that in self management the person with bipolar experiences is actively involved in making decisions about their own mental health. In practice everyone self manages to some extent. Even decisions such as whether or not to attend a clinical appointment are self management decisions. Service user groups for bipolar disorder, such as MDF the Bipolar Organisation (formerly known as the Manic Depression Fellowship), have actively supported self management approaches. These have proved popular with many people with experience of bipolar disorder. Self management approaches often involve learning to identify ways of dealing with ups and downs of mood that are helpful and less helpful for the individual.

Self management need not mean 'sole management'. Many people who actively self manage work with mental health professionals and their families to optimise their mental health. Self management also does not mean that the individual needs to take the blame if they then experience problems with their mental health. Even excellent self management approaches can sometimes be overwhelmed by events.

If people are going to self manage they need the necessary information and skills. Often people have many of these already but may have gaps in knowledge that can be addressed with self help information or through guidance from mental health workers or support groups. Often self management works well when there is explicit acceptance of the expertise and experience of both service providers and service users which can help people to make informed choices about the treatments and approaches they wish to pursue to manage their own health and well-being.

9.2 Beliefs about health problems and self management

The ways in which people think about their bipolar experiences can have a substantial impact on how they engage in self management. For instance, if someone is told that they have a lifelong biological disorder over which they have little or no control they are likely to make different decisions than someone who sees their bipolar experiences as an aspect of their personality over which they can have substantial control.

9.3 Things that can hinder effective self management

Although self management is widely endorsed in the NHS, such as through the NHS Expert Patient Programme (Donaldson, 2006), this is not always the case. Some clinicians do not welcome people attending appointments who have clear ideas for their own care as they see it as their role to be the 'expert'. Therefore good self management will often be aided by training and support for both clinicians and service users.

Even when professionals are supportive of self management, this can be difficult to achieve if the individual is fearful or avoidant of taking responsibility for their bipolar experiences. Conversely if the individual does not see any of their bipolar experiences as problematic, even if some of them are risky, they will be reluctant to engage in formal self management approaches. This is therefore not an approach to be forced on people but to be discussed with each individual according to their individual needs and wishes.

9.4 Advance directives

Advance directives can be used to specify what forms of treatment a person wants to have (and/or to avoid). These are particularly important when someone is admitted to hospital especially if they are deemed to have temporarily lost capacity to make self care decisions under the terms of the Mental Capacity Act 2005. The Act explicitly identifies the role of advance directives in allowing people to continue to influence treatment decisions during hospital admissions. Often advance directives are drawn up in collaboration between the individual and their clinicians. This can be very helpful especially when it is a truly collaborative process.

9.5 Things that can support self management

When services work with people with bipolar experiences as 'co-managers' this supports self management and contrasts with more 'paternalistic order-following' approaches to treatment which would have the opposite effect. Indeed, services which operate in this way have been shown to be both popular and effective (Bauer et al., 2006). Consistent with the Expert Patient Programme (Donaldson, 2006), wider recruitment of service users who have the confidence and experience to help others may encourage services to develop increasingly pro-self management approaches. This will allow services to see people with bipolar experiences as experienced partners in the process of health care, instead of as inexperienced recipients of treatment (Lorig, 1993).

MDF the Bipolar Organisation (formerly known as the Manic Depression Fellowship) has developed and implemented self-management programmes for the past decade which are organised and delivered entirely by people with a diagnosis of bipolar disorder, rather than by professionals. These self management programmes are very successful and could usefully be rolled out further.

9.6 Self management self help resources (see Appendix)

Section 10: Psychological therapies for bipolar experiences

> **Key points**
> - Psychological therapies which can help include educational groups, cognitive behavioural therapy, interpersonal and social rhythm therapy and family focused therapy. This report describes these forms of help, which are usually offered over several months or longer and can greatly assist the person in developing skills to reduce the risk of further episodes.
> - All these therapies give the person the opportunity to discuss their experiences in a calm and nonjudgmental atmosphere, help them to work out what causes their problems and keeps them going, and assist the person to develop strategies for preventing the problems returning.
> - It is important to tailor therapies to fit the individual and reassess and revise the approach as circumstances change and develop.
> - Despite the popularity of psychological therapies and the evidence for their effectiveness, only a minority of mental health service users are currently able to access them. This needs to change.

10.1 Aims of therapies

The main aim of most psychological therapies is to help individuals to develop strategies that will reduce the chances of them experiencing future episodes of mania or depression. Typically these therapies are most effective when offered at times when people are not experiencing a period of extremely high or low mood. Although reducing the risk of future mood episodes is a reasonable aim, it is important to acknowledge that not all mood episodes are the same. Also many people experience some mood problems when not fully depressed or manic. So, often the contributions that psychological therapies make to day-to-day life between episodes are actually as important as their impact on the likelihood of future episodes. In line with this view, the work of the recovery movements has highlighted that recovery may not necessarily mean having no symptoms, but may be better viewed as a process of working towards valued life goals (See Part 4 for a discussion of recovery in more depth).

There are a number of different forms of structured psychological therapy for which there is scientific evidence. These include:
1) group psychoeducation;
2) individual cognitive behaviour therapy;
3) interpersonal and social rhythm therapy; and
4) family focused therapy.

In addition, research is currently investigating the efficacy of schema therapy in bipolar disorder (Ball et al., 2006). Although there are differences in emphasis within these therapies they all contain elements of psychoeducation, consider the role of instability of behaviour and sleep patterns and work towards developing skills to reduce the risk of further mood episodes. All are also quite extensive, usually lasting six months or more, and are delivered by clinicians with specific training.

One of the most important aspects of psychological therapies is psychoeducation. This involves a thorough discussion of bipolar experiences and the potentially helpful

approaches to remaining well. Psychoeducation can be very helpful if it is delivered in a collaborative style building on the clients' expertise and enhancing their sense of control over experiences through understanding more about what causes them. To do this effectively requires that the clinician devote significant time to understanding and mapping the client's history of mood experiences so that psychoeducational input can be individually tailored. In contrast, psychoeducation is likely to be much less effective, or even off-putting for the client, if it is delivered in an instructive style in which the clinician takes an expert role and expects the client to be a passive recipient of information. The clinician should be aware that they are not the expert on the client's experience and it is not only the client who can learn from the therapy.

> *'What matters the most and touches me the most in a mental health worker is if they are able to share a little about themselves, or just show some sign that they are just human, yet still maintain professional boundaries. I much more respect a professional who admits lack of knowledge to a question than somebody who tries to cover up their ignorance with some mumbo jumbo. I would much prefer to have somebody inexperienced but warm than someone experienced and cold, which is the way it usually goes in my experience.'*

<div align="right">Karin Falk – service user</div>

10.2 Types of therapy

A primary focus of cognitive behaviour therapy (CBT) is around understanding the links between external events, thoughts, behaviour and mood. Understanding of these links comprises part of other approaches as well. Based on a shared understanding between clinician and client of mood history, this approach examines ways in which thoughts and events influence behaviour and mood of the individual. This will include identifying patterns of thinking likely to make depression or mania more likely as well as identifying patterns that work well for the individual and enhance recovery (Lam et al., 1999; Lam et al., 2003). Many elements of CBT are included in psychoeducation interventions which seek to provide people with useful information about bipolar disorder which can help prevent future episodes (Colom et al., 2009; Lobban et al., 2010).

Interpersonal therapy and social rhythm therapy explores reactions to external events and relationships and places a particular emphasis on helping the individual to develop stable sleep and behaviour patterns. This involves careful recording of activities throughout therapy and target setting to achieve progressive increases in the number and frequency of behaviours that help establish a stable day and nighttime routine (Frank et al., 2005).

The emphasis in family focused therapy is on improving understanding, communication and problem solving as a joint venture between family members and the individual with experience of bipolar disorder. This is based on evidence that difficulties in family relationships are commonly reported in association with bipolar disorder and that when family relationships are fraught the outcomes for the individuals with bipolar disorder tend to be worse (Miklowitz et al., 2003).

All approaches aim to help clients to detect changes in mood and behaviour that might signal increased risk of developing depression or mania. In each approach there is also scope for working with the client to identify adaptive responses to these early changes in mood and behaviour. In some approaches these responses are more around rapid access to services whereas in others there is more of a balance between the individual dealing with

changes themselves initially but being alert to the possible need to access additional support if required.

10.3 The future of therapy

Although each of these approaches is supported by research evidence they are currently only available to a few individuals experiencing bipolar disorder. Where psychological therapies are offered it is unlikely that clients will be offered a choice. This situation needs to be improved by more training for clinicians and increased awareness of the importance of psychological therapies for bipolar disorder.

It is crucial that we move towards offering people options for therapy that fit with their needs and wishes. Different people can benefit from different approaches and the same individual is likely to have varying requirements across the course of their bipolar disorder. When deciding on which therapy to use, the best approach is to use a matched care approach where the clinician discusses the various options with the client, and together they decide which approach would be most beneficial. As circumstances and environments change over time, the approach is likely to need to be revised or changed. Additionally, different therapies and approaches will be required depending on whether the person is experiencing depression, mania or is stable. In many services this will remain an ideal until levels of psychological therapy provision are substantially improved.

In addition to specific psychological therapies there are other psychological aspects to clinical treatment in general. There is increasing awareness of the importance of advance directives in which the client identifies their wishes for treatment should they become unwell (as noted in Section 9). However, agreements of these sorts might be seen as challenging to the clinical expertise of some clinical team members. Psychological understanding of the role of choice and autonomy in therapy engagement might be helpful in working through some of these issues at a team level.

It is typically not possible to maintain the standard structure of therapy when the client experiences a relapse requiring a hospital admission. However, it is usually helpful to maintain regular contact through this period, providing support for the client and ensuring a shared understanding of this relapse episode when the client returns to structured therapy. There can also be a role for the psychological therapist here through modelling a constructive approach to the client which may be helpful for inpatient staff less familiar with the client's broader history.

Bipolar disorder experiences vary therefore individual presentations vary. Because bipolar disorder is characterised by variability, people's needs often do not fit well within traditional services. This variability does not automatically indicate the person is resistant to engage with treatment or has lack of insight into their experiences. It is therefore important to tailor therapeutic approaches to fit the individual, and reassess and revise the approaches as circumstances change. This indicates that a successful clinical service needs to be flexible and open-minded to the range of individuals with whom they will work. This is potentially challenging when service demands are high and resources scarce.

Section 11: Medication

> **Key points**
> - Medication offered to people with a diagnosis of bipolar disorder can be separated into three categories: mood stabilisers, anti-depressants (for depression), and neuroleptics (also called major tranquillisers – for mania). Doctors usually recommend that people take medication every day, even when they feel well and sometimes for years after an episode.
> - Medication is helpful for many, but not all people with a diagnosis of bipolar disorder.
> - Each person has to weigh up the advantages and disadvantages, for them, of taking medication. For example it may help prevent the problems returning but can also have unwanted ('side') effects, may have a negative effect on things that are valued by the individual, such as periods of creativity, and can raise questions about the person's self-identity.
> - It is important for medication to be reviewed regularly in the context of a collaborative partnership between the prescriber and the individual. There is evidence that this does not always happen.

11.1 Types of medication

Medication is one of a range of options available to people with bipolar disorder to help manage mood swings. They should always be offered as part of a comprehensive range of options, including psychological therapy and community care. There are a number of medications which can help in either preventing extreme mood swings or managing mood states when they occur. These fall into three categories:

- Mood stabilisers can be prescribed as maintenance treatments. They are taken long term to prevent manic and depressive episodes.
- Anti-depressants are used to control depressive episodes.
- Major tranquilizers (sometimes called 'anti-psychotics') which are used to treat and control manic episodes.

Medications affect the chemical messages in the brain, but the exact mechanism to account for their effect on regulating mood is not clear. Although antidepressant medication may be prescribed following a first episode of depression, it is likely that following subsequent episodes, or an acute manic episode, mood stabilisers will be prescribed. These have the advantage that they can reduce the risk of future episodes occurring by approximately one third (Geddes et al., 2004; Goodwin, 2003). In addition, they are not likely to trigger a manic episode – which can be a problem with antidepressant medication for people with bipolar disorder. Mood stabilisers include Lithium, sodium valproate and carbamazepine and are prescribed to try to prevent future episodes occurring and so have to be taken daily even when the person feels well. They are prescribed for long time periods, often many years after the experience of an episode. It can take some time to find the ideal medication/combination of medications to suit any one individual, although the reality is that people can remain on the same medication without frequent review.

'In the central nervous system, where there is a multiplicity of receptors for each drug to act on, and where all of us have different proportions of each of these, the likelihood of a uniform response to any one drug is rather low. A diversity of responses, rather than uniformity, should be expected.'

Professor David Healy (Healy, 1997)

Stopping mood stabilisers suddenly can be dangerous and is associated with increased risk of recurrence of a mood episode (Keck et al., 1998; Scott & Pope, 2002). Therefore it is extremely important that prescribing is done in a collaborative way, that the person with bipolar disorder makes an informed choice about their medication use, and that this is reviewed on a regular basis so that any problems can be identified. Some people may want to involve their family and friends in this process.

11.2 Making decisions about medication

Decisions about medication use can involve weighing up the advantages and disadvantages. These will be different for each individual, but some of the common pros and cons are summarised in Table 1.

Table 1: Advantages and disadvantages of medication use.

Advantages of medication use	Disadvantages of medication use
Reduces relapse	Side effects
Feel more in control of the disorder	Loss of positive aspects of bipolar experiences
	Questions of self identity
	Remembering to take tablets
	Regular health checks and blood tests

The main advantage to taking medication is that research shows it can be effective in increasing time to next episode (e.g. Geddes et al., 2004). However, this conclusion is drawn by looking at the average response across a large group of people. The effectiveness of each medication varies from person to person and over time. Effectiveness needs to be evaluated for each individual on an ongoing basis.

A common disadvantage of taking medication is the unwanted effects they can cause (sometimes called 'side effects'). Each drug has specific unwanted effects that should be discussed fully at the point of prescribing, and provided in written form. The most common include:

Mood stabilisers:

■ **Lithium** can cause some unwanted effects as the body adjusts, including thirst, diarrhoea, mild tremor, and dry mouth. More serious long-term effects include weight gain, underactive thyroid (causing weight gain, tiredness, sensitivity to cold, depressed mood), and diabetes. If levels get too high, this can lead to lithium toxicity which causes seizures. Symptoms include vomiting, diarrhoea, slurred speech, blurred vision, confusion.

- **Sodium valproate** can cause nausea, vomiting and tremor as the body adjusts. Long-term effects include weight gain, hormonal abnormalities that are dangerous for females of child-bearing age, liver damage, extreme tiredness, weakness, and jaundice.
- **Carbamazepine** can cause dizziness, unsteadiness, nausea and vomiting as the body gets used to it – then more serious effects can include low red and white blood cell counts, liver damage, thyroid problems, and more rarely a severe skin rash that needs medical attention.
- **Antidepressants**. The specific side effects vary depending on which type is used (specific serotonin reuptake inhibitors (SSRIs) are thought to have fewer side effects), but commonly dry mouth, constipation, blurred vision, sedation, sleep problems, weight gain, headaches, diarrhoea, sexual dysfunction, loss of libido and agitation occur.
- **Major tranquillisers** can cause unwanted effects that include muscle tremor, stiffness, spasm, sexual dysfunction or loss of libido, nausea, dry mouth, blurred vision, constipation, heart arrhythmia, sedation, weight gain, diabetes, loss of white blood cells (can be fatal), tardive dyskinesia, and neurolptic malignant syndrome.

For some people, the effect of the medication in reducing mood changes can be a disadvantage. Many people report positive effects from their mood swings – particularly in the periods of hypomania where feelings of euphoria and creativity can be experienced without the loss of functioning associated with mania or depression. The prospect of losing these highs can lead some people to decide against taking medication.

Our feelings and moods are an essential part of who we are. Taking medication that controls these can cause problems with self identity, raising questions such as 'Is this really me? Am I a different person when I take the medication?' This is another reason why some people choose not to take medication.

Even when weighing up the advantages and disadvantages leading to a decision to take medication, further difficulties can arise. Firstly, medication may not be an option, for example in the case of pregnant women, as the potential side effects of the medication are too dangerous. Secondly, the practicalities of remembering to take tablets everyday need to be addressed. Finally, the cognitive changes associated with mood can cause fluctuations in motivation to take the tablet: when depressed it is easy to question the point in taking it and to assume that it won't work; in hypomania there may be an underestimation of any dangers in mood escalation and it may be difficult to see a good rationale to take tablets that will reduce positive emotions that are currently valued and enjoyed.

Highlighting these factors emphasises the potential complexity inherent in deciding whether or not to take medication. Different people will require different medicines and regimes to suit their needs. Opportunity needs to be given for discussion of these issues within a collaborative partnership between the prescriber who brings knowledge of the medication and their actions, and the individual who brings knowledge of their own mood experiences, how the medication feels for them, and their own attitudes towards taking medication. All of these factors need to be taken into account in agreeing an ongoing strategy around medication. It may then be useful for the agreed strategy to be clearly documented and shared with relevant parties – particularly if there are specific medications that the person does not wish to have.

If someone decides against taking medication, professionals should be aware that this could be a rational decision made in the person's best interest and not necessarily irrational or illness-related. People who make this decision should be supported to withdraw safely and be given access to appropriate information and websites, for example www.comingoff.com.

Although, medication remains the primary treatment option offered to service users, other approaches have been shown to be effective and should also be accessible through all services. Service users must be provided with information and choices about all the treatments available to them so that each individual can find a combinations that suits them best.

> *'As far as my psychiatrist was concerned, although he presented taking medication as a choice it felt like the sort of false choice you might give to very small children – either take the medication or risk the extremely severe consequences of experiencing a crisis and hospitalisation. My CPN, close to my final discharge from the services, sort of quietly whispered, "if ever you want to come off your medication – get in touch", as if it could be an option.*

> *'I now obediently take my medication morning and night. I reason that if it does help keep the mental health services away from me and my life, then that is great. Any thoughts that it may make me dopey I push to one side as it is a small price to pay for my quality of life now. Any thoughts that it may damage my body long term or even reduce the length of my life I also suppress. However, my main difficulty is that I have never really believed that I have a permanent biologically-based condition that needs constant medication. Yes, I have had some extremely difficult situations to face in life at times but that doesn't make me ill does it?'*

<div align="right">Service user</div>

11.3 Safe use of medications

Medication can be prescribed by the GP in primary care services. However, referrals should be made to more specialist secondary care services where relapses continue to occur or the person does not want to take the medication for any reason. Specialist services should also be involved for people experiencing first episode psychosis, high levels of comorbidity, and for women who may become pregnant. Medication regimes should be reviewed on a regular basis to make sure that it still meets the needs of the individual and to check physical health status. NICE (2006) recommends annual health checks to include cholesterol, plasma glucose, weight, smoking, alcohol and substance use, and blood pressure. People should also have access to independent impartial information about drugs, which is crucial bearing in mind the amount of money that drug companies spend on advertising their products and the fact that many people are prescribed doses above recommended limits.

11.4 Collaborative prescribing

Professionals involved in prescribing and administering medication should work with people with experience of bipolar symptoms to explore the benefits and costs of medication. This collaborative approach enables people to explore both whether education in general is helpful for them, and if so which drug and which dose suits them best. Professionals should also help people to work out whether regular consumption of medication is required or whether it is more appropriate to take medication strategically in response to particular stressors. A decision on the correct approach will vary from one person to the next depending on their personal experiences.

Section 12: Risk and bipolar experience

> **Key points**
> - People with a diagnosis of bipolar disorder are at higher risk of suicide. It is estimated that 10 to 15 per cent of people admitted to hospital with the diagnosis will eventually die by suicide.
> - A kind of talking therapy, known as mindfulness based cognitive therapy (MBCT), is a promising new approach for people who have thoughts of suicide. Participants are encouraged to focus on self-acceptance and compassion as opposed to self judgment and criticism, and learn to recognize warning signs such as certain thoughts and feelings.

12.1 Risks

There are a number of risks related to bipolar experiences. These include risks of self harm and suicide, risk of harm to self through drink and drugs and risk of exploitation from others when in a vulnerable mental state. This section will also consider whether there is a potential for risk to other people.

12.2 Self harm and suicidal behaviour

Bipolar disorder carries with it an increased risk of suicidal ideation and behaviour (Rihmer & Kiss, 2002). Many individuals have thoughts about killing themselves or indeed engage in behaviours that could be harmful such as cutting or otherwise hurting themselves. In contrast only a minority of people with bipolar experiences actually die by suicide. This said, the risk for suicide in individuals with experience of bipolar disorder seems to be higher than rates in the general population. It has been estimated that between 10 per cent and 15 per cent of people with the diagnosis whose problems are severe enough to have led to a hospital admission eventually die by suicide (Hawton et al., 2005). Suicide is associated with both depression and mixed states in which the individual experiences symptoms of both depression and mania.

> *'There are many times that I have asked myself what the point is in all this and I'm not going to lie and say that I have never considered how it would be like to not be here. Many many times the feeling has become too intense and I have felt that I would do anything, anything, to stop it. From my own experience I tend to focus on the negatives of life and how to avoid it, but I always forget to ask myself what the reasons are to remain alive.'*

<div align="right">Karin Falk – service user</div>

12.3 External and internal events

The events which can lead someone with a diagnosis of bipolar disorder to contemplate and perhaps attempt suicide are the same sorts of events as for anyone else. For instance, recent experience of significant problems or losses in day-to-day life render most individuals more likely to engage in suicidal behaviour than during periods when life is going relatively well. Also, people who are suicidal are typically in low/depressed mood. In such mood states patterns of thinking can be very negative. This can make even relatively minor problems appear insuperable. This combination of negative events and negative thinking can sometimes lead people to feel trapped in their suicidal behaviour. Helpful

interventions will therefore often centre around helping people to take a different perspective on their problems and accessing help and support that might address practical difficulties (Hawton et al., 1995; Williams & Pollack, 1993). Recent studies also suggest that Mindfulness-Based Cognitive Therapy (MBCT) is a promising new approach for those who have experienced suicidal ideation in the past (Williams et al., 2006; Williams, et al., 2008). MBCT integrates cognitive therapy techniques with training in meditation and is specifically designed for people in recovery, rather than in an acute state of crisis.

12.4 Crisis plans
Once recognised, a person's patterns of emotional response and negative thinking (sometimes called relapse signatures) can serve as warning signals. Detecting these warning signs can help avoid suicidal feelings in the future by helping the individual to adopt coping strategies to reduce the impact of these signs on mood.

12.5 Risk through drugs and Alcohol
People with experience of bipolar disorder seem to be more likely to use drugs and alcohol than members of the general population or indeed people with experience of psychosis or depression alone. Studies have indicated that 40–50 per cent of people with experience of bipolar disorder will be dependent on, or use significant amounts of, drugs or alcohol in their lifetime (Care, 2007; Cassidy et al., 2001; Regier et al., 1990). These rates are higher than those in the general population, although it is important to note that potentially harmful levels of substance use are apparent in up to a quarter of adults in the general population if alcohol use is included (Care, 2007; Regier et al., 1990). Use of drugs and alcohol are notable across mood states so are not limited to periods of mania or depression only. The high rates of substance use are important because individuals who have problems with drugs and/or alcohol as well as experience of bipolar disorder tend to have more severe mood problems and benefit less well from available treatments than individuals who do not use substances in this way (Salloum & Thase, 2000; Strakowski et al., 1988).

12.6 Risk to other people
There are often reports in the press of people with mental health problems who have engaged in violent acts. This can lead to the perception that people with experience of psychosis, bipolar disorder or depression tend to be more violent than the general population. The research evidence does not support such a proposal. A key factor in risk of violence seems to be the extent to which the individual is using drugs or alcohol independent of particular mental health diagnosis (Monahan et al., 2000; Monahan et al., 2005). Additionally, when individuals with a history of mental health problems (including bipolar disorder) were compared with individuals without mental health diagnoses who lived in similar areas there were essentially no differences in rates of violence if individuals were not abusing substances (Steadman et al., 1998).

12.8 Risk from other people
In contrast to reports concerning violence by people with mental health problems, the popular press rarely covers the extent to which the same individuals can be at risk of victimisation from society at large. Many individuals with experience of bipolar disorder report histories of physical or sexual abuse preceding their mood problems (Hammersley et al., 2003). Additionally, there is evidence that a significant proportion of individuals with

experiences of psychosis or bipolar disorder experience violence from others. A recent study of a group of individuals with experience of psychosis and bipolar disorder found that over 17 per cent were victims of violence over a 12-month period (Chapple et al., 2004).

12.9 Stigma and discrimination

In common with individuals with other mental health issues, people with a diagnosis of bipolar disorder can be subject to stigma. This can lead to discrimination in personal, work and health areas which impede people's progress towards recovery. Over time people can internalise their experience of stigma and discrimination so that they feel pessimistic about their own capabilities to recover. These issues are discussed in more detail in Section 17, 'Social inclusion'.

Part 4: Recovery

Section 13: Recovery and staying well with bipolar

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Key points

- Recovery is defined in a variety of ways. Some people think of recovery as no longer using services or taking medication, whereas others see recovery as gaining back control of one's life and achieving valued goals whilst perhaps continuing to draw on support.
- People use a variety of strategies for recovery. The most common involve learning to notice early warning signs of mood changes and knowing what is likely to help at that point.
- Recovery is an ongoing journey that is unique to each individual.

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13.1 Definition of recovery

'Many people hope for instant recovery. It takes time to learn how to control it. We learn to monitor ourselves and accept what our bodies can do.'

Service user, quoted in Rusell & Browne, 2005

We know that a sizeable proportion of people with bipolar disorder have a good outcome in the long term (Coryell et al., 1998). Recovery from bipolar disorder is not like recovery from a broken leg where a doctor can confirm that the bone is fully healed. Recovery associated with a mental health problem can only be determined by the person with the problem, and it does not necessarily involve a complete elimination of distress. In fact, part of recovery may involve working out what features of the 'illness' can now be regarded as acceptable and manageable and how to engage with services in ways that feel constructive for the individual. Service users have offered a range of ways of viewing recovery(Russell & Browne, 2005). Some examples are listed below: each definition has strengths and limitations:

1) **Prevention of relapse.** Long-term recovery can be defined as not having further relapses of mania or depression. This is a relatively clear-cut definition. Yet people can experience chronic depressed mood and still not return to a 'normal' life despite not having had a relapse. On the flip side, people can recover by learning to manage their relapses better – for example spending less time in hospital.

    'Ultimately recovery is about staying well and avoiding major episodes.'   Teresa

    '*Recovery is being independent and managing to control extremes and avoid becoming very unwell/admitted.'*   Tim

2) **Medication:** While many people would see taking medication as an integral part of recovery, many others see managing without medication as a key sign of recovery (Mansell et al., 2009).

3) **Taking control of one's life:** When interviewed, many people define recovery as taking back control of their lives. During mania and depression, people feel that they have lost control of their mood, thinking and behaviour. Their relationships with other people may be compromised and overly dependent. Therefore they see recovery as regaining their independence and starting to live a life that they can determine for themselves. Sometimes this can be particularly difficult when people feel that friends and relatives are over-monitoring them for signs that they might be becoming depressed or high, leading to disagreements and frustrations for all involved.
Self awareness is often seen as an important part of taking responsibility and control of one's life

'I see the problem as the manic depression and not me. I separate the two and see the need for me to be in control of the manic depression, so that it doesn't influence my life too much.'
<div align="right">Service User, quoted in Rusell & Browne, 2005</div>

4) **Redefining one's sense of self:** For many people, recovery involves accepting a self-identity that is less varied in mood, or it may involve learning to separate their personal identity from the label of bipolar disorder – they are not 'a bipolar' but a person 'with' bipolar disorder. For some this involves finding ways to live a fulfilling life despite their difficulties by integrating the concept of bipolar disorder into their understanding of themselves and their life experiences. This may be done by viewing bipolar disorder as a long term medical condition that requires life-long medical management. Others, redefine a sense of self by rejecting a medical view that they have an illness (Van der Gucht, 2009).

'I don't believe a cure is possible. If you are looking for a cure, you are not dealing with the real issues.'   Interviewee

'You can't recover from being human. You can't cure humanity.' Amy Sanderson Diedra

5) **Recovering from the stigma and trauma of being diagnosed:** *'When people find out about what you've got, people reject you or make fun of you or tell you how to live your life.'*

For some individuals, one of the greatest difficulties is the impact diagnosis has on their sense of self and their life. Whilst some people find a diagnosis helpful others can find them disempowering, particularly if they do not make sense of their experiences within an illness framework. When this is the case, recovery can be about adjusting to or rejecting information and support that does not have space for their own understanding. (Lindow, 1996; Campbell, 1996)

'I object to the way power is stripped from me, the way that I am approached not as an individual but as a manic depressive.'   Peter Campbell (Campbell, 1996)

6) **Self acceptance, coping with criticism and letting go of perfectionism:** For some people, recovery in bipolar disorder is less about avoiding episodes of low or high mood, and more about learning self acceptance of oneself. Sensitivity to perceived

criticism from others coupled with high expectations of oneself can lead to some people with bipolar disorder identifying the need to be kinder to oneself as the key goal of recovery. This can be particularly important when someone has experienced thoughts or acted in a way they feel was incongruent with their own or other people's expectations during a manic episode. Not engaging in excessive self criticism and learning to be compassionate with oneself can be a fundamental part of recovery for some people.

'Self acceptance for me is linked to a sense of balance and stability and being able to enjoy the here and now without being haunted by the past. All of those were a major trigger for my first depression. Being able to deal with that and move forward was a huge thing, and will always risk being a trigger again.'   Interviewee

13.2 Strategies for recovery

People use a variety of strategies (Mansell et al., 2009; Russell & Browne, 2005). There is little evidence to tell us which of these, or which combination of these, is more effective, and so the most common strategies are included in Figure 13.2 below.

'What goes around in my head is also important for me to keep track of to detect eventual relapses. I am lucky that I have fairly clear signs of impending illness. If I start irrationally worrying about insignificant little things and when these thoughts start to take over most of my day (and night!) it is a warning sign that things aren't going too well. It's hard to do much about this, though. The best solution to these symptoms is to take some anxiolytics like diazepam but I can only take these in absolute crisis since they're very addictive, and dependence on them is a problem that I really can do without. So, I have to come up with other ideas. I guess it's very individual what practical strategies are best employed in these situations. I generally go out for a power walk and then I feel a bit better. If I don't, and things are getting from bad to worse, I keep the number for psych in my wallet at all times."

Karin Falk – service user

The following quote illustrates how recovery can be a way of life, which taps into basic human needs:

'I am on [medication] daily, which I make sure that I take, sadly. I have tried to cut them down or stop them, but each time this ended in disaster. I attend a mental health day centre, where I do voluntary work, classes, and my art work, and talk to the other clients and staff. Occupation helps me a lot. My religion helps me a lot too. I regularly talk to God, and tell him all my problems. He/She quite often talks back, but I'm aware this is only a voice, so I try to ignore it. I pray and meditate. Talking helps me a lot, and I have very good relations with some very good mental health professionals, who I see regularly. Exercise too, I try to get out every day, even if it just a trip to the shops. Contact with people helps, and country walks. A proper balanced life is very important, just life and living really, keeps me well."

John Exell – service user

Figure 13.2: Mood related coping strategies

Mood Management and Self Awareness
- Noticing warning signs and using coping strategies
- Gaining a better understanding of mood swings
- Understanding the types of things that might be triggers for oneself
- Acceptance of normal energy levels
- Using self help resources

Psychological
- Learning to be more empathic and forgiving of oneself
- Learning to recognise when the way we are thinking may be unhelpful or biased
- Balancing success and perfectionism

Interpersonal
- Developing and maintaining supportive relationships
- Learning to assert one's own needs
- Learning to grow from, rather than feel crushed by criticism, rejection or disagreement
- Choosing who and when to talk about bipolar with
- Sharing a relapse plan with significant others

Physical wellness
- Eating healthily and regularly
- Not relying on alcohol, tobacco or substances
- Exercise
- Relaxation

Identity
- Having meaning and purpose
- Self awareness and acceptance
- Not seeing bipolar as the defining feature of one's identity
- Self appreciation – recognising one's strengths as well as one's difficulties

Support from services
- Making informed decisions about medication
- Access to psychological therapies
- Supportive relationships with services
- Being involved in decisions about one's care and treatments
- Access to alternative treatments

Spirituality and faith
- Having faith in a deity (or deities)
- Connection with one's spirituality
- Being at one with nature
- Using meditation, yoga or visualisation

Self care

- Having 'me' time
- Building up lifestyle fundamentals (e.g. lower stress, daily routine, good sleep)
- Being involved in personally meaningful activities (such as work, further learning or creativity)
- Taking time out to relax
- The opportunity to stimulate senses (e.g. massage or aromatherapy)
- Taking responsibility for one's actions
- Being involved in care planning decisions

Hope and optimism

- Experiencing success
- Taking control
- Working towards personally meaningful goals
- Self belief that one can cope and manage

Risk and responsibility

- Having the freedom to make choices and mistakes
- Having support and advice regarding financial risks and difficulties

Part 5: Wider implications

Section 14: Implications for mental health services

> **Key points**
> - Services should not insist that all service users see their problems as an 'illness' and take medication.
> - There is increasing evidence that talking treatments can be very effective and they should be much more widely available.
> - Trusting, collaborative relationships between workers and service users are a prerequisite of, and arguably as important as, any specific treatment.
> - People should be offered information and choice about all aspects of the help offered by services.
> - Service users are experts by experience and services should draw on their expertise to help improve services and train staff.
> - Sources of funding are needed for research that is not based uncritically on a medical model of 'bipolar disorder'.

14.1 The culture of mental health services needs to change

The main message of this chapter is that the culture of mental health services needs to change.

Traditionally, mental health services, particularly crisis services such as acute wards, have been based on a view that sees the tendency to experience extreme mood states primarily as an illness to be treated by medication. This idea is also enshrined in mental health law. The idea that this is not the only approach, and that such experiences can be understood in the same way as other human experiences, has wide-ranging implications for the culture of mental health services. Increasingly, there is recognition that greater emphasis needs to be placed on the perspectives, values, goals and beliefs of the individual and their family (DoH, 2004) and that services need to offer a wider range of options to suit the diversity of needs of service users and their families. There are several principles that underpin how mental health services can, and are moving in this direction. Some of these are summarised briefly in the following section.

14.2 A person centred approach to care

14.2.1 A whole-person approach to helping

Firstly, what people say they want is to be treated as a whole person and not a collection of symptoms to be managed. Professionals and other mental health workers should not insist that all service users accept any one particular framework of understanding. This means, for example, that professionals should not insist that people agree with their view that experiences are symptoms of an underlying illness. Some people will find this a useful way of thinking about their difficulties and others will not.

Use of a 'non-illness' model

'Loss of control, whether truly lost or merely removed by others, and the attempt to re-establish that control have been central elements in my life since the age of eighteen. My argument is that the psychiatric system, as currently established, does too little to help people retain control of their lives through periods of emotional distress, and does far too much to frustrate their subsequent efforts to regain self-control. To live eighteen years with a diagnosed illness is not incentive for a positive self-image. Illness is a one-way street, especially when the experts toss the concept of cure out of the window and congratulate themselves on candour. The idea of illness, of illness that can never go away, is not a dynamic, liberating force. Illness creates victims. While we harbour thoughts of emotional distress as some kind of deadly plague, it is not unrealistic to expect that many so-called victims will lead limited, powerless and unfulfilling lives.'

Peter Campbell (Campbell, 1996)

Use of an 'illness' model

'It was helpful for me to regard myself as having had an illness. This made me respectful of the need to maintain and titrate medication … the medication has helped me to make more, not less, use of my psychological insight and thus genuinely to gain ground … It has none the less to be said that for this … to be maintained over years, spiritual, psychosocial and cognitive-behavioural methods were required – otherwise medication dosage would have needed to have been extremely high.'

Dr Peter Chadwick (Chadwick, 1997)

Professionals and other workers should respect and work collaboratively with the service user's frame of reference – whether he or she sees the experience primarily as a medical, psychological or perhaps even spiritual phenomenon. Often, of course, people are unsure, or even actively searching for a way of understanding and coping with their experiences. These people will find the research described in this report helpful.

Arriving at a joint understanding

One obvious implication of this report is that services need to offer a broader assessment process, one which enables the professional and the service user together to explore all the different factors that may be playing a role. An important part of this will be for the worker to ask about what the experiences mean to the person and how he or she understands them. It is vital that this process should take into account cultural differences, and should extend beyond those factors usually considered by health services to look at the person's possible needs in the areas of housing, employment, leisure, finances and friendships.

It is only when they have looked at all the possible contributing factors in turn that the client and professional can arrive at the most accurate and helpful understanding of the person's experiences. What they are likely to identify is some sort of vicious circle that is maintaining the situation in its present state. This emerging understanding will suggest what is most likely to help. For example, the most important thing to do might be to make changes in the person's environment. If the person is living in a stressful environment, the most important 'treatment' might be to help them find somewhere less stressful to live. On

the other hand, it may be that the person can usefully make changes in the way he or she responds to the environment, for example by identifying a tendency to interpret situations in particular ways and attempting to change this. Alternatively, if medication is helpful, the first thing to do might be to try to find the most helpful drug and dose. Each change that a person makes will also provide more information about what is and what is not helpful. This systematic approach is rather like an experiment: a picture of what is going on can gradually be built up, adding or removing links over time.

14.2.2 Services as a choice, not a requirement

It is important to remember that not everyone needs or wants help. Perhaps the first thing that the professional needs to ask about is whether the person is distressed by his or her experiences. If the person is not, then there is usually no need for services to intervene at all. If the person's friends or relatives disagree, then it may be worthwhile focusing efforts to help around that network rather than the one person. Sometimes the best thing mental health services can do for someone is to help them negotiate the changes needed to live the sort of life they want (holding down a job, for example) rather than attempting to prevent episodes of extreme mood.

14.2.3 Providing information and a range of choices

A whole-person framework of understanding implies that mental health services should adopt a whole-person approach in the types of help that they offer people, paying attention to all the aspects of someone's life that may be playing a role. This whole-person approach should be the cornerstone of services. Mental health services should provide help in a number of different ways, depending on what seems to be most important for each individual rather than on the basis of the diagnostic category to which he or she has been allocated. Different things may also be more or less important for someone at different times. Ideally services should be offering a range of talking treatments, practical support and alternative therapies as well as access to medications.

As it is difficult to know which treatments will help particular individuals, people may need to try several approaches to work out what is most beneficial to them. Professionals must therefore acknowledge the limitations in what they know and provide people with information and choice regarding all available treatments. Information and choice are not only an ethical requirement but also may affect outcomes as treatments which meet with people's preferences are generally more effective (Deane, 1987).

14.3.1.1 Talking treatments

As shown in this report, there is now good evidence from large-scale trials that talking treatments can be very helpful. However, despite their effectiveness and their popularity they are not yet widely available on the NHS for people with a diagnosis of bipolar disorder. There is a powerful argument that they should be more widely available. Psychological help should be available to every service user who wants it, either individually or in a group depending on their preference. This is one of the most important messages of this report.

There are a number of different 'brand name' therapies, with cognitive behavioural therapy and/or psychoeducation most widely available and experienced by many people as helpful. The content of any talking treatment should be tailored to the individual. For

example, some people might find it helpful to try and identify what has caused their problems, whilst others might prefer to focus on how to make positive practical changes in their life (Drayton et al., 1998).

Central to all therapies (and, some would argue, the most important 'active ingredient') is the establishment of a good, trusting and collaborative relationship between client and worker so that the person is able to talk and think about their experiences in a calm, supportive and non-judgmental atmosphere. This can, of course, also happen outside of a formal 'talking treatment', for example between a service user and his or her care manager in the context of a community mental health team. Both client and worker also need access to the information contained in this report in order to make an informed judgement about what is likely to be maintaining the problem and what is likely to help.

14.3.1.2 Information and choice: Medication

As with talking therapies a range of medications are used in the treatment of bipolar disorder. Services users have the right to information about the pros, cons, side effect profiles and evidence base for any treatment they may commence. Particularly when individuals may be contemplating commencing prophylactic treatment, individuals should be encouraged and supported to ask questions about the medications and alternatives that are available.

14.3.1.3. Information and choice: Complementary therapies

There is a high level of demand from service users for access to complementary therapies such as massage (Faulkner & Layzell, 2000), exercise therapy, meditation and acupuncture. Many of these therapies are effective in reducing the high levels of stress and arousal which appear to play a role in many episodes of extreme mood, and they can be very helpful. There is a good argument that they should be more widely available.

14.3.1.4 Information and choice: Self-help

Many people report finding self-help groups very useful. Professionals and other workers should give their clients information about such groups. MDF the Bipolar Organisation (formerly the Manic Depression Fellowship – www.mdf.org.uk) runs a national network of self-help groups. Many groups also offer self-management training courses which help people learn to recognise early signs of depression or 'mania' and take active steps to manage the situation.

14.3.1.5. Information and choice: Crisis services

Many people need help only occasionally when their problems become so extreme that they, or their family and friends, feel unable to cope. When friends or relatives are suggesting that help is needed, workers need to bear in mind that those making this suggestion may have coped with their friend or relative for some time, and try to understand why help is being sought now. What do the friends/relatives and the potential service-user actually feel would be helpful at this point? Is it possible to negotiate a contract of work with commonly agreed goals? There is a need for more creative responses to such situations, which build on what service users themselves say is helpful (Grey, 2007). In the past, often the only help available at such times has been admission to an acute psychiatric ward, and the only treatment has been medication. Sometimes the person has had little opportunity to talk about the reason for their admission and has been left feeling powerless

and confused. In 1998 a report by the Sainsbury Centre for Mental Health found that 'hospital care is a non therapeutic environment' and recommended an overhaul of the care and amenities on acute wards (Sainsbury Centre, 1998). Despite some improvements, many people still find acute psychiatric wards frightening and unhelpful (RCP, 2008). Talking treatments should be available in hospital, and the importance of 'ordinary human interaction' between staff and service users cannot be overemphasised (Rose, 1998). The increasing administrative burden on staff in psychiatric wards can also make it difficult for them to find time to talk to service users. Many nurses find this frustrating and demoralising, and since people often find interaction with nurses the most helpful aspect of their stay in hospital, it also represents a considerable waste of resources (Rose, 1998).

A range of alternatives to acute psychiatric hospital admission have recently been developed. These include non-hospital crisis houses such as the women's crisis house run by Camden and Islington NHS Trust (http://www.candi.nhs.uk/our_services/services/ drayton_park_womens_crisis_service.asp). There are also examples of crisis services run by service users and ex-users, for example the Wokingham Crisis House (http://www.wokinghammentalhealth.org.uk).

Workers should help every service user who wants it to draw up an 'advance directive' stating what he or she wants to happen should a crisis occur in which he or she is considered temporarily unable to exercise appropriate judgment. 'Crisis cards' which summarise these wishes should also be available to all users of mental health services. All service users should also have access to independent advocacy (BPS, 1999).

14.3.1.6 Information and choice: Practical help
Many people find medication, talking treatments or both helpful. However, this is not the case for everyone and even for those who do find them helpful, help with things like housing, income, work and maintaining social roles can often be equally important in their recovery. Services should be flexible enough to offer each individual what he or she finds most helpful and, as outlined above, sometimes this will be practical help (for example with accommodation or employment) rather than 'treatment' or 'therapy'.

Work and/or education are often particularly important. People who are under-occupied are much more likely than others to experience recurring problems with extreme mood and work can bring about clinical improvement, particularly when this work is paid (Seebohm et al., 2002). Indeed, there is evidence that getting back to work has a greater positive impact than any other single factor (Warner, 1994). Helping people to find meaningful employment (or places on educational or training courses), and supporting them whilst they are in it, should therefore be a core task for mental health workers (Meddings & Perkins, 1999; Perkins et al., 1999).

14.3.1.7 Information and choice: Making rights and expectations explicit
The principle of informed consent is paramount, as any treatment has the potential to do harm as well as good. It should be standard practice for service users to have access to the same information that is available to workers and should have the right to refuse treatments, from ECT and psychological therapies to medication.

It is the recommendation of the British Psychological Society's Division of Clinical Psychology that every service should publish a statement explicitly setting out what users

can expect from that service. An example of such a statement follows. Some services may not be able to offer all of the items on this list, and it would need to be adapted in view of local circumstances (Newnes, 1993).

As a client you have the right to:

- receive respectful treatment;
- refuse treatment or a particular intervention strategy;
- ask questions at any time;
- know your worker's availability and waiting period;
- have full information about your worker's qualifications including registration, training and experience;
- have full information about your worker's areas of specialisation and limitations;
- have full information about your worker's therapeutic orientation and any technique that is routinely used;
- have full information about your diagnosis, if used;
- consult as many workers as you choose until you find one you are happy with;
- experience a safe setting free from physical, sexual or emotional abuse;
- agree to a written contract of treatment/care;
- talk about your treatment with anyone you choose, including another worker;
- choose your own lifestyle and have that choice respected by your worker/s;
- ask questions about your workers' values, background and attitudes that are relevant to therapy and to be given respectful answers;
- request that your worker/s evaluate the progress of therapy/treatment;
- have full information about the limits of confidentiality;
- have full information about the extent of written or taped records of your therapy/treatment and your right of access;
- terminate therapy/treatment at any time;
- disclose only that personal information that you choose;
- require a written report on therapy/treatment; and
- have access to any written summaries about your therapy/treatment.

14.3.3. Information and choice: The issue of coercion and mental health legislation

The legal context within which mental health services operate makes the issue of information and choice of particular importance. In the past, a paternalistic approach was taken by mental health services, making use of the powers under mental health legislation, often in the context of limited resources. As a result, many people's experience of mental health services has been of a coercive and restrictive nature, which has damaged the development of trusting, collaborative working relationships which are crucial for an effective service.

Coercion

'I am ever ready to support consideration of alternative models of care where there is less emphasis on coercive treatment. I still wake up from nightmares that I have been readmitted and highly medicated against my will. In my community work I recognise the same fear in clients who are desperate to not be misunderstood or judged hospitalisable. This fear of losing one's freedom is a massive obstacle to collaborative mental health care. Where possible therefore I believe it is important to not see sectioning and locked wards as given and fundamentally necessary.'

Rufus May – Clinical psychologist

14.3.4. Collaborative relationships between Clients and mental health workers

Collaborative alliance

'Clearly, any individual faced with living with serious mental health problems has some very hard thinking to do, some difficult decisions to make and perhaps some risky experiments to try. Anyone in such a situation might value an ally who could help them to work through the issues involved and come to decisions that are right for them. Having decided on a course of action, the person may well then require … assistance that will enable them to carry through their chosen course and help them to review their decisions from time to time in the light of events. But that is not compliance, rather collaborative alliance.

Quoted in Perkins & Repper, 1998

The importance of being able to talk about experiences

'Only once in 15 years of psychiatric intervention, and at the age of 36, was I able to find someone who was willing to listen. This proved a turning point for me, and from this I was able to break out of being a victim and start owning my experience. The nurse actually found time to listen to my experiences and feelings. She always made me feel welcome, and would make arrangements so that we would not be disturbed. She would switch off her bleeper and take her phone off the hook, and sometimes, as there were people outside her room, she would close the blinds. These actions made me feel at ease. She would sit to one side of me instead of across a desk…. Over a six-month period, I was able to develop a basic strategy for coping. The most important thing that she did was that she was honest – honest in her motivations and in her responses to what I told her… Thanks to the support this worker gave, I have been able to develop a range of coping mechanisms.'

Quoted in Romme & Escher, 1993

One of the key propositions of this report is that those operating in mental health services should be collaborators with service users rather than present as experts who have all the answers.

A trusting, collaborative relationship between clinician and service user is a necessary prerequisite of, and arguably as important as, any specific treatment. Any treatment (including drug treatment) is unlikely to be very helpful on a long term basis unless the clinician and the service user have a positive and meaningfully collaborative relationship (Frank & Gunderson, 1990). Although effective relationships between staff and users would seem to be an obvious necessity, services often do not operate as if this were the case.

Relationships between workers and service users

'I needed someone who would just be there – solid, non-judging, not trying to force me to do this or that, just being with me and helping me to make sense of some very frightening, but also very beautiful and visionary experiences. My essential need was to be grounded, connected to life and the world, not excluded and punished.'[163]

Quoted in Cobb, 1993

A number of psychologists are of the opinion that separate legislation that only applies to people deemed 'mentally ill' is discriminatory. This is only compounded by the difficulties in defining 'mental illness' previously referred to. The British Psychological Society has

argued that decisions should be based on someone's ability to make decisions ('capacity') rather than on whether he or she has a psychiatric diagnosis (BPS, 1999). This is the case under Scottish law: however, unfortunately in our view, the recently revised mental health legislation in England and Wales is still based on whether someone's difficulties fit the criteria for a 'disorder'.

> **A positive experience of services**
>
> *[In hospital] I was listened to seriously and attentively; my requests … were all complied with quickly and treated with respect. Doctors did not look straight over or through me, they treated me like a substantial human being and were very sympathetic, especially concerning the terrible feelings of humiliation I had about my delusions. Nurses did not generally adopt a controlling, domineering attitude but were usually sensitive, responsive and human. Even ward domestics played a significant role in my recovery.*
>
> Peter Chadwick (Chadwick, 1997)

14.4 How services need to change

14.4.1 Learning from users and ex-users of services

Professionals must listen to what service users and ex-users have to say about services and treatments; it is only by listening that professionals can learn what really is helpful to those they are treating. It should be standard practice for service users to be involved at all levels, from planning the service as a whole to providing feedback to individual teams and, essentially, in planning their own care. Because service users and ex-users are experts by experience, a number of services have begun not only to involve service users in decision making at high levels, but also to employ them as members of their clinical teams.

14.4.2 Employing 'experts by experience' as workers

One example of such a service is the South West London and St George's Mental Health Trust, which identifies personal experience of mental health problems as 'desirable' in its selection criteria for staff, including senior clinicians (http://www.swlstg-tr.nhs.uk/work/index.asp).

14.4.3 Service users as trainers

Service users, ex-users and relatives are experts by experience, and so they should also be involved in the process of training mental health workers. Clear guidelines and auditing structures should be established to enable this inclusion of valuable insights for professional training courses and for training within services for mental health teams (e.g. ward or Community Mental Health Team 'away days'; Donaldson, 2006).

14.4.4 Specialist bipolar services

Major population centres within the UK would benefit from specialist services for bipolar disorder similar to those that are available in some cities in the US. Services for young people experiencing mood instability are also needed: Early Intervention with Psychosis services (EIS or EIP) are being developed round the country but tend to focus on young people experiencing paranoid thoughts or unusual sensory experiences rather than on those experiencing mood instability. It is vital that services address this gap in provision, especially as some young people may not initially see elevated mood as a problem and so may not seek help.

14.5 How research needs to change

There are a number of problems with the exclusive use of randomised controlled trials as the basis for evidence based practice (Pilgrim, 1997). Such methods provide useful information about doing the same thing (e.g. giving medication) to groups (e.g. people with a diagnosis of 'bipolar disorder'). They are particularly suited to testing interventions which fit this 'black box' model, in which the treatment given is always the same, and in which groups of people with a diagnosis of bipolar disorder are regarded as being in all relevant respects identical. This type of research ignores individual variation. Studies, therefore, actively discount the experience of service users, are based on diagnostic groups which are of questionable validity, and when used to investigate talking therapies often involve testing a poor analogue of what will be possible in routine mental health services.

The issue of funding for research is also important. Traditionally, drug companies have funded much research into 'bipolar disorder' (Bregin, 1983), which raises several important issues. Firstly, this research has often been based on the assumption that the tendency to experience extreme mood states is primarily a biological phenomenon. As this report has demonstrated, both this assumption and also the view that everyone who has a diagnosis of bipolar disorder needs to take medication long term, are increasingly being challenged. A second issue surrounding drug company funding is one of reliability and bias of findings. In recent years, concerns that studies funded by drug companies are more likely to report positively skewed findings have been supported by a number of studies (Als-Nielsen et al., 2003; Bhandari et al., 2004).

Although the National Institute for Health Research is beginning to fund drug studies independent from drug companies, there remains an urgent need for expansion of such alternative sources of funding. Given the inherent imbalance in research funding for biologically-based research (from drug companies) compared to other areas of research, the evidence presented in this report implies a need to focus more research funding on psychological approaches to extreme mood states.

14.6. How professional training needs to change

Perhaps even more important than the availability of specific talking treatments is the need for all mental health workers to be aware of the information contained in this report. Many workers are unaware of the psychological perspective on extreme mood states, and are unfamiliar with the research described in this report. A fundamental message of this report is that extreme mood states are understandable in the same ways as 'normal' mood states, and can be approached in the same way.

In the above introductory section, we noted that bipolar disorder is not an easy fit in services designed to work mainly with more persistent, rather than episodic problems. Similarly, counsellors and psychologists working in primary care or in secondary care psychological services often lack training in working with people with a diagnosis of bipolar disorder. Trusts must begin to roll out training, and to provide supervision and set-aside clinical time with alacrity.

Making use of the information presented in this report, such training should not be focused primarily on specific skills but on attitudes and beliefs about what causes some people to experience extreme moods, and what can help. A culture change is needed in

mental health services: with this in mind, training should be delivered on a whole-team basis, and should include managers and team leaders.

14.7 Making services more recovery-oriented

An important aspect of what people with experience of bipolar disorder can contribute is their stories of hope and recovery. This is of crucial importance because mental health workers frequently only come into contact with people who continue to need their help (or for those who need help only occasionally, at those times that they need it) and thus risk falling into the trap known as the 'clinician's illusion' because the people they see by definition continue to use services. Likewise, although there are thousands of former service users who either no longer have bipolar experiences , or have found effective ways to cope with them and no longer need help from services, current service users and clinicians rarely have the opportunity to meet them. Because of this both staff and service users are in danger of developing over-pessimistic views about the future. One way of overcoming it is for people who have recovered to be involved both in working directly with service users and in staff training, in order to give both staff and service users access to stories of hope and recovery.

Section 15: Social inclusion

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Key points

- People diagnosed with bipolar disorder may encounter difficulties with practicalities such as obtaining a driving licence or a travel visa.
- There are both advantages and disadvantages in choosing to disclose mental health difficulties to existing or potential employers. Whilst there is no legal obligation to inform employers of diagnoses, people can be protected under the Disability Discrimination Act (1995) and some employers actively seek people recovering from mental health difficulties.
- Some aspects of our culture are arguably unhelpful to anyone at risk of mania or depression, for example long working hours and valuing of excess work over a balanced life.
- Mood problems can both cause and be caused by relationship problems. It is important to maintain good levels of social support and share difficulties with those around you.
- The information in this report should be used as part of public information campaigns in order to reduce stigma and discrimination and promote social inclusion.

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15.1 Overview

Studies suggest that people diagnosed with 'severe' mental health difficulties are amongst the most socially and financially excluded groups in society (Huxley & Thornicroft, 2003, Leff & Warner, 2006). When individuals are also from ethnic minority, lesbian, gay or transgender communities, or asylum seekers, prejudice can operate on multiple levels and exclusion and social isolation be even greater. Unemployment, relationship difficulties and loss of social networks can all potentially impact on an individual's mental well-being (Bradshaw et al., 2006). A recent review of recovery literature in mental health highlighted that change is required on two levels: individually and on a societal level (Onken et al., 2007). The following section considers some of the practical and social issues faced by individuals with bipolar experiences.

15.2 Stigma and 'otherness' versus continuum

It is vital that health professionals begin to appreciate the vast individual differences among people diagnosed with bipolar disorder. Some people only have hypomanic episodes, some manic; some may have extremely distressing depressive episodes, some no apparent depressive episodes at all. Some may spend money extravagantly when 'high', others may go on very long walks at night, others may drink, and others may make little change to their routine, yet become much more gregarious. As with all of us, each person is wholly different from the next, and 'symptoms' vary considerably from one person to the next. It is also vital to understand that there are many people who do not meet the full criteria for bipolar disorder: 'sub-clinical' in the professional jargon. These people are sometimes described as 'cyclothymic' or of an 'artistic temperament,' 'running hot and cold', or simply 'moody'. Almost everyone, additionally, has a 'manic moment' now and again, even if inconsequential and quickly resolved, and most of us will know, at some

point, what it feels like to be depressed. This is not to say that people's difficulties cannot be severe enough to be meaningfully thought of as 'disorder', but merely to emphasise that psychologists believe they lie at one end of a continuum of mood variance.

15.3 Work and employers

One of the major considerations for individuals diagnosed with bipolar disorder is whether or not to inform existing or potential employers about their diagnosis and the nature of their difficulties. There is an obligation to respond truthfully to direct questions from potential employers concerning any existing conditions prior to accepting posts, and employers often expect these employees to provide a signature verifying the truth of their statements. Where such questions are not raised by employers then employees are not required to volunteer it. In practice, we know that many people with a diagnosis of bipolar disorder, and no doubt with other mental health diagnoses, omit this information when applying for jobs.

> *'When I applied for a job I felt very nervous about the occupational health part of the form. The occupational nurse phoned me up to ask me questions. I felt put on the spot and could not answer questions off the top of my head about dates of hospitalisation, etc. The nurse reported this as evasiveness.'*
>
> Interviewee

There are pros and cons to both disclosing and not disclosing one's diagnosis to employers. Many people are justifiably concerned that, despite legal protection under the Disability Discrimination Act (1995), they will face discrimination in the workplace (for example, that their team, not just their direct supervisor or manager, will be informed of their diagnosis) or, worse, be passed over for appointment or promotion. There are increasing numbers of case law precedents which side with those who are discriminated against, with some payouts for wrongful dismissal and the like amounting to six-figure sums. Employers are increasingly aware of their obligation to be inclusive toward people with mental health difficulties. Some people choose not to disclose, hoping that they will not experience problems severe enough to affect their work whilst in that particular post or that if they do that their employer will deal appropriately with their difficulties. Sometimes this choice is taken because of the fear of discrimination outlined above, sometimes because the individual wants to avoid being seen or treated as different, and sometimes simply because the individual feels that health-related concerns are a private, personal matter which need not be known to employers.

Others, especially those with a history of struggling to maintain consistent control over their moods, opt to inform employers. These people often feel reassured that their boss knows what may happen in the future and that he/she may be able to help with work-related aspects of relapse prevention.

It is important that the individual seeking work, or needing to return to work after a period of time off due to problems with mood instability, gives full consideration to the option to disclose or not, and seek out support and counselling (perhaps ideally from a voluntary-sector based employment scheme) if needed to determine the best course for them.

15.4 Balancing need for achievement with mental health

Many individuals diagnosed with bipolar disorder will come from high-achieving families (Coryell et al., 1989; Johnson, 2005; Myerson & Boyle, 1941; Tsuchiya et el., 2004) and have had imparted to them a strong work ethic. Not surprisingly, then, some people struggle with careers which require long, intense and often late hours of work, whether they are artists or financial sector workers. Many people who meet with a psychologist at or around the time of an acute episode of mood instability tell us that they have been working too hard, and not spending enough time with family and friends, or getting enough 'me-time'. Others report that, because of the difficult and intense work they undertake, they struggle to wind down and routinely go out after work, staying out late and, for example, drinking or using drugs, or dancing into the early hours.

We hope this report will go some way toward challenging the status quo of unbalanced working lives, in particular those careers which expect the work agenda to be placed far ahead of social and leisure pursuits in the 'work-life balance' or which encourage a 'work-hard, play-hard' ethos which leads to burnout for most, and mood instability for many. Our advice to those diagnosed with bipolar disorder, in particular, is to give your career aspirations a re-think (do you really want to exhaust yourself pursuing partnership, at the risk of your mental health?), to re-negotiate terms of your working contract with your employer (or, if you are self-employed, to set clear limits on when work starts and stops) and, finally, to ensure that you consciously set a work, social life and leisure/rest balance which optimally correlates with a balanced, stable mood.

15.5 Relationships

Both manic and depressive episodes can be triggered by difficulties in close relationships and, of course, can also have an impact on relationships.

Social stressors and losses are commonly cited as a precipitating factor of mood instability, but of course these factors are present in everyone's life at one point or another. It is useful to identify developing problems early on. If, for example, a person finds that their partner is undermining their confidence or is putting pressure on them to change, this would usefully be addressed before they began to develop low self-esteem or a sense of inadequacy. Other events are unexpected and impossible to prepare for; here, it works best to maintain good levels of social support and to develop your capacity to share your difficulties with those around you so that they do not get on top of you and negatively impact your ability to cope.

People with bipolar disorder often find that some family members and friends rally round when they are experiencing worsening mood problems, while others create a bit of distance in the relationship. The rallying round can be helpful, but can also be felt to be intrusive, or overly paternalistic sometimes (many people with bipolar disorder complain that loved ones suggest that they are manic when they are just in a happy mood).

> *'When my nephew was 18 two years ago, I wore my best purple shirt and I wanted to streak my hair purple for the party but my husband and sister in law told me I was inappropriate for my age. I'd have loved to dance, but I felt I had to reign myself in, in case they thought I was going high.'*

> Interviewee

15.6 Lifestyle practicalities

People with a diagnosis of bipolar disorder regularly report difficulty securing driving licences, obstacles to world travel and challenges to purchasing insurance, to name a few areas of daily living that most of us can take for granted. When prescribed psychiatric medication, drivers are responsible for informing the DVLA. To drive legally, people prescribed psychiatric medication must be well and stable for at least three months, be compliant with treatment, be free from the adverse affects of medication and may be subject to a favourable specialist report. When there have been four or more mood episodes within the previous 12 months, at least six months' stability is required before the person is able to drive legally. Some countries, such as the USA, do not always issue travel visas to individuals who are taking psychiatric medication; it is best to check with relevant embassies or consulates before planning international travel. Countries typically ask for written certification regarding the disorder which includes the diagnosis, duration of treatment and prognosis. MDF the Bipolar Organisation is a useful resource for all of these concerns, and can advise on companies which will provide insurance to individuals with bipolar disorder.

> *'The whole language in which we think about those of us who experience discrimination and exclusion as a result of our mental health problems is one of violence, danger, treatment, compliance and needs for services… It is my contention that those of us who experience mental health problems don't need services so much as we need a life. Mental health problems are not a full time job – we have lives to lead. Any services, or treatments, or interventions, or supports must be judged in these terms – how much they allow us to lead the lives we wish to lead. As for other oppressed groups – the reduction in discrimination – our inclusion in as ordinary in everyday life lies not in the domain of "health", but in the domain of rights.'*

Dr Rachel Perkins – clinical psychologist and service user (Perkins, 2000)

15.7 Changing attitudes

15.7.1 The need to educate policy makers and the public

Perhaps an even greater challenge is to educate the public about the information contained in this report. The report has shown how people can be affected as much by the reaction of people around them as by the actual mood problems themselves. For example, people who are seen as 'mentally ill' often experience prejudice, rejection and social exclusion, which can be significant – sometimes even insurmountable – obstacles to recovery. For many people, prejudice based on misinformation presents a greater obstacle to recovery (in terms of being able to lead a fulfilling life) than the original mental health problems.

> *'Maybe (my) sensitivity to criticism is because being given a diagnosis is like a kick in the teeth. They're not saying that there's something wrong with your liver, but that something is wrong with you'*

OR

> *'Acceptance is really important within yourself, but also to feel accepted by others. I know people who have no understanding and see mental illness as very different. We need a lack of stigma to feel belonging.'*

'Even the psychiatrists themselves, when you are telling them something and their pre-judging what you're saying and you're trying to say … because you are stigmatised with a label you don't get your full allowance that you're … sensible and it's really quite frightening. It's only happened to me a couple of months ago with the psychiatrist … I was trying to tell him, something quite sensible and he was quite fobbing me off and I thought 'no", you know, "why do you do this? Why don't you listen?"'

Sally

The harmful effects on health of discrimination and social exclusion were highlighted in the National Service Framework for Mental Health (DoH, 1999), which states that health and social services should 'combat discrimination against individuals and groups with mental health problems, and promote their social inclusion'. Hopefully the current government-funded Time to Change campaign (http://www.time-to-change.org.uk/) will use the information contained in this report to help educate journalists, politicians, policy makers and the public and to challenge the 'us and them' thinking which is so widespread. Truly helpful responses from services and the community as a whole will only be possible when it is widely recognised that mood problems severe enough to be called 'bipolar disorder' are not something completely other and alien, but something we could all experience in certain circumstances, and which can be thought about in the same way as 'normal' moods.

15.7.2 Changing attitudes: The role of the media
People with a diagnosis of bipolar disorder, like those with other mental health problems, also have to live with the prejudice and discrimination of others. Indeed, it is often not the mood swings themselves but the way in which people with the diagnosis are treated in society that is disabling. Too many people have been taken in by inaccurate media images and do not wish to associate with people with mental health difficulties, wrongly believing individuals with mental health difficulties to be incompetent, unreliable, unpredictable, and dangerous.

For many people, the mass media are a major source, and for some perhaps the only source, of information about mental health. The media will have a very important role to play in informing policy makers and the public about the information and ideas contained in this report, and in helping to change attitudes.

Mental health problems are often portrayed unhelpfully in the media. Part of the reason for this is the lack of good information available to journalists. In the absence of other sources of material, they currently often have to rely on court cases and inquiries. Obviously this will lead to a preponderance of stories about crime and tragedy. Alternative sources of material are badly needed. Initiatives by service users and professionals can help here. One example is the publication of this report, which we hope will be a useful source of such information. A second is Open Up (www.time-to-change.org.uk/what-were-doing/open-up), a grassroots anti-discrimination project run by the charity MIND and linked to the government's Time to Change campaign. Open Up is run by people with lived experience of mental health problems and works on the principle that talking about mental health is the best way to confront stereotypes and tackle prejudice. The project

looks for positive and constructive ways to communicate what it's really like to live with a mental health problem. It links up people with experience of mental health problems so they can support each other to speak out about their experiences. Through the Open Up network, members can access support, advice, training and inspiration for their work challenging mental health discrimination.

We hope that this report will prove to be part of an ongoing major shift in public attitudes that sees prejudice against people with mental health problems become as unacceptable as racism or sexism.

Social inclusion

'I have a vision:

'That one day I will be able to talk about my mental health problems and attract no more than interest in those around me.

'That I can go back to work after a stay in a psychiatric hospital and have my colleagues ask what it was like, rather than delicately avoiding the subject.

'That one day the law will be changed to allow me to do jury service.

'That one day we will see a prime minister who openly talks about his or her experience of mental health problems.

'That one day I will be able to get travel insurance, life assurance, just like everybody else.'

Dr Rachel Perkins – clinical psychologist and service user (Perkins, 2000)

Appendix

Websites

http://www.mdf.org.uk
Website of the MDF the Bipolar Organisation (formerly the Manic Depression Fellowship), a UK user-led charity for individuals and families affected by bipolar disorder. Includes information about self help, bipolar disorder and an e-forum. MDF members automatically receive *Pendulum,* the organisation's quarterly journal.

http://www.theicarusproject.net
The Icarus Project is a grassroots network of independent groups and individuals 'living with the experiences that are commonly labelled bipolar disorder'. It promotes a new culture and language that looks beyond a conventional medical model of mental illness.

http://www.rufusmay.com
Set up by clinical psychologist Rufus May who currently works with the Bradford Assertive Outreach service, this website provides a resource of articles, interviews and other media that Rufus has taken part in promoting a positive psychology approach to emotional health and recovery.

http://www.recoverydevon.co.uk/
A website dedicated to promoting recovery methods and theories to help individuals make an informed decision about their recovery journey.

http://www.mentalhealthrecovery.com/
Mary Ellen Copeland's website about recovery and the Wellness Recovery and Action Plan (WRAP) including links to resources.

http://www.mind.org.uk/foodandmood
Mental health charity MIND's website, including information for anyone interested in how diet can affect mental and emotional well-being. MIND also publish a magazine, *Openmind,* which can be ordered via the website.

http://www.bbc.co.uk/health/tv_and_radio/secretlife_index.shtml
BBC website based around Stephen Fry's two part documentary *The Secret Life of the Manic Depressive* exploring what life is like with bipolar disorder. Includes a bipolar diary and eight short videos of individuals talking about their bipolar experiences.

http://www.bipolarscotland.org.uk/
Bipolar Fellowship Scotland's website resource about bipolar disorder including information, recommended reading and support groups in Scotland.

http://www.youngminds.org.uk/
Young Minds is a UK charity committed to improving the emotional well bring and mental health of young people and empowering their parents and carers. Whilst there is nothing specific to bipolar disorder on the website, it includes useful information about treatments, campaigns, policies and resources.

http://www.mentalhealth.org.uk/information/have-your-say/personal-stories/
The Mental Health Foundation is a UK charity which provides information, carries out research and works to improve resources for people affected by mental health difficulties

with a focus on recovery and wellbeing. The website includes a selection of personal stories, including two by people who have had bipolar experiences (Sara and James) and what they have found useful in their recovery journey.

http://bipolarblast.wordpress.com/recovery-stories/
A website advocating alternative approaches to understanding and supporting bipolar disorder. Includes a selection of recovery stories.

http://www.comingoff.com
This website aims to give you up-to-date information about psychiatric medication, how it functions and the withdrawal process. It is put together by people who have been prescribed medication and withdrawn from it, and clinicians who have been involved in supporting this process.

Podcast: **http://www.mentalhealth.org.uk/information/mental-health-a-z/exercise/**
Podcast with downloads detailing the benefits of exercise on emotional well-being and mental health.

http://www.hafal.org
Welsh charity dedicated to recovery in mental health. Hafal sees recovery as having three key parts: empowerment and self management, commitment to progress and a whole person approach. Hafal's website includes information and resources including a step by step recovery guide.

http://www.evolving-minds.co.uk/
A West Yorkshire-based group, Evolving Minds aims to provide a space to discuss, debate, share, learn value and campaign for alternative and compassionate approaches to emotional and mental health.

http://www.moodgym.anu.edu.au
A free self help programme to help people understand and use basic cognitive behavioural therapy techniques for depression and anxiety.

http://www.livinglifetothefull.com

An online life skills resource using CBT principles to help individuals with life difficulties using CBT approaches.

Books

- Steve Jones, Peter Heywood & Dominic Lam (2005). *Coping with bipolar disorder: A guide to living with manic depression.* Oxford: Oneworld.
- William Styron (2005). *Darkness visible.* London: Vintage Classics.
- Lesley Berk, Michael Berk, David Castle & Susan Lauder (2009). *Living with bipolar.* Crows Nest: Allen & Unwin.
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- Patrick Holford (2007). *Optimum nutrition for the mind.* London: Piatkus Books Ltd.
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- Peter Roger Breggin (1993). *Toxic psychiatry: Why therapy, empathy and love must replace the drugs. Electroshock, and biochemical theories of the 'New Psychiatry'.* New York: St Martin's Griffin.
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- Vera McDonald (1998). *Rosie's mum.* Glasgow: Manic Depression Fellowship. (A story for young children about a mum with bipolar.)

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