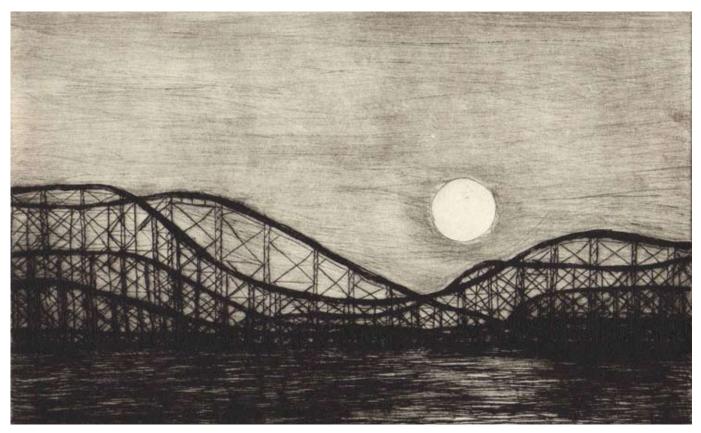


# A guide for caregivers of people with bipotar disorder



A Rollercoaster Life - Larissa MacFarlane





Lesley Berk, Anthony Jorm, Claire Kelly, Michael Berk, Seetal Dodd and the clinicians, caregivers and people with bipolar disorder who helped to develop this guide.

### Welcome

### Bipolar disorder can affect not only the life of the person with the illness, but also their close family, partners and friends.

If you are a family member, partner or friend who is 18 years or over and a primary source of support for a person with bipolar disorder, this guide was designed for you. It involves information and suggestions about:

- Bipolar disorder, how it is managed and treated and helpful resources.
- Ways that you can help a person with bipolar disorder who is 18 years or over (bipolar disorder can present in different ways in childhood and adolescence).
- Ways to cope with the personal impact of the illness and to take care of yourself.

The information and suggestions in this guide resulted from a study that combined the latest research with the opinions and consensus of international panels of caregivers, people with bipolar disorder, clinicians and researchers, all with experience and expertise in dealing with bipolar disorder.

This study was conducted at the University of Melbourne as part of a PhD project by Lesley Berk under the supervision of Professor Anthony Jorm, Dr Claire Kelly and Dr Seetal Dodd in consultation with Professor Michael Berk.

A number of artists with mental health problems and caregivers also created some of the artwork that is used to illustrate this guide. You will find their names recorded under the respective artwork. Not all of the information or suggestions may be relevant to you. Bipolar disorder can manifest in different ways, and caregiving experiences differ. Finding what works for you to deal with your situation can be a trial and error process. Along the way it is vital to acknowledge and give yourself credit for what you are already doing to help the person and deal with your situation.

This guide is NOT a replacement for medical advice and we strongly recommend that you or the person you care for discuss issues related to treatment with a clinician. Although this guide is covered by copyright, you can freely reproduce it for non-profit purposes provided the source is acknowledged.

Enquiries should be sent to Lesley Berk at lberk@unimelb.edu.au

Bipolar disorder can manifest in different ways, and caregiving experiences differ. Finding what works for you to deal with your situation can be a trial and error process.



### Contents

Chapter 1: Bipolar disorder	5
1.1 Bipolar episodes	5
A manic episode	5
A hypomanic episode	5
A depressive episode	6
A mixed episode	6
1.2. Different types of bipolar disorder	7
1.3. Patterns of illness	7
1.4. Causes and triggers of bipolar episodes	8
1.5. Bipolar disorder often occurs with other conditions	8
Chapter 2: Treatment and management	9
2.1. Medical treatment	9
2.2. Psychological treatment	11
2.3. Reducing triggers of illness and making lifestyle adjustments	12
2.4. Dealing with bipolar warning signs	13
2.5. Developing a good support system	14
Chapter 3: Supporting the person when they are ill	15
3.1. Helping when a bipolar episode occurs	15
Supporting the person with depression	16
Supporting the person with mania or hypomania	17
3.2. Dealing with risky or inappropriate manic or hypomanic behavior	18
3.3. Dealing with a bipolar crisis	19
3.4. Planning for times when the person is severely ill	20
3.5. Helping to prevent suicide	21
3.6. Supporting the person after a bipolar episode	23
3.7. Supporting the person with mild ongoing symptoms or difficulty functioning	23
Chapter 4: Helping the person to keep well and enjoy life	24
4.1. Supporting the person's medical treatment	24
What if the person decides to stop or reduce their medication?	24
4.2. Considering psychological treatment?	26
4.3. Helping to reduce bipolar triggers	27
4.4. Helping to recognize warning signs of illness	27
4.5. Helping the person to gain confidence and live well with bipolar disorder	29
4.6. Helping the person adjust to wellness	30
4.7. Stepping back to let the person do more for themselves	30

Chapter 5: Taking care of yourself	31
5.1. Helpful coping strategies	32
Getting organized	32
Restoring your energy	32
Getting rid of unrealistic expectations	32
Maintaining boundaries and setting limits	32
Developing your own support system	33
Taking steps to sort out problems	33
5.2. Caring about your health	34
Developing good habits	34
Reducing your own stress or depression	34
5.3. Adapting to caregiving	35
Coming to terms with the illness	35
Acknowledging your natural reactions and deciding how to deal the situation	with 35
5.4. Maintaining or rebuilding your relationship	36
Using good communication skills	36
5.5. Recognizing the positives	38
The positive side of caregiving	38
Positive things about the person	38
The tasks you manage to do and the support you provide	38
Chapter 6: Ways to take care of yourself in specific challenging situations	39
6.1. If the person is ill a lot of the time	38
6.2. Reducing stress if a bipolar crisis occurs	40
6.3. If there is a lot of conflict between you and the person	40
6.4. If the person is ill, irritable and very critical of you	40
6.5. If the person is physically aggressive	41
6.6. Dealing with negative consequences of risky behavior	41
Chapter 7: Working with the person to deal with the illness	42
7.1. Considering how involved to be in helping the person with their illness	42
7.2. Helping without mentioning the illness	42
7.3. Talking to the person about how to help	43
7.4. Making agreements and plans	43
7.5. Working with the person and their doctor	44
7.6. Supporting the person who is disappointed about relapsing	44
7.7. When the person has difficulty with their illness management strategies	44
7.8. Difficulties in working with the person to deal with the illness	45
If the person doesn't want your help	45
If the person refuses to treat their illness	45
If the person refuses responsibility for managing their illness	46

11

### Contents (cont)

Chapter 8: Dealing with stigma, discrimination and disclosure	47
	47
8.1. Ways to deal with stigma and discrimination	47
8.2. Ways to assist the person to deal with stigma	48 48
8.3. Disclosing the illness or your caregiving role	48
Chapter 9: Resources	49
9.1. Dealing with bipolar disorder	49
Australia	49
United States	50
United Kingdom	51
Ireland	52
New Zealand	52
Canada	52
The Netherlands, Portugal, Brazil	53
Spain	53
9.2. Caregiver organizations and programs	54
Australia	54
United States	55
United Kingdom	55
9.3. Crisis Help Lines	56
Australia	56
United States, United Kingdom, Ireland, New Zealand	56
9.4. Suicide prevention and support for those bereaved by suicide	57
International	57
Australia	57
United States	57
Canadia	57
New Zealand	58
UK and Europe	58
9.5. Drug and alcohol services	58
Australia,	58
United States, United Kingdom,	59
New Zealand (NZ), Canada	60
9.6. Anxiety management	60
Australia, United States, United Kingdom	61
Ireland, Canada	61
9.7. Guidelines on bipolar disorder and its treatment	62
9.8. Information on medications for bipolar disorder	62
9.9. Mental Health First Aid	62
9.10. Books on bipolar disorder	62
Personal accounts of bipolar disorder and coping	62
Books by family members	62
Books by health professionals/researchers	63
9.11. Books on dealing with anxiety	63
References	64
IVEIEI EI IVE3	04

### PLEASE NOTE:

The artworks in this guide are copyrght.

To contact any of the artists see bipolarcaregivers.org

### Chapter 1: Bipolar disorder

Bipolar disorder involves more than the ordinary mood changes people experience in response to the ups and downs of life. It involves mood episodes where the person's thinking, feeling and behavior changes noticeably for a considerable duration of time and affects their daily functioning. Sometimes the person will only have a few symptoms rather than an actual episode. Knowing some of the episodes and symptoms can help to identify when the person you care for is ill.

### 1.1 Bipolar episodes

People with bipolar disorder experience mania, hypomania or mixed states. Most people experience some level of depression as well.

### A manic episode

A manic episode involves *excessively happy, elevated, or irritable mood* that lasts at least a week (or any length of time if the person needs to be hospitalized) and at least 3 or 4 of the following symptoms:

- Excessive confidence or grandiose ideas
- Decreased sleep (appear to need much less sleep)
- More talkative than usual
- Very easily distracted

- Very active (e.g. in carrying out work, social or sexual goals) or restless and agitated
- Pursues lots of pleasurable, but risky activities (e.g. buying sprees, gambling or sexual indiscretions)
- Racing thoughts or speech is continuous, rapid and goes off topic so it is hard to follow

These symptoms disrupt the person's work, relationships or daily functioning. In addition, psychotic symptoms such as hallucinations (when people perceive things that are not actually there) or delusions (strong beliefs that are not based on reality) or disordered and racy thinking can be part of mania.

### A hypomanic episode

A hypomanic episode involves noticeable changes in mood that are *similar to mania, only much milder and less disruptive.* Also, people who are hypomanic do not have psychotic symptoms or need hospitalization. Hypomania can be diagnosed if the person has symptoms for at least 4 days.



Hues of Mania - Natasha Simon

### A depressive episode

A depressive episode occurs when for most of the time over at least 2 weeks, the person experiences:

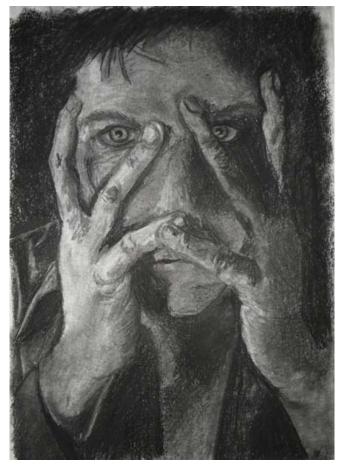
*Depressed mood* (sadness or flatness) or this is observed by others (e.g. person is tearful) OR, *loss of interest or pleasure* in things AND at least 4 of the following symptoms:

- Lack of energy and tiredness
- Being noticeably slowed down or much more agitated
- Noticeable changes in appetite and weight
- Sleep problems (e.g. sleep too much or can't fall asleep)
- Feelings of worthlessness and excessive guilt
- Difficulty in concentrating, thinking or making decisions
- Recurrent thoughts about suicide or death.

These symptoms cause personal distress or disrupt the person's social, occupational or other daily activities. Some people experience psychotic symptoms (e.g. delusions, which are strong beliefs that are not based on reality).

### A mixed episode

A mixed episode occurs when the person has *symptoms of both mania and depression at the same time* for at least a week. Symptoms cause significant disruption to the person's daily life and hospitalization may be necessary. For example, the person may be restless, racy or overactive, unable to sleep, and feel guilty and suicidal.



Depression- Rachael Westbrook



Bipolar A - Deirdre Oliver

### **1.2.** Different types of bipolar disorder

There are different types of bipolar disorder including:

- **Bipolar I disorder:** involves one or more manic or mixed episodes. Most people experience symptoms of depression as well.
- **Bipolar II disorder:** involves at least one episode of hypomania and an episode of depression.
- **Cyclothymia:** involves hypomania and mild symptoms of depression (not an episode of depression) that are experienced most of the time over at least a two-year period.
- When bipolar disorder does not fit into the above categories: For example, a person may experience mild depressive or hypomanic symptoms that last less than the two years specified for cyclothymia. Another example would be when a person has depressive episodes, but their experiences of mood elevation are too mild or brief to be diagnosed as mania or hypomania.

Many people with bipolar disorder, especially those with bipolar II disorder, spend far more time with various degrees of depressive symptoms than in elevated bipolar moods.

### How prevalent is bipolar disorder?

About 1 in every 100 adults is likely to have bipolar I disorder. When including bipolar II disorder and the milder forms, the prevalence goes up to about 4 in every 100 adults.<sup>1</sup>

> The course of bipolar disorder and its impact on daily life differs from person to person.

### 1.3. Patterns of illness

Most people with bipolar disorder experience recurrent episodes with different degrees of wellness between them. These episodes are not always predictable.

### Can you predict when an episode will occur?

Bipolar episodes sometimes follow a distinct pattern (e.g. depression usually follows hypomania or the person has a seasonal pattern). However, for many people a distinct pattern does not occur.

Getting to know what typically triggers an episode (e.g. disruption to sleep patterns) (see section 2.3 of this guide) and warning signs that a bipolar episode is about to occur (see section 2.4) can help the person and those who care for them to recognize and respond to high risk times.

### How frequently do people relapse?

Some people stay well for long periods of time. Others relapse more frequently. On average most people have an episode every 2 to 3 years. However, some people have a more chronic type of illness and cycle from one episode to another. People who relapse at least 4 times a year are considered to have *rapid cycling*. If the person you care for relapses frequently, don't give up hope as patterns of illness can change and with time the illness may become more controllable.

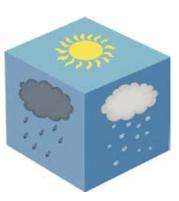
## Different degrees of wellness between episodes

Bipolar disorder can involve periods of wellness when the person you care for is symptom free. However, people can also experience mild symptoms between episodes (subsyndromal symptoms). You may find that certain mild symptoms make it more difficult for the person to do daily tasks or to get along with others (e.g. having no energy, being withdrawn or irritable, having difficulty sleeping or racing thoughts).

If the person has experienced *mild ongoing depression* most of the time for over two years, they might have dysthymia. Lingering depressive symptoms can also result from the losses and changes people experience due to the illness.

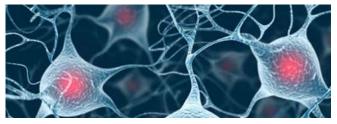
Even when they have no symptoms of depression or mania, the person may find that the illness has affected certain abilities. For example, they might not remember things as well as they used to, or have difficulties sustaining attention or doing things as quickly as before. On the other hand, some people function very well between bipolar episodes. It is clear that the course of this illness can differ widely from person to person.

7



## 1.4. Causes and triggers of bipolar episodes

Factors that cause bipolar disorder and affect the person's pattern of illness include:



### **Biological factors**

The cause of bipolar disorder is similar to other illnesses like diabetes or asthma where the person has a biological vulnerability to develop particular symptoms. This biological vulnerability includes changes in brain chemicals and functioning as well as hormonal and immune changes in the body. Certain medications have been found to reduce some of these changes (while the medication is in the person's system). Researchers are trying to pinpoint specific biological markers of bipolar disorder that will make it easier to diagnose and treat in the future.

A person's genes influence the chance of them having bipolar disorder, but this is not the only factor that contributes to the illness. Identical twins share all their genes. For bipolar disorder to be 100% genetic, you would expect that if one twin had bipolar disorder, the other would have it too. However, although there is an increased risk of the twin developing the illness, this does not always occur.<sup>2</sup> Bipolar disorder arises from the interaction of biological factors and certain personal and environmental stressors.

### **Environmental and personal factors**

Bipolar symptoms can be sparked off by environmental and personal factors called 'triggers' (e.g. stressful events or disruption to sleep patterns). However, episodes do sometimes occur without a trigger. There is more information on triggers in section 2.3.



### The way the bipolar disorder is managed

Some ways people manage the illness are helpful (see the next section on 'Treatment and management') and others are unhelpful or harmful (e.g. drinking alcohol to reduce depressed mood may make depression worse). Although good illness management strategies and treatment can help people to keep well, bipolar disorder is a complex illness and relapse may still occur. Nevertheless, managing the illness and doing things they enjoy or that are meaningful to them, helps many people with bipolar disorder to live well despite the illness.<sup>3,4</sup> Even when bipolar relapse occurs, there are ways to treat it and to try to reduce the negative consequences that sometimes arise.

## 1.5. Bipolar disorder often occurs with other conditions

Bipolar disorder commonly occurs together with other conditions. For example, it is common for people with bipolar disorder to have alcohol or other drug problems or to suffer from anxiety disorders. Having bipolar disorder and another condition can be more challenging for the person and their loved ones. Both conditions need to be treated. There is a little more information on alcohol or other drug problems (section 9.5) and anxiety (section 9.6) and supportive organizations and services.

> Bipolar disorder arises from the interaction of biological factors and certain personal and environmental stressors.

### **Chapter 2: Treatment and management**

Taking ongoing medication (even when the person is well) can help to prevent relapse, reduce hospitalizations and suicide risk.<sup>5,6</sup> Medication can also reduce symptoms if the person is acutely ill. Medication is considered to be the first line of treatment for bipolar disorder. Specific psychological treatments, illness self-management strategies and good support from caregivers and clinicians can also help people to keep well and enjoy life.

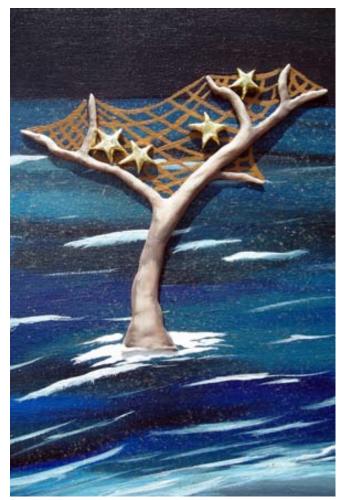
### 2.1. Medical treatment

Some people find that the first medication they take to treat their bipolar disorder helps to keep their mood stable. However, medications do not work equally for everybody. Working together with their clinician, the person might need to try different medications alone, in combination, or at different doses to see what works for them. See Box 1 below for some important points about medications for bipolar disorder.

### Box 1: Some important points about medications for bipolar disorder

Some important points about medications include:

- Medications often take **time to begin to work** and for people to experience the full benefits of taking them. It may be useful to know approximately how long a medication will take to work.
- If the person **stops taking a medication that has helped**, the benefits will no longer be there once the medication is out of their system.<sup>5,7</sup>
- Medicines can have **side effects** and some caregivers and people with bipolar disorder find it useful to know about common side-effects. Some side effects are temporary, or can be overcome by adjusting the dose or changing medications in consultation with the clinician. Sometimes, the person may decide to continue with a medication as the benefits to their mood outweigh the discomfort of the side effects. These are personal choices.
- Some medications need to be stopped gradually.
- If the person develops **new symptoms**, medications that have helped to keep their bipolar mood stable may need to be adjusted.
- **Blood tests** are required to monitor certain medications.
- The person may need to check with their clinician or pharmacist to see if the medications they are taking have **negative interactions** with other medications they may need.
- Certain medications are not recommended during **pregnancy or if a mother is breastfeeding.**
- **Changes in diet** may be required while taking certain medication.



Netting Stars - Sarah K Reece

### What kinds of medical treatment can help?

Medications that have shown the most benefit in the treatment of bipolar disorder include *mood stabilizers* and *atypical antipsychotics* (see Box 2 and 3 below). The use of *antidepressants* alone to treat bipolar disorder is not recommended as they may trigger hypomania, mania, mixed states and rapid cycling (see Box 4 below). <sup>8</sup> *Anti-anxiety medications (benzodiazepines)* are sometimes used for short periods in conjunction with a person's usual medications to relieve restlessness, anxiety, panic or insomnia (see Box 5 below). Different medications and combinations may be used to reduce different kinds of bipolar episodes.

Following are some examples of medications used to treat bipolar disorder. In the first column on the left is the chemical or generic name of the medication. The next column has examples of some of the brand names assigned to these medications by pharmaceutical companies. The last column has a little information about this group of medications.

### Medications commonly used to treat bipolar disorder

### Box 2: Mood stabilizers

Chemical name	Brand names	How they help
Lithium Valproate or Divalproex Carbamazepine Lamotrigine	Quilonum, Camcolit Depakote, Epilim Tegretol Lamictal, Lamictin	Mood stabilizers can help to reduce symptoms of acute episodes and keep mood stable, preventing recurrence if taken in an ongoing way. <sup>5, 7</sup> Certain mood stabilizers help to reduce suicide risk. <sup>6</sup> It can take months before the person experiences the full benefits of the mood stabilizer.

### **Box 3: Atypical antipsychotics**

Chemical name	Brand names	How they help
Olanzapine	Zyprexa	Atypical antipsychotics can help to reduce mania and some are used to
Quetiapine	Seroquel	treat bipolar depression and prevent relapse. <sup>5</sup> They are also used to treat
Aripriprazole	Abilify	anxiety, psychosis, restlessness and sleep problems.
Risperidone	Risperdal	
Asenapine	Saphris	
Amisulpiride	Solian	
Ziprasidone	Zeldox	
Clozapine	Leponex, clozaril	

### **Box 4: Antidepressants**

Chemical class	Brand names	How they help
SSRI's (sertraline, paroxetine, fluoxetine, citalopram, fluvoxamine, escitalopram	Zoloft, Aropax/Paxil, Prozac, Celexa/Cipramil, Luvox, Lexapro	While the literature is unclear in bipolar disorder, antidepressants may assist in some
SNRI's (venlafaxine, duloxetine, desvenlafaxine)	Efexor, Cymbalta, Prisiq	people who have depression provided they are taken together with a mood stabilizer. <sup>8</sup>
MAO inhibitors (tranlcypromine, phenelzine)	Parnate, Nardil	
Tricyclics (amitriptyline, imipramine)	Tryptanol, Tofranil	
Other (mirtazapine, reboxetine, bupropion, agomelatine)	Remeron/Avanza, Edronax, Wellbutrin, Valdoxan/Melitor	

### Box 5: Benzodiazepines

Chemical name	Brand names	How they help
Clonazepam,	Rivotril/Klonopin,	Benzodiazepines can help to relieve anxiety, panic, restlessness and insomnia.
Diazepam	Valium	These are the only medications used in the treatment of bipolar disorder that are addictive. Higher doses are eventually required to get the same benefits. This means that they should be used for short periods when necessary rather than as daily treatments.

### Electroconvulsive therapy (ECT)

When a person is severely depressed or at risk (e.g. they have stopped eating or sleeping, or are very suicidal) and other treatments don't seem to help, ECT can be effective in stabilizing mood.<sup>9</sup> It is most beneficial in reducing severe depression. However, it can help to reduce severe symptoms of other types of episodes as well. In ECT the person is given an anesthetic, and electrical stimulation is applied to a specific area of the brain. Temporary confusion or loss of memory may occur for a certain time after treatment.

## Additional treatments sometimes used to supplement usual medications

- Some studies have found Omega-3 *fatty acids* helpful in reducing depression when added to the person's usual medications.<sup>10</sup>
- If a person is deficient in *vitamin D, folate or vitamin B12* (can be checked with a blood test), taking supplements in addition to their usual medication may help to reduce depression. However, vitamin D or other supplements have not been comprehensively studied in people with bipolar disorder.<sup>11</sup>
- *St John's Wort* has *not* been studied for use in bipolar disorder and can have a negative effect when taken with certain medications prescribed for bipolar disorder.
- *Exercise* is helpful in reducing depression and has additional general health benefits.<sup>12</sup> There is some evidence of benefits in reducing bipolar depression and anxiety.<sup>13</sup>
- Research to improve the treatment of bipolar disorder is ongoing and there are some treatments currently being tested such as the antioxidant, *N-acetyl cysteine* (NAC) which may have some benefit in reducing bipolar depressive symptoms when combined with the person's usual treatment, and ketamine.<sup>14, 15</sup> More information is required before these treatments are generally recommended.

PLEASE NOTE: The information in this guide is introductory and for any treatment decisions and more information we recommend you consult a clinician. In addition, there are treatment guidelines you can refer to in section 9.7 of this guide.

### 2.2. Psychological treatment

The main psychological treatments that have shown some benefits include *Psychoeducation, Cognitive Behavioral Therapy (CBT), Family Focused Therapy (FFT) Interpersonal and Social Rhythm Therapy and enhanced care programs* (see Box 6 and 7 below). In research studies these treatment programs were added to the person's usual medication for bipolar disorder and programs were conducted by trained health professionals. Benefits included reductions in certain types of bipolar relapse, time spent ill, hospitalization, and improved functioning. For example, in a study of group psychoeducation, people with bipolar disorder who participated in group psychoeducation showed a greater reduction in bipolar relapse than those who participated in a supportive group without psychoeducation.<sup>16</sup> Some of these benefits, especially those related to depression, may still be experienced 5 years after treatment.

## Box 6: Psychological treatments involving the person with bipolar disorder

### Psychoeducation

Psychoeducation involves learning about and discussing bipolar disorder, its treatment and positive ways to manage it and keep well.  $^{16}\,$ 

## Cognitive behavioral therapy (CBT) or Cognitive Therapy (CT)

These approaches involve psychoeducation with a focus on assisting the person to alter their thinking patterns to help change their mood, mood monitoring and setting small goals to build up activity levels when depressed.<sup>17,18,19</sup>

### Interpersonal Social Rhythm Therapy (IPSRT)

IPSRT involves psychoeducation with a focus on assisting people to regulate their sleep patterns, social and daily activities, and dealing with the changes and losses sometimes connected to bipolar disorder.<sup>20</sup>

#### Enhanced care programs

These are long term treatments that involve psychoeducation and frequent contact with a nurse care coordinator to help the person monitor their mood and medication, and work as a team with the treating doctor.<sup>21, 22</sup> Positive results can occur when caregivers are included and work together with the person to deal with the illness. For example, people with bipolar disorder who participated in Family Focused Therapy (FFT) spent more time well and had fewer relapses and hospitalizations that those who did not receive this treatment.<sup>23</sup> FFT also helped to improve people's daily functioning and reduce the duration of depressive episodes.<sup>24</sup> Caregivers who participated in a caregiver psychoeducation group experienced less distress connected to the illness than those who did not.<sup>25</sup> Their relatives also benefited in that they experienced less hypomanic and manic relapse.<sup>26</sup>

#### Box 7: Psychological treatments that include the family

### Family Focused Therapy (FFT)

FFT includes the person with BD together with their family member(s).<sup>23, 24</sup> It involves information and discussion about the illness, its treatment, ways to manage it, solve problems together and improve family communication.

### Caregiver group psychoeducation

Caregiver group psychoeductaion involves groups for caregivers of people with bipolar disorder.<sup>26</sup> Caregivers can learn more about the illness, its treatment, ways they can help to prevent relapse, deal with family stress and take care of themselves.

#### Family focused treatment for caregivers

Family - Focused Treatment - Health Promoting Intervention is for caregivers.<sup>27</sup> It combines information on the illness and ways to manage it (as in FFT) with a focus on helping caregivers to set personalized self-care goals and reduce depression and other health problems.

Certain people with bipolar disorder may benefit more from specific types of psychological treatment.<sup>19, 28</sup> However, overall the research suggests that combining medication and specialized psychological treatment for bipolar disorder can be helpful and this is recommended in treatment guidelines (see section 9.7).

## For more information if you or the person are considering psychological treatment see section 4.2.

## 2.3. Reducing triggers of illness and making lifestyle adjustments

'Triggers' are 'stressors' that increase the risk of the person developing symptoms (see box 8 below). The presence of a trigger does not automatically mean that the person will become ill. Recognizing a trigger provides the opportunity for the person to either reduce the stressor or find helpful ways to cope with it. Triggers can also make the person's bipolar symptoms worse if they are already ill.

To keep well the person may need to make some adjustments to their *lifestyle* and *goals*. The extent of this adjustment can differ from person to person. It usually takes time for the person to make these changes and work out how to live well with the illness.

#### Box 8: Common triggers of bipolar symptoms

#### **Common triggers include:**

- **Stressful negative or positive life events** (e.g. the birth of a baby, a promotion, losing a job, ending a relationship or moving house).<sup>29</sup>
- **Disruption to sleep patterns** (e.g. due to jet lag or social events). Decreases in the time the person sleeps can contribute to hypomanic or manic symptoms, and increases in sleep or bedrest may sometimes be followed by depressive symptoms.<sup>30</sup>
- **Disruption to routine.** A regular structure (e.g. regular going to bed and waking up times, regular activities and social contact) can help to maintain the body's sleep patterns and usual energy levels.<sup>31</sup>
- Too much stimulation from external sources (e.g. clutter, traffic, noise, light, crowds, work deadlines or social activities).<sup>3</sup>
  - Too much stimulation from within the person. (e.g. overstimulation from lots of activity and excitement when the person tries to achieve challenging goals or having stimulating substances like caffeine (e.g. in coffee or cola) or nicotine (e.g. in cigarettes or nicotine patches).<sup>3, 32</sup>
  - Abusing alcohol or street drugs (see section 9.5 for more about how alcohol and other drugs can affect a person who has bipolar disorder).<sup>33</sup>
  - Conflict and stressful interactions with people. <sup>34</sup>
  - Illness that is not treated or managed.

### 2.4. Dealing with bipolar warning signs

Warning signs are changes in the way the person behaves, thinks or feels that are much milder than actual symptoms and indicate that they may be developing a bipolar episode. Many people get warning signs of illness. The person you care for may share some of the more common warning signs or have their own individual signals (see Box 9, 10, 11). Catching these warning signs early gives the person a chance to prevent an episode from occurring. If the person does not get early warning signs, recognizing and trying to manage symptoms as early as possible may reduce the severity or duration of the episode.

## Box 9: Common and individual warning signs of mania and hypomania

## The most common warning signs of hypomania and mania include when the person:<sup>35, 36</sup>

- Sleeps less
- Is more active or pursues more goals (has lots of energy)
- Is more sociable
- Is irritable or impatient
- Is agitated or restless
- Talks much more than usual
- Speaks very fast
- Can't concentrate well or is easily distracted
- Has increased self-confidence, self-importance or optimism
- Has an elevated mood
- · Has racing thoughts

## **Other warning signs of hypomania or mania** that have been reported include when the person:<sup>37, 38</sup>

- Has lots more ideas and plans
- Starts doing more risky activities
- Has an increased sex drive
- Drinks lots of alcohol
- Has heightened senses (e.g. everything looks more colorful or scents are more intense)

### Individual warning signs of hypomania or mania

Examples of more individual warning signs include when the person changes their hair color more often, wears more make up or more seductive clothing. These signs are more unusual. It can be useful to work out if the person behaves in certain distinct and noticeable ways before becoming hypomanic or manic.

Importantly, the person may not always be aware that these changes are warning signs of illness.<sup>39</sup> Some caregivers and people with bipolar disorder work together to recognize these signs (see 'Helping with bipolar warning signs' section 4.4).

### Box 10: Common and individual warning signs of depression

## The most common warning signs of depression include when the person: $^{35}$

- Is less interested in doing things that they usually enjoy
- Is less interested in being with close friends
- Is anxious or worries a lot
- Has sleep problems
- Is tearful or sad

## **Other warning signs of depression** include when the person:

- Is tired a lot
- Neglects certain tasks and does less
- Has physical aches and pains
- Is more forgetful
- Withdraws from social interaction

## More individual warning signs of depression include when the person:

- Does not want to make phone calls
- Loses their sense of taste

These signs are very individual. It can be useful to work out if the person behaves in certain distinct and noticeable ways before becoming depressed.

Sometimes the person may have more ongoing difficulties in certain areas of functioning that need to be distinguished from warning signs of depression.<sup>40</sup>

### Box 11: Common warning signs of mixed episodes

People who experience mixed episodes may get warning signs that are typical of depression or mania. **Common warning signs of mixed episodes** include when the person is:<sup>37</sup>

- Agitated and restless
- Loses weight
- Is easily distracted
- Feels tired
- Engages in harmful activities
- Loses interest in things
- Has increased activity levels
- Talks very fast
- Has sleep problems

### 2.5. Developing a good support system

Many people with bipolar disorder recommend developing good support networks.<sup>41</sup> These networks may include:

- Certain *family members and friends* for companionship and to help with the illness when necessary. Research has shown that caregivers can assist the person to reduce manic and hypomanic relapse, and appropriate support may help with depression.<sup>26, 42</sup>
- More *distant acquaintances* may also help out at times (e.g. a neighbor may give the children a lift to school).
- Selective work colleagues or other people who share the person's interests.
- *Peer-support groups* provide the opportunity to communicate with like-minded people.
- A good relationship with a *clinician or mental health team* can help the person to deal with the illness and get the best from treatment.

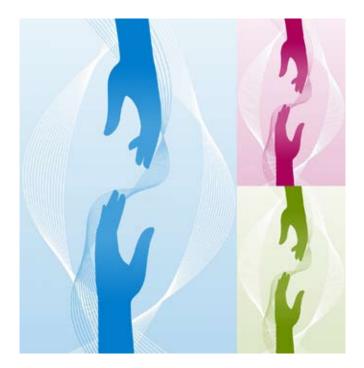
Taking ongoing medication, leading a healthy lifestyle, responding to triggers & warning signs & having good social and clinical support networks helps many people with bipolar disorder to keep well.



### Chapter 3: Supporting the person when they are ill

Caregivers differ in how much and what type of support they provide (e.g. some help only when there is an emergency, while others also assist the person to try to prevent relapse). The phase and severity of the illness influences what support the person needs. They may not need much help with their illness when they are well.

There are lots of things you can do to support a person with bipolar disorder. You can see what suits you, the person and your caregiving situation (see 'Considering how involved to be in helping the person with their illness' section 7.1). Below are some suggestions.



#### Box 12: Different kinds of support

### Different kinds of support include:

- **Practical help** (e.g. give the person lifts to the doctor or help with the housework when they are ill).
- **Information or suggestions** (e.g. discussing information about the illness or resources with the person).
- **Companionship** (e.g. talking things through or doing enjoyable things together).
- **Emotional support** (e.g. letting the person know you care for them or that you believe in their ability to deal with the illness and make a good life for themselves).
- Non-verbal support (e.g. being available to listen, to monitor symptoms or give an encouraging gesture can be supportive). You don't always have to say something to be supportive.

## 3.1. Helping when a bipolar episode occurs

There are helpful ways to communicate with the person and support them when an episode occurs.

### **Communicating calmly**

When the person is ill, it is best not to communicate with them in emotional or loud ways (e.g. by shouting or very emotional expressions of concern). Keep in mind that the person is ill and try not to react impulsively to what the person says or does (e.g. if the person is irritable try not to respond in the same way).

Being supportive does not mean you have to agree with what the person says when they are ill. You can acknowledge that what they say is very real to them (e.g. "I know you are convinced that you should quit your job, but I am not so sure"). Validating the feeling behind what they say can be supportive (e.g. "I can see you are feeling fed up with your job right now, but maybe you need to wait until you are a bit less upset about things before making a decision to quit").

### Supporting the person to access treatment

Encourage the person to contact their clinician or mental health team if they have not already done so. You can offer to assist them to access treatment. If the person is severely ill or there is a risk to their wellbeing or that of others, they need emergency assistance (see 'Dealing with a bipolar crisis' section 3.3). Encourage the person to focus on getting well as their primary goal.

### Helping to monitor the illness

Keep in contact with the person and observe, listen and tactfully enquire about how they are. In this way you can help monitor symptoms to see if they get worse. There are also formal ways that people with bipolar disorder can monitor their mood, sleep and activities with the aim of stabilizing their mood. You can find out more about this on: http://www.manicdepressive.org/moodchart.html OR http://www.pendulum.org/bpcoping.htm

### Helping if the person needs to go to hospital

Some episodes are more severe than others. While many people can be treated at home, sometimes people with bipolar disorder need to be treated in hospital.

Hospitalization may be recommended if:

- There is a bipolar crisis, such as the person is severely ill and their functioning is very impaired or they are in danger of doing something with damaging or life threatening consequences (see 'Dealing with a bipolar crisis' section 3.3).
- Treatment and support does not seem to help their symptoms.
- Changes to their treatment require close supervision by medical staff.
- In addition to their bipolar disorder, they need to address alcohol or drug problems.
- The person has symptoms that have a disruptive effect on their life, and they need timeout to focus on getting well.

If the person has severe symptoms and is finding it hard to function, encourage them to talk to their clinician or mental health team about whether hospitalization may be helpful. In some countries there are halfway houses, which offer a peaceful and contained environment for people who are not too severely ill. This may also be an option for the person to discuss with their clinician.

If the person's clinician recommends hospitalization, encourage the person to seek *voluntary* admission to hospital rather than to be admitted against their will. Discuss with the person that going to hospital may be an opportunity to take time off to get well, away from stressful demands. In extreme situations *involuntary* hospitalization may sometimes be recommended (see 'Planning for times when the person is severely ill' section 3.4).

If the person is admitted to hospital, you can:

- If necessary, provide information to assist with treatment (e.g. about the person's recent symptoms or medications).
- Tailor your contact with them to what the person is comfortable with, as the person may feel vulnerable about social contact.
- Take time to rest while the person is hospital.

Depression can make it hard to do things.



### Supporting a person with depression

There are some suggestions below for ways to support a person who is depressed (see Box 13)

### Box 13: Tips for supporting a person who is depressed

## If the person is depressed, in addition to helping them to access medical treatment (see 3.1 above) :

### Let them know you care

Letting the person know you care may be reassuring and comforting for them. It is good to express concern for the person, but not to the extent that it makes them feel overwhelmed and helpless.

### Don't force the person to talk or to 'snap out of it'

When a person is depressed they may not be able to tell you what they are feeling or what help they need. Avoid telling the person to *"pull themselves together"*. Sometimes, *just being there* without telling the person what to do can be comforting for them.

### Consider suicide risk

Although not all people with bipolar disorder become suicidal, depression is a high risk time for suicide. For more information on warning signs of suicide and ways caregivers can help see section 3.5 'Helping to prevent suicide'.

### Encourage small activity goals

Don't try to get the person to do something they find very stressful or overwhelming. Consider encouraging them to do something more manageable, especially something that might give them even a slight sense of achievement or pleasure. If necessary divide the task into even smaller steps (e.g. if they are very depressed, first invite them to sit outside in the sun with you before you ask them to go for a walk). If the person does not maintain basic hygiene, encourage them to do something small in this regard (e.g. to brush their teeth or take a shower).

### Try not to take over

If you find that the person does things very slowly, don't take over and do everything for them. However, if the person is so depressed that they are unable to do a certain task, consider temporarily doing this task yourself or delegating it.

### Encourage as much lifestyle routine as possible

Bipolar moods can disrupt a person's routines and sleep patterns. However, this disruption can also make moods worse. For example, sleeping in the day can make it much harder to sleep at night. Going to bed and getting up at regularly times may help. Having something in particular to do in the morning helps some people with depression to get up at a regular time.

### Box 13: Tips for supporting a person who is depressed (cont)

### Provide a bit of perspective

Assisting the person to acknowledge their achievements, (no matter how small) can have a positive effect on mood. Also consider mentioning positive events and experiences if they occur (e.g. acknowledge some good news the person receives).

### Keep in mind that what comforts one person might not comfort another

For example, while some people with symptoms of depression like to be reminded that they will feel better in time, others might not relate to this.

## If the person worries excessively and is preoccupied with a particular problem consider the following options:

• Tell the person that problems seem bigger than they are because of the illness, and suggest that they postpone trying to sort out the problem until they feel a bit better.

• Invite the person to do something that will distract them from their worries.

• If the person is not too ill, discuss solutions to the problem with them, and assist them to do something small towards these solutions.

### Offer the person kindness, patience and attention even if this is not reciprocated or does not seem to help

You may feel frustrated if your support does not appear to help, and that is understandable. Depression can be persistent. Don't stop supporting them because they don't seem to change or to appreciate or reciprocate your efforts. While they are depressed it may be hard for them to appreciate anything. However, they may still need your patience and care.

It is vital to take care of yourself (see chapter 5) when the person you care for is depressed as caregivers can become exhausted and depressed too.

For ideas about dealing with warning signs or early symptoms of depression (see 'Ways to assist the person with warning signs of depression' section 4.4 Box 20)

### Supporting a person with mania or hypomania

There are some suggestions below for ways to support a person who is manic or hypomanic (see Bbox 14)

## Box 14: Tips for supporting a person who is manic or hypomanic

## If the person is manic or hypomanic, in addition to supporting the person to access medical treatment (see 3.1):

### Help create a calm environment

Reducing triggers that aggravate the person's symptoms can help (e.g. reduce stimulation that makes their hypomania or mania worse such as noise, clutter, caffeine, social gatherings). If the clinician has prescribed medication to assist the person to relax, rest and sleep, consider how you can support the person to do this.

Don't believe that you have to participate in the persons' numerous projects and goals

Be cautious about becoming swept up by the person's hypomanic or manic mood.

### Ways to communicate when the person is manic or hypomanic

Answer questions briefly, quietly and honestly, and avoid being drawn into long conversations or arguments with the person. People with elevated moods are vulnerable despite their apparent confidence, and they tend to take offence easily. If the person starts to argue try to remain detached. Consider postponing the discussion (e.g. say something that is kind but firm such as "*I can see this means a lot to you and we need to discuss it, but I am upset and tired now. Let's discuss it in the morning when my head is clearer*"). Consider trying to find some common ground with the person (e.g. "*Spring has started and it might be an idea to go for a walk in the park sometime*").

### Set limits on certain behavior

If the person's behavior is very risky or abusive, you may need to set limits with this behavior (See 'Dealing with risky or inappropriate manic or hypomanic behavior' in section 3.2 below).



The Redoubt 1 - Artur

Risky or unrealistic ideas or plans when manic can lead to negative consequences.

## 3.2. Dealing with risky or inappropriate manic or hypomanic behavior

If the person is manic, very hypomanic or in a mixed episode, their behavior may become inappropriate or risky (e.g. spending sprees, sexual indiscretions, reckless driving). Below are some ideas to try to prevent or reduce this behavior and its consequences as much as possible.

### Put precautions in place

Discuss with the person when they are relatively well *precautions* they can take to prevent risky activity and negative consequences (e.g. give their credit cards to you temporarily to prevent reckless spending, give their car keys to you to prevent reckless driving, or stay at home if promiscuity or socially inappropriate behavior is a problem). If severe negative consequences have occurred previously, take more *extreme measures* to prevent them in the future (e.g. if the person has spent large sums of money you could arrange to put certain restrictions on their access to finances, such as requiring co-signatures for large expenditures and keeping separate bank accounts).

### Set limits on what behavior you will accept

Where to set limits to protect yourself (or the family) from illness related behavior you find unacceptable is a personal decision. Keep in mind that you cannot control the person's behavior, but you can control how you deal with it. Be careful that you don't simply accept verbal, emotional, physical or financial abuse because the person is ill.

There are ways to set limits with a particular behavior to try to decrease the risk of it occurring again such as:

- 1. Telling the person what behavior you are concerned about and making a positive request that they find ways to try to prevent this behavior from re-occurring. Mention the benefits this would have for the person, yourself and the family.
- 2. Telling the person that the behavior has overstepped a personal boundary and explaining what this boundary is, and what consequences will result if this boundary is not respected. It could also help to specify the benefits that will occur for both of you if this boundary is respected. If you mention consequences, you need to be prepared to follow through with them.

If you let the person know what illness-related behavior you find unacceptable and set limits on this behavior, the person will *know where they stand* and have the option of doing what they can to prevent this behavior from re-occurring. If the person tries hard to prevent this behavior in the future, it is essential to *acknowledge their effort*. Knowing that the person is trying to respect your boundaries can be reassuring.

## What can you do when risky behavior is about to occur?

If the person who is about to do something risky is ill, they need medical help. Besides assisting them to get medical help, what you can do to prevent the risky behavior may depend on the type of behavior. For example, if the person is at risk of carrying out projects with negative consequences tactfully try

to *stall decisions* about these projects (e.g. "*Need to give that idea more thought*").

If the person is offended because you do not agree with their risky ideas or plans, you can tell them that you care about them and are concerned about the consequences. Although aggression is not common, if they are at risk of becoming aggressive, take steps to ensure your safety (see 'If the person becomes physically aggressive' section 6.5).

There may only be a *brief opportunity* to reason with the person to reduce

risky behavior before they become too manic and lose insight into their condition. If you have this opportunity, consider the following options:

- Request that the person does not pursue the risky behavior, and mention the benefits this will have (e.g. if the person is hypomanic: *"I would like us to stay home rather than go to the party, as we can have a nice quiet evening together and you might find it easier to get to sleep"*).
- Point out the link between their bipolar mood and the risky idea or activity.
- Ask the person to consider whether their thinking about a certain project has become so over-optimistic that it is difficult to see the risks or negative consequences.
- Encourage the person to postpone acting on a risky idea until they are well, by defining a specific wellness goal (e.g. *"How about you hold off acting on this idea until the doctor says your mood is stable"* or *"until you have managed to sleep through the night for a week"*).
- Recommend that the person avoid alcohol and other drugs, as these substances increase the risk of acting impulsively.

Although at times it may be possible to prevent risky behavior, sometimes risky behavior and its negative consequence might still occur (see 'Dealing with negative consequences of risky behavior' section 6.6).



### 3.3. Dealing with a bipolar crisis

Bipolar crises include times when the person becomes severely depressed or manic, unable to function or to look after themselves or others, or at high risk of suicide or other negative consequences. Getting help and communicating calmly can assist you and the person to get through a bipolar crisis:

### Get help

If you think that things may be reaching a crisis point, call the person's clinician or mental health team and express your concerns (if the person does not call them). Do not hesitate to call the *mental health crisis team, clinician or an ambulance* if a crisis occurs. If the person urgently needs to be restrained to stop them from harming themselves or others, you might need to call the police. If you are in danger, consider your own safety first and then get medical help for the person (see 'If the person is physically aggressive section 6.5).

If you do not get the help you expect from these emergency services, be persistent and contact another clinician (e.g. the GP), or take the person to a hospital emergency department. Sometimes caregivers find that emergency health services are not available or able to assist them in a crisis, and they need to care for the severely ill person at home. If you are caring for a seriously ill person at home, make sure you have the necessary support (e.g. from clinicians, appropriate family and friends). In a crisis don't be afraid to ask for assistance to prevent negative consequences.

It might be worth finding out about helplines in your area that assist people or their family or friends in a crisis, as these helplines can be a valuable source of support. Counselors are usually trained to listen and assist people to deal with crises and they may offer referral to appropriate services.

Your local telephone directory will have numbers of helplines in your area and you can also look in section 9.3 for some listings of national crisis helplines.

### Communicate clearly and calmly

In a crisis communicate with the person clearly and calmly. It is also not a good idea to give the person lots of instructions. Don't argue, criticize or behave in a threatening way towards them. If appropriate, give the person choices to reassure them that they have some control over the situation (e.g. If you are trying to distract them from risky behavior, you could ask *"Should we* go for a walk or would you prefer to watch a movie?").



I see you falling - Sarah K Reece

In a crisis don't be afraid to ask for assistance to prevent negative consequences.

## 3.4. Planning for times when the person is severely ill

When the person is relatively well, you can make plans with them about what to do if they become severely ill. Making plans in advance helps to be more prepared. You can also help the person to be treated in ways they would prefer to be treated when they are severely ill by planning things in advance. This is a type of advance directive. When the person is relatively well consider discussing:

### Who to contact in a crisis

Find out who the person would prefer you to contact if they become severely ill and you need to access treatment on their behalf. There may be local service options (e.g. mental health crisis team or ambulance). You might also need to enquire if certain emergency services will assist a person with bipolar disorder when they are very ill, but not in immediate danger of harming themselves or others. If you live in a remote area where there are no local emergency services, find out where you can get help if you need it urgently. If the person has established a good relationship with a particular clinician, this clinician may be helpful in a crisis.

### When and how to act on their behalf

You might need to discuss when to intervene on the person's behalf (e.g. when certain symptoms or behaviour are present). If necessary, discuss Power of Attorney agreements to arrange for yourself or others to make urgent decisions on the person's behalf, temporarily and in specific situations.

### What information to provide

Based on their previous experience the person may prefer certain treatments over others. Ask the person about information that you may need to provide to clinicians or

hospitals (e.g. information about the history of their illness and treatment, and about their health fund and social security). Reassure the person that you recognize the sensitivity and confidentiality of this information.

## What hospital or treatment centre the person can go to

You might need to discuss what hospitals will admit the person, as in certain places hospitals might only accept people with specific medical insurance or who have been referred by affiliated doctors. If there is a choice, the person may prefer a particular hospital or treatment. Make sure you have directions to the hospital in case you need them.

### Involuntary hospitalization

If the person has been severely ill in the past, you may need to discuss with them under what conditions to consider involuntary hospitalization. Find out about involuntary hospitalization procedures in case you need to use them. Confirm with the person that actions that you have both agreed upon about obtaining involuntary hospital admission are acceptable to them and will not damage your long-term relationship.

### Who does what?

If the person is usually temporarily unable to complete certain tasks when very ill, it may also be helpful to establish who does what to share some of the tasks. The person may be relieved to know there is a plan in place to take care of urgent responsibilities.



### 3.5. Helping to prevent suicide

Not everyone with bipolar disorder becomes suicidal. However, the risk of suicide is high in bipolar disorder and caregivers need to take even casual or occasional mentions of suicidal thoughts seriously.

If the person is currently suicidal see Box 15.

• **Get medical help:** Contact their clinician or mental health team. If the person is in immediate danger of harming themselves, call the emergency services or take them to the closest emergency department.

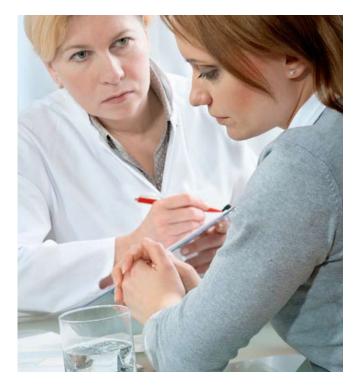
• **Do not leave the person alone.** If you cannot be with them, arrange for someone else to keep them company.

• **Remove whatever means** the person has to kill themselves (e.g. lock away medicines, guns).

• **Contact a suicide or crisis helpline** (see sections 9.3 and 9.4 for some listings of national suicide helplines).

• If the person has a **suicide prevention plan**, assist them to use it.

If the person is currently suicidal, it is possible that they will resent any action you take to prevent them from killing themselves. However, don't let this stop you from taking action to help.



### Help reduce the person's risk of suicide

As a caregiver, there may be some things you can do in conjunction with health professionals and the person themselves to help to reduce the person's risk of suicide. Suggestions include:

- Don't avoid *talking about suicide*, as the person might feel unable to discuss their suicidal thoughts or intentions with you.
- If you think the person might be suicidal, *ask them directly* if they have any thoughts about suicide.
- If the person does discuss their suicidal thoughts, *listen* without judging them. Let the person know that you have heard how they are feeling, recommend medical help and if necessary assist them to access it.
- Be aware that the person may express suicidal thoughts *indirectly* rather than verbally.
- Learn to recognize *warning signs* that they are becoming suicidal or planning to attempt suicide in the near future (see Box 16).
- Be aware of factors that *increase the risk* of suicide (see Box 17)
- *Discuss* with the person ways that you can help them to get through the times when they feel suicidal.
- Assist the person to develop a *plan to prevent suicide* that you can both rely on if they become suicidal.
- Even if the person only has very occasional, vague, passing suicidal thoughts, and none of the factors that increase their risk, still encourage them to discuss these thoughts with their clinician. Keep an eye on the person to see if these thoughts become more specific, frequent or intense.
- It is not always easy to assess the risk of suicide. If you are uncertain about the extent of the risk, assist the person to get a *risk assessment* from their clinician or mental health service.
- Don't try and deal with the suicidal person alone. Contact *family or friends* you can trust (see also 'Reducing stress if a bipolar crisis occurs' section 6.2).

There are organizations dedicated to preventing suicide that offer support, information and training courses for caregivers (see section 9.4).

#### Box 16: Examples of warning signs of suicide

A warning sign is something the person does or says that makes you think they intend to kill themselves in the near future (minutes, hours, days or few weeks). Examples include if the person:<sup>43</sup>

#### 1. Expresses their intention to kill themselves

The person may either threaten to kill themselves or mention their intention casually.

2. Writes or talks more generally about suicide or death

#### 3. Has a plan to kill themselves.

Having a plan increases the suicide risk and the person needs urgent medical help.

### 4. Has mood or behavior changes such as:

• A depressive or mixed episode or has recently had such an episode.

• Hopelessness (e.g. the person can see no hope for their future or reasons to live).

• Putting their affairs in order before they die (e.g. makes a will, takes out life insurance, gives their possessions away or sells their house).

• Apathy and lack of interest in things they used to enjoy.

• Withdrawal from friends and family (e.g. cancels arrangements and isolates themselves).

• Anxiety, agitation or insomnia

• Increased recklessness as if they don't seem to care what happens in the future.

• Increased use of alcohol or street drugs. Also, a person who is suicidal and intoxicated is at risk of impulsively attempting suicide.

• Extreme anger, irritable or desire for revenge.

• A sudden lift in mood. Once a person has a plan to kill themselves, their mood sometimes temporarily improves. If the person has been talking about suicide and their mood suddenly improves, ask them if they still have any intention to attempt suicide.

**Please note:** It can help to look out for warning signs. However, sometimes the person may attempt suicide without warning. Also, the warning signs may be so individual that it is understandable if they were not noticed.

### Box 17: Factors that increase the risk of suicide in bipolar disorder

## Factors that increase the risk of suicide in people with bipolar disorder include if the person has: <sup>44</sup>

- Previously had suicidal thoughts or attempted suicide.
- Someone else in their family who died by suicide
- A depressive or mixed episode or has recently had such an episode.
- Rapid cycling (see 'Patterns of illness' section 1.3).
- A plan to kill themselves (e.g. the means to do it or a time frame).
- A number of previous bipolar episodes or hospitalizationsSymptoms between episodes
- Anxiety or drug or alcohol problems in addition to bipolar disorder

• If the person lives alone

**Please note:** Although these are common risk factors, it is possible for suicide to still occur if the person is suicidal and these factors are not present.

### If suicide has occurred

If a person is determined to kill themselves, there is only a limited amount anyone can do to stop them. Don't blame yourself. You don't have to go through this alone (see section 9.4 for resources for those bereaved by suicide).

Warning signs that a person is suicidal can be verbal expressions or more subtle mood or behavior changes.

## **3.6. Supporting the person after a bipolar episode**

What people with bipolar disorder need after a bipolar episode can vary from person to person. The person may need time to get better and get over the impact the episode had on their lives. They might not be able to immediately resume their usual activities. You may need to adjust your expectations of the person.

If the person was manic, they may feel embarrassed and try to distance themselves from those who know what happened when they were manic. Sometimes the person may not even recall what happened when they were manic.

There are a number of ways to support the person after an episode of illness. Consider the following suggestions:

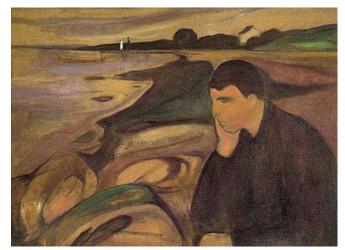
- Some of the things the person might need when trying to get well are rest, routine, something to do, something to look forward to and love and friendship.
- If the person still has some symptoms or is finding it hard to cope, ask them how you can help.
- Try to be available to support the person (within personal limits that are realistic for you), without being domineering or overindulgent.
- The period after an episode of illness (especially a depressive episode) can be a high-risk time for suicide. You may need to be alert to signs that the person is suicidal (see 'Helping to prevent suicide' section 3.5).
- When possible focus on wellness and positive behavior, rather than illness and problem behavior (e.g. talk about what the person is doing to get well rather than just things that happened when they were ill).
- Do things with the person rather than for them, as this can help to rebuild their confidence.
- Encourage the person not to try to get everything done at once. Initially it might be easier for them to prioritize essential tasks and do less stressful activities.
- Let the person recover at their own pace, but actively encourage or invite them to do things if they find it difficult to become involved in life again.
- If the person finds it hard to make a start on things, encourage them to set a small manageable goal.
- Offer assistance if the person has difficulties with remembering things or concentrating (e.g. assist the person to remember appointments by writing them down).
- Discuss ways to prevent future relapse once the person is well.

# 3.7. Supporting the person with mild ongoing symptoms or difficulty functioning

Some people do not need or want support with their illness between episodes. However, if the person has mild ongoing symptoms and difficulty functioning they may welcome a little appropriate support:

- Ask the person if they have consulted their clinician about ways to manage these symptoms or difficulties.
- Consider what has helped to deal with such symptoms or difficulties in the past.
- Encourage the person to keep to a basic routine that includes regular sleep patterns and time for relaxation.
- Offer the person assistance depending on their actual symptoms, and the extent of the person's difficulty with daily tasks. However do not take over, as this may undermine their confidence and be careful not to exceed your personal limits.

The strategies for managing mild ongoing symptoms of depression may be similar to some of those used to deal with warning signs of depression (see 'Ways to assist the person with warning signs of depression' section 4.4 Box 20).



Melancholy - Edvard Munch

### Chapter 4: Helping the person to keep well and enjoy life



When my past meets the future, it will be exactly the right time - Larissa MacFarlane

Encourage the person to take an active role in making treatment decisions with their clinician.

## 4.1. Supporting the person's medical treatment

Supporting the person with their treatment does not mean you should manage their medications for them. This can make you exhausted and undermine the person's confidence. However, if the person is severely ill and unable to manage their own treatment, you may temporarily need to have a more active role in assisting them.

When possible encourage the person:

- To find out about the range of treatments that has been shown to be effective.
- To take an active role in making treatment decisions with their clinician (e.g. by getting information on their treatment, monitoring its effect and openly discussing problems and options with their clinician).
- To have regular appointments with their clinician to help monitor their progress.

You can support the person in taking medications to treat their illness that have been agreed on by the person and their clinician. If treatments are slow to work, or the person needs to try new treatments, encourage them to persevere and not give up hope. Caregivers can also assist the person to monitor the effectiveness of the treatment or provide support if side effects occur. Telling the person if you see improvement in their bipolar disorder since starting treatment can be useful feedback for them.

## What if the person decides to stop or reduce their medication?

Sometimes, people stop taking their medication, or do not take it regularly or at the required dose. People with bipolar disorder have a biological vulnerability to develop bipolar symptoms and taking ongoing medication helps to prevent relapse and the negative consequences of the illness. There are many reasons why people stop or reduce their medications (see Box 18 for some examples).

## Box 18: Examples of reasons for stopping or reducing medication

## Reasons why people stop or reduce their medications include when the person: $^{45,46}$

- Has decided together with their doctor to reduce or stop a particular medication due to side effects or because it is not helping.
- Is currently experiencing an episode of illness and sees no reason for medication.
- Seeks to experience elevated moods.
- Is anxious about the long-term safety of the medication or a fear of possible side effects.
- Denies the severity of the illness, or that bipolar episodes are likely to re-occur.
- Believes that the medication will control them or that taking it is a sign of weakness or dependence.
- Has concerns about the stigma sometimes connected to taking medication for a 'mental illness'.
- Believes that other strategies besides medication are sufficient to manage bipolar disorder.
- Forgets to take the medication.

Close family or friends may become concerned if the person makes a decision to stop or reduce a medication (especially one that has minimal side effects and helps them to keep well) without discussing this with their doctor. If this is a concern of yours consider the following suggestions:

## Listen to the person's reasons for making changes to their medication regime.

Try to understand their point of view. You don't have to agree with them.

## Let the person know you understand their reasons, and if appropriate offer them a different perspective.

For example, if the person wants to stop their medication to experience elevated moods, consider mentioning that depression or the negative consequences of mania are also part of bipolar disorder. If the person is concerned about stigma, reassure them that taking charge and using medication to treat an illness is nothing to be ashamed of. Taking medication is an active coping strategy not a sign of weakness. If the person is worried about dependence on their medication, they may need to know that the only type of medication (Benzodiazepines) (see 'Medical Treatment' section 2.1).

### Discuss your concerns with the person using 'I statements'

(e.g. "I am concerned that stopping your medication may increase your chances of becoming ill again." and not "You are a fool to stop your medication as you will become ill").

## Encourage the person to talk openly about their medication with their clinician.

If the person has anxieties about the long-term safety of their medications, their doctor may help to exclude those fears that are baseless. Also, the doctor can discuss how certain side effects may be dealt with so the person can make an informed choice about stopping their medication. To make an informed choice, the person may need to know that certain medications do not work as well when they are stopped and then started again. Also, certain medications should be stopped gradually. If the person does want to stop their medication, they may also need to discuss how to stop with their doctor.

### Adapt your response to how well or ill the person is.

If the person is *relatively well*:

- Ask them to consider the pros and cons of taking medication, and what is at stake if they relapse.
- If the person has stopped their medication, negotiate an agreement with them to resume medication if signs of relapse appear.

### If the person has symptoms of depression, mania or hypomania

- Suggest that they wait until they are well to make such important treatment decisions.
- Mention to the person who is ill that their medication may relieve symptoms that the person finds particularly unpleasant (e.g. agitation or racing thoughts).

If you are concerned because the person wants to stop their medication when they are *very ill*, call the person's clinician or mental health team and express your concerns.

## Help to sort out difficulties with remembering to take medication.

If the person often forgets to take their medication, suggest strategies that might help (e.g. using a pill organizer or taking medication at the same time as doing another routine activity).

## 4.2. Considering psychological treatment?

Psychological treatments are not an alternative to medication. However, there is growing evidence that combining medication with certain psychological treatment programs can help some people to prevent bipolar relapse, reduce symptoms and improve their daily functioning.

The main psychological treatment programs that have been tested in research studies are summarized in section 2.2. These specialized psychological treatment programs are not always available. Some people report that they have found more informal psychological treatment or counseling helpful (e.g. when the person wants help with some of the losses or changes that have occurred, wants to learn ways to deal with stress or warning signs). What is of primary importance when seeking psychological treatment is that the health practitioner (psychologist, counselor or psychiatrist) the person chooses is *knowledgeable about bipolar disorder and how to treat it.* 

Psychological treatment may be most helpful when the person is relatively well and wants to find ways to prevent relapse and deal with the illness.<sup>47</sup> There is currently no psychological treatment to help reduce symptoms when a person is acutely manic. However, psychological treatment can help to reduce symptoms and enhance functioning when a person is depressed.<sup>48, 24</sup>

If you think psychological treatment may be helpful for the person, discuss this option with them. Encourage them to discuss this possibility with their doctor or mental health team.



### 4.3. Helping to reduce bipolar triggers

It is not possible to protect the person from all stress. Although certain stressors that trigger symptoms should be avoided, not all stress is avoidable. The person needs to find ways to manage stress (e.g. exercise, talk things over with someone, write or paint). However, there are things you can do to assist the person to reduce triggers and maintain a lifestyle that helps them to keep well.

### **Identifying triggers**

To get to know some of the triggers that may affect the person it may help to:

- Have an idea of what commonly triggers bipolar symptoms (see 'Common triggers of bipolar symptoms' section 2.3 Box 8).
- Discuss with the person what they think triggers their illness
- Think back to the person's previous episodes, and work out if there were particular stressors that occurred just before they became ill (e.g. their sleep routine was disrupted by travel).
- Notice what factors made their mood worse when the person was ill.

### Lifestyle factors to encourage

You can support certain strategies the person uses to reduce triggers and keep well such as:

- Having regular sleep patterns.
- Maintaining a basic routine.
- Exercising regularly (provided this is not done close to bedtime as this can interfere with sleep). Besides enhancing physical health, regular exercise has a positive effect on anxiety, depression, sleep problems and self esteem.<sup>49, 14, 50</sup>
- Taking ongoing medication prescribed for bipolar disorder.<sup>5</sup>
- Regulating the stimulation they receive (e.g. support the person's decision to have quiet times between social engagements or restore sleep habits after celebrations).
- Not setting unrealistic or excessively demanding goals.<sup>28</sup>
- Stopping or reducing the use of substances that make bipolar moods worse (e.g. caffeine, alcohol or street drugs).<sup>51, 3</sup>
- Eating a healthy diet.<sup>3</sup>
- Finding ways to relax and unwind.
- Adopting a problem solving approach to difficulties (see 'Taking steps to sort out problems' section 5.1 Box 21).<sup>38, 4</sup>
- Accepting that not all problems can be solved, but people can try to make the most of things the way they are.

### **Practical help**

There might also be *practical things* you can do to help reduce triggers such as arranging more quiet evenings at home together if the person is becoming manic. The person may also benefit from practical assistance if *a stressful event occurs*. When a stressful event occurs you could also:

- Offer to listen if the person needs to talk
- Offer to discuss solutions to a problem the person is finding stressful, without solving the problem for them

### **Reducing conflict**

Some people with bipolar disorder are very sensitive to *stressful interactions* (e.g. conflict or distressing criticism), and this can contribute to relapse.<sup>34</sup> Bipolar disorder can put a strain on relationships. If there is conflict in your relationship with the person, it may help to find out about good communication skills (see 'Maintaining or rebuilding your relationship' section 5.4), and ways to express grievances that are not hostile and can bring about positive change. In relationships it is also important to communicate about positive things; not only about problems. However, do not blame yourself for the occasional emotional outburst.

Caregiver assistance with recognizing and responding to warning signs helps some people to prevent full bipolar relapse, especially hypomanic or manic relapse.<sup>26</sup>

## 4.4. Helping to prevent relapse by recognizing warning signs of illness

Many people with bipolar disorder experience warning signs of impending illness. However, they may not always be aware of these changes <sup>39.</sup> If you know the person's warning signs, you may be able to help them to recognize when they occur and to take steps to prevent relapse. If the person does not want assistance with their warning signs, noticing when the signs occur can make it easier for you to understand the person's behavior and plan how to respond to it.

Research studies suggest that learning ways to recognize and respond to warning signs may help reduce bipolar relapse .<sup>26,52</sup> There is some introductory information below and community and health services in your area may be able to provide additional training.

### Knowing the person's warning signs

To get to know the person's typical warning signs:

- Find out about common and individual warning signs so you know what to look out for (see 'Common and individual warning signs' section 2.4 Box 9).
- Ask the person about their warning signs and what they do when these occur.
- You may have noticed certain warning signs that appeared before the person became ill in the past.
- Some people with bipolar disorder and caregivers find it helpful to have a list of the person's warning signs.

## Identifying the person's warning signs when they occur

To identify warning signs, you need to:

- Be alert to changes in the person's usual behavior and thinking. Everyday emotions such as joy, sadness, anger, frustration and dissatisfaction need to be distinguished from bipolar moods. Emotions that are NOT linked to bipolar disorder may depend more on good or bad things occurring in the environment and usually resolve more quickly causing minimal disruption to daily life.
- If the person already has mild ongoing symptoms, be alert to changes that signal that the person is becoming more ill or developing new symptoms. It is important to keep an eye on mild ongoing symptoms between episodes, as they increase the person's risk of relapse.

Be careful not to constantly question everything the person says and does for signs of illness, or it may be difficult for them to enjoy the times when they are well. Being very familiar with the person's pattern of illness may assist you to distinguish if something is a warning sign or not.

## Communicating with the person about their warning signs

- Discussing warning signs with the person can be a sensitive issue. Misinterpreting mood fluctuations and behavior that are common to us all as part of bipolar disorder can be hurtful and frustrating.
- Talk to the person when they are well about how they would prefer you to communicate when you have noticed warning signs.
- Let them know what warning signs you have noticed as soon as possible, as there is a greater chance of preventing relapse if the person deals with their warning signs early.
- Inquire if the person has noticed the changes you observed, and if they could be warning signs of illness.
- Express your concerns in a way that is non-judgmental and unthreatening (e.g. "*I have noticed that you have been a bit down lately*").
- If the behavior you have noticed occurred in a previous episode, explain that this is the reason for your current concern.
- If you are unsure whether something is a warning sign, discuss this possibility with the person.

## Ways to support the person when warning signs appear

Below are some tips you might find useful:

- When warning signs appear avoid getting caught up in the person's bipolar mood state (e.g. in the excitement or irritability of the person's growing hypomania).
- If the person is anxious about becoming ill, reassure them that they can deal with the illness and that you are available to support them.



# • The way to support the person can depend on the type of warning signs they are experiencing see Box 19 and 20.

• Monitoring warning signs can help to see if they are subsiding or getting worse.

## Box 19: Ways to assist the person with warning signs of mania or hypomania

## Encourage the person who has warning signs of mania or hypomania to:

- Contact their clinician to get medical treatment early.
- Reduce stimulation (e.g. reduce social activities).
- Rest (with the help of prescribed medication if necessary).

• Take medication that has been prescribed specifically for times when warning signs appear. Medication prescribed to assist the person to relax, rest and sleep when they have warning signs, can help to prevent a manic episode.

## Box 20: Ways to assist the person with warning signs of depression

Warning signs of depression can be difficult to recognize. Some people with bipolar disorder find that they only recognize their depression once it has begun. Even if the person does not get warning signs of impending depression, recognizing and responding to early symptoms of depression may help to reduce the severity of the episode. If the person has warning signs or early symptoms of depression, encourage them to:

- Restore or maintain a basic routine.
- Restore or maintain regular sleep patterns (e.g. go to bed and get up at a regular time each day and not sleep during the day).
- Set small manageable goals to do things, and divide these goals into smaller steps if they are hard to achieve.
- Acknowledge their small achievements, as experiencing a sense of achievement can have a positive influence on mood.
- Recognize positive events and experiences when they occur (e.g. you can talk about an experience you both enjoyed or acknowledge good news the person has received).
- Discuss their warning signs or early symptoms with their clinician.

• If the person is becoming less active than usual, encourage them to do something that involves a bit more physical activity (e.g. ask the person to help bring parcels indoors from the car) or to persist with whatever regular exercise they can manage.

Some of these suggestions may also be useful if the person has mild ongoing symptoms of depression between episodes (see section 3.7). PLEASE NOTE: there is more about supporting a person who is depressed in section 3.1 Box 13)

# 4.5. Helping the person to gain confidence and live well with bipolar disorder

Besides assisting the person with their illness, you can support their efforts to regain their confidence and make a good life for themselves.

## Supporting the person to live well with their illness

People may go through a natural grief process when coming to terms with their bipolar disorder. They may deny the illness or experience a number of different emotions such as sadness, anger or shame. It can take time for people to adjust to the illness. 'Recovery' is a term used to describe "a way of living a satisfying, hopeful and contributing life even with limitations caused by the illness"<sup>53</sup>. Rather than being an end point that the person achieves, 'recovery' may be an ongoing and very personal process of finding ways to manage the illness and live well.

When the person is well, encourage them to do things they enjoy that are not overstimulating or too stressful. Adjusting to the illness may be easier for the person if they set manageable goals that involve their interests, talents, skills or values. If the person needs to make changes to their job or study plans in order to keep well, take time to listen and discuss alternatives, as this can be a challenging time for the person.

### **Rebuilding confidence**

Sometimes the illness can dominate the person's life so that they forget their strengths, and abilities. You can help to rebuild confidence by encouraging the person to do *manageable* things, especially things that involve their strengths and interests. The timing of this encouragement is important as encouraging the person who is hypomanic or manic to do more activities may overstimulate them and make their symptoms worse.

When appropriate, mention things you appreciate about them. However, be careful that this does not come across as condescending or patronizing.

Doing things for themselves helps people develop confidence and independence. What the person can manage to do may depend on how ill or well they are. Even when the person is ill, they may still be able to do things for themselves depending on the severity of the illness.

### Avoid focusing on the illness all the time

When appropriate, do things together that have nothing to do with the illness and let them know that they are important to you. Whenever possible try not to make the illness the central topic of conversation between you. Rather, relate to the person as the friend, partner or close relative they are. It can also be good for family relationships if the focus in the family is not constantly on the person and their illness.

> It can take time for people to adjust to their bipolar disorder and find ways to manage it and live well.

## 4.6. Helping the person adjust to wellness

Being well can free the person to enjoy life; however some people find it hard to adjust to wellness. They may struggle to take on new opportunities that become available when they are well, or be reluctant to engage in social activities. If the person seems well but still needs a lot of help, be cautious about automatically assuming that they are finding it difficult to adjust to being well. They may have mild ongoing symptoms or ongoing difficulties in daily functioning and find it difficult to carry out their usual tasks (see section 3.7). However, if the person is symptom free and able to do things, but finds it hard to step out of the 'sick role' consider:

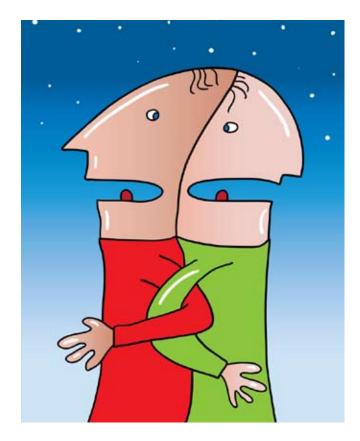
- Stepping back and encouraging the person to do more for themselves.
- Encouraging them to do things they enjoy (e.g. visit friends or pursue a hobby).
- Reminding the person that although they may have a lot to do, they don't have to do everything at once.
- Showing them that there are other ways the two of you can relate to each other, besides through the illness (e.g. pursuing activities together that you both enjoy).
- Asking the person when appropriate for help or a favor, so they can experience how good it is to be the person who is doing the giving.
- If you have the type of relationship where you can discuss things consider asking the person how they feel about the changes and demands involved in being well.

If the person can do more for themselves, step back and encourage them. This can help the person develop independence and confidence.

## 4.7. Stepping back to let the person do more for themselves

People can become used to caregiving relationships. Some caregivers find it hard to step back and adjust to the person's independence, even though they are happy that the person is well. This ongoing caregiving can be exhausting for the caregiver and make it difficult for the person to develop confidence in their own abilities. If you think this may be occurring in your situation:

- Look at the benefits of being less involved in caregiving than you were before.
- Take time to relax and focus on other aspects of your life, relationships, hobbies or work.
- Find other ways to relate to the person that do not involve the person's bipolar disorder.



### Chapter 5: Taking care of yourself

As a caregiver, you need to take care of yourself as well as the person, or you might end up feeling overwhelmed and burnt out. Although some caregivers report positive aspects of caregiving, this role can be very stressful at times. *Caregivers are at increased risk of becoming depressed and having other health problems.* 

You might find that all your energy goes into helping the person. However, if you neglect your own health and wellbeing, you may develop health problems. Also, you can't provide optimal support if your own health is compromised. This chapter is about ways to take care of yourself.



Spring Hills - Leigh Kibby

### 5.1. Helpful coping strategies

Certain ways of coping are more helpful in reducing stress than others. Below are some suggestions:

### **Getting organized**

Although it might take a little time, getting organized will probably save you time in the long run:



- If you are overloaded with tasks, prioritize what is essential to do and postpone or cancel other tasks.
- Arrange to share or delegate certain caregiving tasks and other demands.
- Make use of appropriate services and community organizations available in your area to support the person, yourself and the family (e.g. financial or respite services and peer support groups).
- If it is hard to manage work and the demands of the illness, find out about possibilities for leave and flexible working hours. Discuss these possibilities with your employer before deciding to leave to become a full-time caregiver.

### **Restoring your energy**

Making even a little time to do things that you find relaxing, or enjoyable may help to restore your energy. If the person is severely ill and cannot be left alone, arrange for someone else to be with them or for respite care while you have a break.

### Getting rid of unrealistic expectations

Dealing with bipolar disorder can be stressful. If you try to live up to *unrealistic expectations* of what you 'should' do as a caregiver you might increase your stress levels and become exhausted and resentful. Examples of unrealistic expectations include:



- "I should cure the person's bipolar disorder"
- "I should be able to fix everything"
- "I should never feel angry or stressed"
- "I should always be perfectly supportive of the person."

Keep in mind that while you can be supportive, it is the person's illness and their responsibility to manage it. Bipolar disorder is a complex illness that needs ongoing management, rather than something that can be fixed forever. The extent of your involvement in helping the person may change depending on the severity of the illness, your other demands and commitments, your own preferences and that of the person (see 'Considering how involved to be in helping the person with their illness' section 7.1). It is natural to feel stressed and angry at times. No one can be perfectly supportive all the time.

As a caregiver you probably already do a lot to help. You don't have to be the person's therapist or doctor as well. If you feel out of your depth when trying to help the person, say something supportive that acknowledges the need for extra help (e.g. "I really care about you, but I think we need extra help here."). Encourage the person to develop a support network involving professionals, family, friends and the community. However, if the person has recently been diagnosed with bipolar disorder, you may need to provide more support until they have had time to establish a good support network.

Having unrealistic expectations of what the person and their clinician can do to control the illness can also lead to frustration and disappointment. While there is a lot that they can do to try to control the bipolar disorder, relapse sometimes occurs despite everyone's best efforts.

### Maintaining boundaries and setting limits

Below are some suggestions for ways to maintain your boundaries with the person and set limits on your caregiving:

- Acknowledge that you have needs too.
- Use the time when the person is well to focus on things that are important to you, besides the illness.



- Loss of identity
- Learn to say "no" to demands that are unreasonable or unmanageable (both caregiving and other demands).
- Keep in mind that although you can help, the person needs to find ways to deal with their own illness.
- Devote some time to outside interests and goals; doing something that you enjoy.
- Encourage the person's efforts to maintain their own identity and interests.
- Maintain contact with friends and family.
- Set limits with risky, dangerous or inappropriate illness behavior you find unacceptable (see 'Dealing with risky or inappropriate manic or hypomanic behavior' section 3.2).
- You may also need to consider how to respond if the person refuses to get their bipolar disorder treated or to take any responsibility for managing their illness (For more information on ways to deal with these difficulties see 'Difficulties in working with the person to deal with the illness' section 7.8).

### Developing your own support system

Bipolar disorder can be challenging and having someone to talk to whom you can trust or joining a peer support group can make it easier to cope. Keep in mind that different people may be able to help in different ways and it can be useful to build up a support network.

There are some caregiver support organizations listed in section 9.2 of the resources. Some organizations run peer support programs such as the **WellWays program** run by the Mental Illness Fellowship of Australia, or **Family to Family Education Program for Caregivers** run by the National Alliance on Mental Illness in the US.

Caregivers may also benefit from counseling to assist with the changes and problems that sometimes arise from dealing with bipolar disorder. Group information sessions or 'psychoeducation' for caregivers run by trained health professionals can be useful and help to reduce some of the stress involved in caregiving.<sup>25</sup>

### Taking steps to sort out problems

A problem solving approach can be very useful to deal with difficulties. There are 4 steps (seeBox 21):

### nd having someone to The 4 problem solving steps are:

### 1. Cleary define what the problem is

Box 21: Problem solving steps

To come to a clear understanding of the problem, without blaming yourself or others consider *how* it developed, *when* it occurs and *why* it is a problem.

### 2. Work out what solution or solutions to try by:

- Making a list of possible solutions to try: Use your imagination. Ask others if you like. It doesn't matter how unrealistic the solutions are at this stage.
- Evaluating each solution
- How practical or realistic is this solution in your circumstances?
- What are the possible risks and negative consequences that may occur if you choose this solution?
- Are there ways to prevent or deal with these consequences if they occur?
- What are the possible benefits if you choose this solution?
- Deciding which solution (or few solutions) you would like to try.

### 3. Develop a plan of action and follow the plan

Decide what you need to do first to implement the solution and work out a step-by-step plan.

Then put your plan into action.

### 4. Review how the solution worked

Acknowledge the effort you have put into trying to manage the problem and congratulate yourself if the solution worked. Many problems require that you try different solutions before solving them. If the solution was not helpful or there are still parts of the problem that need to be solved, return to earlier steps to try other solutions. Sometimes people learn from trying to solve a problem that there is another underlying problem that needs attention first.

Some problems are more difficult to solve than others. Difficult situations can take time to change or may not even be able to be changed. If this is the case, find ways to make things a little easier and enjoyable for yourself, despite the situation.



### 5.2. Caring about your health

Sometimes caregivers find that they don't have time to consider their own wellbeing. Small changes are important when trying to develop a healthier lifestyle. Also picking up signs that your emotional health is deteriorating gives you the opportunity to take timely action to keep well.

### **Develop good habits**

Rather than aiming to lead the perfect lifestyle, see what you can include in your life from the following list:

- A little regular exercise
- Eating healthy balanced meals
- A bit of regular time off to relax or pursue a hobby
- Time off to keep in contact with selective friends, family or a peer support group
- Regular sleep
- Treatment if you have a health condition.

It is vital to find ways of coping that are not destructive to your health. Examples of ways of coping that *can be destructive* in the long term include:

- Drinking too much alcohol, smoking or overeating to relieve stress.
- Neglecting your own hygiene or health to save time when you are busy.
- Isolating yourself from everyone to attend to chores or because they may not understand your situation.

## Reducing your own stress or depression

Be alert to signs that you are stressed or depressed. If you notice signs of stress or depression, develop a plan for coping (e.g. delegate more of your duties and take time off). If you have symptoms of depression, contact your doctor for an assessment and to discuss treatment options. Do not ignore depression.

### Signs of stress

Some of the signs of *stress* include:

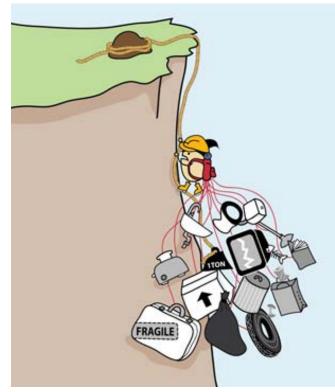
- Being more irritable, short-tempered tense or anxious than usual
- Overeating or loss of appetite
- Difficulty falling asleep
- Having minor aches and pains or feeling run down and becoming ill often.
- Using alcohol or other drugs to cope.

### Signs of depression

Signs of *depression* include flat or sad mood or loss of interest in things and other symptoms such as:

- A lack of energy and feeling very tired
- Being noticeably slowed down or much more agitated and unable to settle
- Noticeable changes in appetite and weight
- Sleep problems (e.g. you sleep too much or can't fall asleep)
- Feelings of worthlessness and excessive guilt
- Difficulty in concentrating, thinking or making decisions
- Recurrent thoughts about suicide or death

People who are depressed may withdraw from social contact or be very irritable in company. They can find it much harder to function at work or to complete daily tasks. If these symptoms persist for at least two weeks you may be depressed (for more information on symptoms of depression see section 1.1).



Depression - Jennifer Lee

### 5.3. Adapting to caregiving

Caregivers can experience a range of understandable reactions when trying to come to terms with the person's illness and its consequences. There are things that can make adjusting to the changes a little easier.

### Coming to terms with the illness

Caregivers may go through a number of stages after the person's first bipolar episode that are part of a natural grief process. These stages range from initial shock, disbelief and emotional turmoil, to gradual understanding, acceptance, and hope that there are ways to deal with bipolar disorder and live well.<sup>54</sup> The emotional turmoil may involve anger, sadness, anxiety, guilt or shame. Some family members or friends may deny that the person is ill or needs treatment. Depending on the pattern and severity of the person's illness, this grief process may be more severe for some caregivers than for others. The grief often subsides, even if some sadness remains. However, grief may return from time to time, for example, when the person relapses.

If you experience emotions linked to this natural grief process:

- Allow yourself to grieve.
- Reassure yourself that while the changes and losses connected to the illness are real, people with bipolar disorder and caregivers often find new meaning and ways to enjoy life despite the illness.
- You might find it helpful to make contact with others in similar situations who can relate to what you are going through.
- Consider setting small goals to do things that you enjoy.

## Acknowledging your natural reactions and deciding how to deal with the situation

You may experience a range of intense emotions. Some of these feelings may be part of the process of coming to terms

with the illness. Others may be reactions to your situation. Acknowledging these natural reactions and deciding how to deal with them can make it easier to cope.

Examples include:

- Feeling angry
- Feeling sad or rejected
- Feeling guilty and blaming yourself
- Feeling like you want to withdraw from the person or to leave



Fighting forms - Franz Marc

### **Feeling angry**

Depending on your situation some of these options may be relevant:

- Find a constructive release for your anger (e.g. go for a walk, play sport, paint, write in a journal, or talk things through with someone you trust).
- If you are feeling burnt out and resentful, devote more time to your own needs and increase the limits on the support you provide.
- Bipolar moods are not always predictable and you (and the person with the illness) may become frustrated or disappointed as plans can be disrupted. Some people find that making short term plans or arrangements (not too far in the future) increases the chance that these plans will be carried out.
- Consider if your frustration or anger might be connected to factors the person cannot control (e.g. how long medicines take to work).
- If you are angry about something the person has done, wait until you have calmed down to discuss the person's behavior with them. If possible, delay discussing your angry feelings until the person is well and more able to deal with these issues (see 'Using good communication skills' in section 5.4).

### Feeling sad or rejected

There are times when all of us feel hurt or rejected by people we care about, but this can be intensified for caregivers due to the impulsive and extreme bipolar mood states experienced by their loved ones. There might be times when the person is too ill to respond to you in the way you would like them to (emotionally, or where partners are concerned, sexually). If you had a close relationship with the person, you may be sad and worry that you have lost this relationship.

If you are feeling sad or rejected consider the following:

When the person is ill, try to separate the bipolar disorder

talk and behavior from the person. Try not to take this talk and behavior personally.

• Do something you enjoy to distract yourself from feeling sad or rejected.

• Talk to someone you trust.

• If you are sad about the way your relationship with the person has changed try to rebuild the relationship (see 'Maintaining or rebuilding your relationship' section 5.4).

### Feeling guilty and blaming yourself

There are many causes of bipolar disorder and the illness is nobody's fault. However, sometimes caregivers feel guilty and blame themselves for the person's illness. For example:

- Parents sometimes feel guilty about passing on the illness genetically. None of us can control the genes we have.
  When a person has bipolar disorder, approximately 7% of their first degree relatives will also have the illness. This means that while there is a genetic risk, there is also a good chance that a first degree relative will not get the illness.<sup>2</sup>
- Caregivers sometimes feel guilty in case their stressful interaction with the person sparks off symptoms (see 'Common triggers of bipolar symptoms' section 2.3 Box 8). Bipolar disorder can put a strain on relationships and the occasional emotional outburst is understandable. The person needs to find ways to build up their resilience to this stress. However, if these outbursts are more frequent it might be an idea to work out what is causing them and to address the problem. For example, you might find that you are very irritable and impatient with the person because you are feeling stressed and burnt out. What might help in this situation is to explain this to the person and take some time out.

## Feeling like you want to withdraw from the person or to leave

There are **different reasons** why caregivers feel like withdrawing at times. For example:

- It is common to feel the need to withdraw from the person when they have been behaving strangely due to the illness, but this feeling often subsides as the person gets better.
- Feeling the need to withdraw may be a sign that you are exhausted and need some time out.
- If you are withdrawing from everyone or everything, this could be a sign of depression (see 'Reducing your own signs of stress and depression' in section 5.2). Try to find ways to provide less support and focus more on your own wellbeing.

On the other hand, if you decide that you cannot continue in your current situation and would like to leave or withdraw from your relationship with the person, **before** you do:

- Discuss what you are going through with the person, as you may be able to find ways to resolve some of the difficulties together.
- Address problems with the help of a counselor or relationship or family therapist.

### 5.4. Maintaining relationships - good communication

Bipolar disorder can challenge relationships and sometimes it takes a bit of time, patience and effort to maintain or rebuild them. Once the person is not so ill, it may be possible to slowly regain some of the closeness you had previously. Some ideas to do this include:

- Share enjoyable experiences that have nothing to do with bipolar disorder.
- Encourage giving and taking in your relationship. For example, providing the person is not severely ill ask them to help out at times and accept their support when it is offered. Relationships that involve even a little giving as well as taking can be less stressful and more rewarding for both people.
- If the person is your partner and they have lost interest in sex due to depression, offer companionship and slowly start to rebuild an intimate relationship once the depression has subsided.
- Use good communication skills to help sort out difficulties.

### Using good communication skills

There are ways of communicating with each other about grievances that are constructive and are less likely to come across as hostile or critical. These skills take practice and time to learn. They include:

- Active listening
- Making a positive request for change
- Calmly expressing your feelings about the person's behavior
- Problem solving together
- Reaching a compromise together
- Communicating about positive things

### Active listening 38,55

People seldom take time to really listen to each other's point of view. Difficulties and conflict are much easier to sort out once people understand where the other person is coming from. To actively listen you need to:

- Look at the person who is talking.
- Focus attention on what they are saying.
- Acknowledge what you hear by nodding, verbally indicating that you have heard or asking them to continue.
- Ask for clarification to check that you have understood their viewpoint.
- Summarize what you have heard to check with the person if your understanding of their viewpoint is correct, without adding personal opinions or judgments.

#### Making positive requests for change<sup>38, 55</sup>

Using a positive request for change can be useful if there is a specific behavior that you would like to see the person change (e.g. If your partner has been very busy at work: "I would like it if you could let me know if you need me to fetch the children from school today? Then they will not be left waiting at school when everyone has gone home or need to call me to fetch them. This will make it easier for you knowing you don't have to rush, and I will be able to plan things so that I can fetch them?")

This differs from criticism as it is not about what the other person has done wrong. Instead, it is about what you would like to see change. To make a positive request:

- Look at the person
- Use 'I' statements. For example "I would like your help with ..." "It would mean a lot to me if you would do..."
- Tell them specifically what you would like them to do without asking for many things at once.
- Have a calm manner that is not apologetic, critical, demanding or commanding.
- Tell them how you think this could benefit yourself and where possible, the other person.

# Calmly expressing your feelings about the person's behavior<sup>38, 55</sup>

Another possibility when expressing your grievances to the person is to calmly express your feelings about the person's behavior. To use this technique you need to:

- Address the specific behavior that is bothering you rather than globally blaming the person.
- Look at the person and speak firmly (not apologetically or loudly).
- Tell the person exactly what they did that upset you and how that made you feel using "I" statements (e.g. "I am angry and upset as you fetched the children from school over an hour late again, for the third time this week, although I asked you to let me know if I could help out with lifts.").
- Suggest what the person can do in the future to prevent this from happening again (e.g. "Let's discuss how we can prevent this from happening again. Would it be easier if we arrange that I fetched them from school for a while, just until you are over your busy patch at work? Alternatively, should we arrange for them to go to aftercare so that you can fetch them when you are ready?").
- If the person starts arguing, try not to engage in the argument. If necessary, simply restate your opinion and leave it at that.

#### Problem solving together

If someone does not agree to your positive request or to trying to prevent a certain behavior in the future, another option is to invite them to use problem solving steps together to try to sort out this difficulty (see 'Taking steps to sort out problems' section 5.1 Box 21).



#### Reaching a compromise together

Sometimes conflict can develop into a competition about who can win the argument. Having a winner can make the competition fiercer the next time. What can help to resolve conflict is when both people stand back and decide to work on resolving the conflict together. You may need to invite the person to work things out with you. To find a workable compromise to a problem you are arguing about consider the following:

- 1. Both you and the person make independent lists of ways to sort out the problem that suit you. Discuss these options with the other person without trying to win the argument. Rather aim to find something that is reasonably fair for both of you.
- 2. If the options are not acceptable, you or the person could ask for a counterproposal until you both find something to agree on.
- 3. If it is hard to find a solution that is acceptable to both of you, ask or suggest
  - 'What would you need from me to be able to do this my way?'
  - 'My way this time your way next time'
  - 'Let's meet half way'
  - 'If you do...for me, I'll do...for you'
  - 'My way when I am doing it and your way when you are'
- 4. If compromise is not possible you may need to agree to differ. Even people in a good relationship sometimes need to agree to differ about certain issues. However, if the issue is very important to you and it has not been resolved in a way you think is acceptable, you may need to consider what options are now available to you and decide how to move forward.

#### Communicating about positive things

While it is important to communicate our concerns when someone does something we do not like, it is also important to communicate our appreciation when they do something we like. People are also more likely to continue doing the things that give them positive feedback.

Spending a bit of time doing things together that you and the person both enjoy can strengthen the relationship. Sharing positive experiences can make people keener to sort out stressful interactions and conflict.

For more information on some of these communication skills, we recommend a book by David Miklowitz 'The bipolar disorder survival guide' (see reference section at the end of this guide).

# 5.5. Recognizing the positives

Some caregivers find positive things about caregiving, the person and about themselves that make it a bit easier to cope with the person's extreme bipolar moods. Examples of positive things include:

# The positive side of caregiving

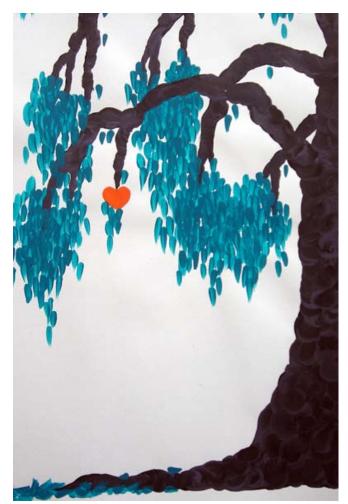
Caregivers sometimes report that they have learnt from caregiving to be more tolerant and empathic and gained confidence in their ability to cope.

# Positive things about the person

Examples of positive things you may notice about the person include the person's creativity, their abilities or talents, their style, their courage in battling the illness, and their kindness. Some caregivers report that noticing the person's positive qualities helps them to deal with the bipolar disorder.

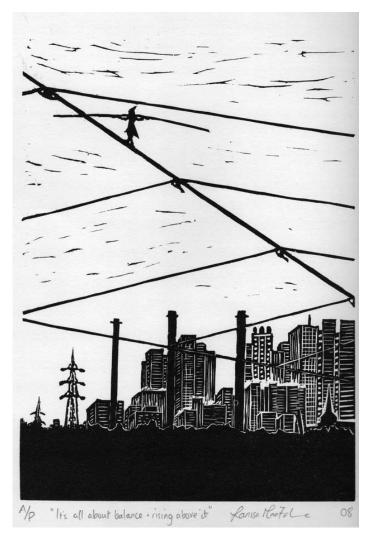
# The tasks you manage to do and the support you provide

Caregivers often do not receive appropriate recognition for what they do. Acknowledge what you do and the effort you make.



Finding hope - Sarah K Reece

# Chapter 6: Ways to take care of yourself in specific challenging situations



If you can't change the situation, focus on doing things that you can control. Make some lifestyle changes of your own. Situations differ and some caregivers may find that they need to deal with specific challenges. There are a few examples of challenging situations and ways to deal with them discussed in this chapter including:

- If the person is ill a lot of the time
- Reducing stress in a bipolar crisis
- If there is a lot of conflict between you and the person
- If the person is ill, irritable and very critical of you
- If the person is physically aggressive
- Dealing with negative consequences of risky behavior

# 6.1. If the person is ill a lot of the time

Some people have patterns of illness that are more severe. They may relapse more frequently or their illness may be more resistant to treatment. This can be very challenging. Don't give up hope as patterns of illness can change and there are things that may help to make it a little easier to cope.

# Ways to cope if the person is ill a lot:

- Find out what resources are available to support yourself, the person and the family when the illness is severe.
- Maintain as much of a routine as possible.
- Do not isolate yourself socially, as this can increase your risk of depression.
- Don't criticize yourself for feeling stressed. Reassure yourself that it is common to feel very stressed in a challenging situation.
- Find ways to relieve stress (e.g. talk to someone you trust, watch a funny movie, go for a walk). Even small things can make a difference.
- It might help to make some lifestyle changes to cope with the person's persistent or recurring illness (e.g. rethinking the household budget, adjusting your work hours or arranging for others to take over more tasks).
- Suggest that the person gets a second opinion from an expert clinician.
- If the person has been ill for a long time, don't give up hope as getting well can be a slow process.
- If you can't change the situation, focus on doing things that you can control.

# 6.2. Reducing stress in a bipolar crisis

Caregivers can feel exhausted and overwhelmed when going through an illness-related crisis. Sometimes the effect of the crisis can linger after it is over.

#### Ways to reduce stress in an illness related crisis:

- Keep a list of contact numbers of people you can call for help in an emergency (see also 'Dealing with a bipolar crisis' section 3.3).
- Reassure yourself that the crisis will pass.
- If you are feeling very stressed during and after a crisis, talk to someone you trust or contact a helpline.
- Schedule a bit of time to relax and unwind after the crisis, even if you are very busy.
- Try to restore your usual routine as soon as possible.
- If some time after the crisis you can't stop thinking about what happened, you feel distressed and unable to focus on everyday tasks, consider getting professional counseling.



From stone - Elena Jomantas

# 6.3. If there is a lot of conflict between you and the person

# Bipolar disorder can put a strain on relationships. However, not all problems are caused by the illness.

Stressful interactions and conflict may be distressing for both you and the person. There are ways to try to improve communication and rebuild your relationship with the person (see 'Using good communication skills' in section 5.4). When trying to sort out problems in relationships it can be useful to consult a health professional who knows a lot about bipolar disorder and counseling for relationships.

# 6.4. If the person is ill, irritable and very critical of you

It can be hard to maintain perspective if the person who is ill is also very irritable and criticizes you a lot. Finding ways to detach and set boundaries without being drawn into arguments can be helpful.

# What to do if the person is ill, irritable, and very critical of you

- It may help to detach from the situation a little by reminding yourself that the person is ill.
- Don't try to defend yourself by arguing logically with the person if they have become so ill that they are not thinking as rationally as they usually do.
- Address the specific comments or behavior (e.g. shouting) that are unacceptable or concerning, without criticizing or blaming the person as an individual.
- Set limits with the person's verbal abuse by saying something like *"I understand you're upset but I'm not going to tolerate being spoken to in this way"* and walk away.
- Take some time out or talk things through with someone you trust to help maintain your perspective, and don't be drawn into reacting to their irritability or believing the criticism.

# 6.5. If the person is physically aggressive

Physical aggression rarely occurs as part of bipolar disorder. It is more often connected with drug or alcohol problems, personality disorders and occasionally with psychosis.<sup>56</sup> However, occasionally if a person who is manic or in a mixed episode, is very angry, they may act out on their emotions.<sup>57</sup>

If you experience fear when the person is acutely ill, angry and does not have much control over their emotions, don't deny the possibility of danger. If aggressive behavior has occurred previously, be especially alert to the possibility of it occurring again.

Never compromise your own or others' safety due to concerns about hurting the person's feelings, as later the person might feel very relieved that they were prevented from hurting their loved ones. Make sure you are safe first and contact the emergency services (see 'Dealing with a bipolar crisis' section 3.3).

# Ways to protect yourself if the person has become aggressive before

- Learn to recognize the warning signs of impending aggression.
- Take even casual threats of violence seriously.
- Work out in advance how to ensure your safety and that of others (e.g. have locks on rooms, leave the house and get help when warning signs of aggression appear).
- Remove objects that could be used as weapons if the person is likely to become aggressive.

For more about what to do *if aggression has occurred*, see 'Dealing with negative consequences of risky behavior'.

Physical aggression rarely occurs as part of bipolar disorder. However, if the person is likely to become physically aggressive, make sure you are safe first and contact the emergency services.

# 6.6. Dealing with negative consequences of risky behavior

If risky behavior has occurred the person may need urgent medical help. You may also need to seek legal advice (e.g. if a contract is signed or a large purchase made when the person is manic).

A good financial adviser can assist with financial problems resulting from the illness. Local services may be able to assist with housing difficulties or unemployment that can sometimes occur. If the person has engaged in risky sexual behavior, encourage them to see a doctor in case they need treatment for a sexually transmitted infection.

If aggressive behavior has occurred, you may need to get medical help for yourself. Use the services available to assist you to put safeguards in place to prevent this abuse. It is common to feel very traumatized by physical abuse and professional counseling can be helpful.

If the person is very ill you might need to wait until they get better before discussing ways to sort out the negative consequences and to prevent these consequences in the future. You may find that it is the bipolar disorder and not the person that is to blame for this behaviour. Some people are very concerned about what they did when they were ill and clearly want to try to prevent this behaviour from re-occurring. Others are not that willing to try to prevent this behaviour. You might need to set limits with illness behaviour that affects you (see 'Dealing with risky or inappropriate manic or hypomanic behaviour section 3.2).

It is important to keep in mind that risky and negative behavior is not always linked to the person's illness. This behavior may be due a person's personality or temperament or connected to an alcohol or other drug problem. If you are unsure if the person's inappropriate or risky behavior is part of the bipolar disorder, consider seeking clarification from a clinician with expertise in bipolar disorder and observing whether the behavior occurs when they have other bipolar symptoms.

# Chapter 7: Working with the person to deal with the illness

People differ in what help they need and want from caregivers. Caregivers may have their own views about what support they prefer to give. Sometimes caregivers are unsure how involved to be in supporting the person. They don't want to come across as patronizing, overprotective or uncaring. It can take time and a process of trial and error to find ways to help the person that suit both of you.

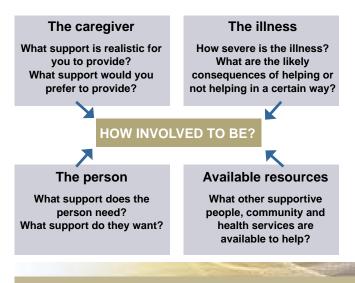
While not all support has to be discussed, there are ways to talk with the person about the illness and how you can help. Making agreements and plans together and working as a team with the person and their clinician may help to reduce the impact of bipolar disorder on both of you. However sometimes difficulties can arise when you try to work together.

# 7.1. Considering how involved to be in helping the person with their illness

There are a number of factors to consider when working out how involved to be in helping the person with their illness (see figure 1).

Although caregivers may be focused on helping the person, they also need to take into account what support is realistic for them to provide (e.g. to consider their other commitments and their own health) and how they prefer to help. The person may have their own ideas about how they would prefer you to help and what they can do for themselves. People may need more support when they are more severely ill or in crisis (see sections 3.1, 3.3, 3.4 and 3.5). It may also be important to consider the consequences of helping or not helping a person in a certain way (e.g. the consequences of helping or not helping the person in an emergency or of mentioning or not mentioning warning signs). If you cannot help in a particular way, there might be others who can or community services that could step in.

# Figure 1: How involved to be in helping the person to manage their illness



# Be cautious about becoming too involved

If a caregiver constantly intervenes in the person's life, the person might experience this as an intrusion, and refuse to ask for help when they really need it. Repeatedly telling the person what they should be doing to manage their illness might come across as nagging.

# Check things out with the person

If appropriate in your situation, mention that you would like to help with the illness, but do not want to be intrusive or get in the way of the person's own illness management strategies. An idea may also be to check with the person when they are well if the support you have been providing is appropriate.



# 7.2. Helping without mentioning the illness

It is not always necessary to mention the illness when encouraging illness management strategies (e.g. invite the person to go for a walk with you because the dog needs walking, not because it might help the person's depression). Also, keep in mind that not all support has to be verbal; sometimes just sitting with the person can be supportive or you can provide practical help (e.g. with household tasks or with the children) or affection (if appropriate) without discussing this in advance.

# 7.3. Talking to the person about how to help

Talking with the person about the illness, its management and how you can help may assist both of you to deal with it.

# Timing is important

It is best to have these discussions when the person is relatively well. If the person has recently been diagnosed with bipolar disorder they may not be ready to accept the illness or discuss its management.

# Keep the lines of communication about the illness open

Invite the person to share their views on what helps people to manage bipolar disorder and listen to their point of view.

# Use ordinary language

Don't feel obliged to use psychiatric jargon. Many families have their own ways of talking about the illness (e.g. feeling really down or very high).

# Ask what you can do to help

You could ask the person what you can do to help in specific circumstances (e.g. what you can do to help when the person struggles to get up in the morning when they are becoming depressed, or how to assist them with their plans to prevent relapse). There is a possibility that the person may not know what help they need. If you have some ideas about how you could help, discuss these options tactfully with the person.

# 7.4. Making agreements and plans

Through discussion with the person, you might come to some *agreement*. For example, you might agree that you will provide specific support when it is needed, and the person will endeavor to let you know if they notice warning signs, episodes or need help. Consider formalizing the way you help into a plan.

It is not always possible to implement exactly what is specified in a plan, but it can provide direction and a basis from which to work. You can have *plans* for dealing with different aspects of the illness (e.g. a plan for dealing with suicide risk and another for what to do when the person becomes depressed). Sometimes people do not want to discuss their illness or to make plans. Even if the person does not want to discuss illness management, having your own plans can help you to be prepared.

# When creating a plan:

- Keep your plans *simple* so they are easy to follow.
- Consider *writing* your plans down and keeping them in an *easily accessible* place.
- Consider if you can be *reasonably consistent* in providing the specific help you offer. Don't feel pressured to always be *perfectly consistent* as unpredictable demands and circumstances do occur. If you cannot provide the usual support, try to arrange with the person for a back-up support person or organization to step in.
- *Review* your plans as circumstances change or you acquire new information.

It is not always possible to implement exactly what is specified in a plan, but it can provide direction and a basis from which to work.

# 7.5. Working with the person and their doctor

Some people with bipolar disorder prefer to manage their treatment with their clinician as *independently* as possible. Others welcome the opportunity to *form a team* with their clinician and caregiver to deal with certain aspects of treatment. If you would like to play an active role in assisting the person with aspects of their treatment, here are some suggestions:

- Discuss with the person that you would like to work with them and their clinician. If you would like to accompany the person to an appointment, offer to do so.
- Ask the person to let their clinician know that you are the primary caregiver and your contact details in case there is an emergency and the clinician needs to contact you.
- Find out about *confidentiality laws* that may restrict clinicians from being able to provide information and discuss their patient's treatment with you (e.g. ask a clinician or caregiver support organization about relevant laws and codes of practice).
- Keep in mind that you do have the option of contacting the clinician if you are concerned about the person's wellbeing.
- In order to overcome restrictions on confidentiality, discuss with the person what information they would like the clinician to share with you and under what circumstances (e.g. if the person becomes very ill, or information to assist in the person's ongoing care after discharge from hospital). Ask the person to let their clinician know what you have agreed upon.
- If necessary, you could discuss with the person developing *power of attorney agreements* or *advanced directives* to arrange what you can do to help with urgent treatment or other decisions when the person is severely ill (see 'Planning for times when the person is severely ill' section 3.4).
- While the person is severely ill, try to keep in contact with the person's treatment team.
- When communicating with the person's clinician, don't be afraid to ask questions, or to ask for clarification if the information provided is confusing (e.g. "What are the possible side effects of that treatment?").

# 7.6. Supporting the person who is disappointed about relapsing

If the person has been trying to manage their illness and is disappointed because they have relapsed anyway, you could support them by:

- Listening if the person wants to discuss their disappointment.
- Reassuring the person that they did their best; bipolar disorder is a complex illness and sometimes symptoms occur despite good illness management strategies.
- Suggesting that sometimes medications and other illness management strategies that worked previously may need to be adjusted.
- Encouraging the person not to give up hope, as finding what works to manage the illness is a trial and error process.

# 7.7. When the person has difficulty with their illness management strategies

It can be difficult for the person to use strategies to prevent relapse or reduce symptoms because they may need to go against what their mood tells them to do. For example, they may need to decrease activities instead of racing around when they are becoming manic, or get out of bed when they are feeling depressed and lacking in energy.

If the person finds it difficult to use strategies that may help them to prevent relapse you could:

- Encourage them to keep trying.
- Temporarily take a more active role in assisting the person (e.g. help them to do an activity when they are becoming depressed by doing it together).
- Support them behind the scenes (e.g. maintain regular household routines to reinforce the person's routine). Discuss your ideas tactfully with them if you have suggestions about what might make it easier to use illness management strategies.

# 7.8. Difficulties in working with the person to deal with the illness

It is not always easy to work together to deal with the illness. Good communication skills can sometimes help to sort out disagreement and conflict (see 'Using good communication skills' in section 5.4). You may also find that the person does not always want your help or they may refuse to treat or manage their illness.

# If the person does not want your help

You may find that the person does not always want your help, for example:

- They person may find it easier to discuss what help they need with someone else, even if they care deeply about you. In this situation, if the person needs help, ask them if there is someone else who they would like to help them (e.g. clinician or another support person).
- When the person is depressed or irritable, they might push you away and try to isolate themselves. In this situation still maintain regular contact with the person in case they need or want help later.
- Sometimes, when a person is very ill, they may see no need for help. Nevertheless, you may need to get help for them (see 'Dealing with a bipolar crisis' section 3.3).

Sometimes, when a person is very ill, they may see no need for help.

# If the person refuses to get their illness treated

Bipolar disorder that is not treated and managed can have a very negative impact on the person and their family.

### Listen, observe and assess how ill or well the person is

If the person refuses to treat their bipolar disorder try to understand why they refuse (see Box 22). Assess how ill or well they are so you know how to respond to this refusal. Get urgent medical help in a bipolar crisis (see 'Dealing with a bipolar crisis' section 3.3). Having an *advanced directive or plan* about what treatment they may want when they are very ill can be helpful (see 'Planning for times when the person is severely ill' section 3.4).

#### Take appropriate action

People who are very ill sometimes do not recognize their severe symptoms or the need for treatment. If the person who refuses treatment is *too ill* to recognize they need treatment:

- Gently let the person know that you think they need treatment and offer to assist them to access treatment.
- Contact the person's clinician, mental health team or if necessary get emergency help.
- If you and the person have organized a plan for what to do when they are severely ill, put this advanced directive into practice (e.g. what clinician or emergency service to contact and what treatment they prefer).

If the person who refuses treatment is *able to discuss things* (e.g. they are not too severely manic or psychotic to follow the discussion):

- Discuss the reasons the person has for not accessing treatment (for more about possible reasons see also 'What if the person decides to stop or reduce their medication' in section 4.1).
- Suggest that they at least have an assessment with a clinician to see if they might benefit from treatment.
- Mention how treatment might help in terms of what is important to the person (e.g. treatment might help to reduce symptoms the person finds unpleasant, make it easier for them to achieve a valued goal, or prevent negative consequences).
- Suggest that the person discusses their concerns about treatment with someone who knows a lot about bipolar disorder.
- Discuss what behavior (e.g. spending sprees) you are not prepared to tolerate, as the person may seek treatment to reduce this behavior once they know that you won't put up with it.
- Let the person know what boundary they have crossed (e.g. caused financial debt when manic), and the consequences if they don't try to manage the illness (e.g. you will not pay off the person's credit card).

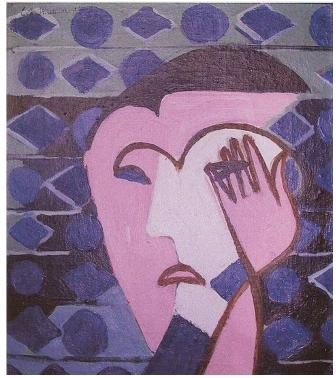
• If they are finding it hard to function, offer to assist them to get treatment.

If the person who refuses treatment has warning signs of illness:

- Let them know that treating warning signs of mania early can prevent relapse.
- Keep an eye on them to see if they develop more symptoms or get worse.
- to negotiate with them to agree to get clinical help if things don't improve or get worse within a set time.

If the person who refuses treatment is *relatively well*:

- Be patient, supportive, and when appropriate, encourage the person to seek treatment.
- Try to negotiate with them to get treatment if they develop symptoms.



Sad woman - Ernst Ludwig Kirchner

#### Box 22: Reasons why the person may refuse treatment

# Some of the reasons for refusing treatment may be that the person:

- Has difficulty *accepting* that they have bipolar disorder or need treatment
- Does not wish to be connected with the *stigma* sometimes linked to bipolar disorder
- Enjoys hypomania or mania and does not want to treat them
- Is too ill to realize they need treatment
- Worries that if they take medication they may get *side effects*
- Does not want to become *reliant* on medication
- Finds that medication *blunts their moods* too much.

# If the person refuses to take responsibility for managing their illness

Consider the following options if over time it becomes clear that the person refuses to take responsibility for trying to manage their illness:

- Talk to the person about the way the illness is affecting their life (e.g. their goals, aspirations, relationships or finances).
- Let the person know your concerns about how the illness is affecting yourself and others (e.g. your relationship with them, your health, work, or the family's financial situation).
- Discuss with them how the negative consequences could be reduced or prevented in the future.
- Request that the person carries out certain illness management strategies (e.g. consults a clinician, cuts down on their alcohol or other drug consumption), and let them know how this could benefit them (and possibly yourself too). If possible give the person a choice when stipulating illness management strategies that they need to carry out (e.g. *"You could see your doctor about your medication or contact the community mental health team"*)
- Contact your own clinician to get professional advice.
- Contact support people you trust (e.g. friend, caregiver advocate or support group).

# Chapter 8: Dealing with stigma, discrimination and disclosure

Dealing with stigma or discrimination from others can be difficult and painful for both the person and the caregiver (see Box 23 and 24).

# Box 23: What is stigma?

**Stigma** involves stereotyped beliefs about the negative qualities of a particular group (e.g. people with mental illness). A person that is considered to belong to this group is automatically thought to have the negative qualities connected with the group. These beliefs distort and taint the person's reputation and status. Stigma can come from external sources (e.g. the family, friends or community). Sometimes, when people experience other people's stigmatizing attitudes, they start to believe them. They may see themselves as being less capable or worthy than others. This is called self-stigma.

# Box 24: What is discrimination?

**Discrimination** occurs when these stigmatized beliefs are acted on and the person is unfairly treated. Stigma can come from others or society in general, or be part of your own beliefs. Dealing with stigma and discrimination can be difficult and painful for both the person and the caregiver.

Caregivers who are concerned about stigma sometimes isolate themselves from social contact and become depressed. Consequently, they may miss out on valuable sources of support and enjoyment.



Self-portrait with straw hat- Vincent Van Gogh

# 8.1. Ways to deal with stigma and discrimination

Below are some suggestions about dealing with stigma and deciding how to respond to discrimination:

# Become informed

Most stigma is based on a lack of information and understanding about the illness. A number of creative and successful people have bipolar disorder (e.g. the artist Vincent van Gogh and composer Robert Schumann). Being well informed about bipolar disorder can help you to recognize some of the *misconceptions* involved in stigma. Bipolar disorder is a health condition like *diabetes*, and not a personality flaw. While certain illness-related behaviors might be socially unacceptable, these behaviors are symptoms of a treatable illness. Some people find that reading books on bipolar disorder helps them to gain a greater understanding of the illness (see section 9.10 for a list of books about bipolar disorder).

# Recognize that there is more to the person than their illness

The person and their illness may seem to merge when they are ill. Don't forget the person's personal qualities, talents and strengths. Although it may be confusing at times, see if you can identify ways in which their personality differs from their illness. Someone who does not know the person might only see the illness, and be more likely to believe stigmatized stereotypes of mental illness.

# Mix with people who accept the illness

Many caregivers find it rewarding to attend a support group where they and the person's bipolar disorder are accepted. This kind of experience may help to counteract stigma.

# Think carefully before deciding to speak out against stigma or discrimination

Some people believe that speaking out against stigma that results in discrimination is always essential. However, whether or not to speak out against stigma or discrimination is *a personal choice*. What you decide might differ depending on the *circumstances*. Asking yourself the following questions may help you to decide whether to speak out or not:

- Is the process of standing up to the stigma or discrimination likely to be very stressful for you or the person?
- Are there likely to be negative consequences to speaking out about stigma or discrimination (e.g. will speaking out about stigma lead to others discriminating more against the person in the future)?

- Are there likely to be negative consequences to not taking a stand against stigma or discrimination (e.g. in a group situation if stigma is not addressed it might escalate, or discrimination at work might result in the loss of a job)?
- Will speaking out in this situation help to change attitudes? Educating people about mental illness can sometimes change their attitudes and behavior, and improve conditions for people affected by mental illness.
- Can you keep your personal situation private when standing up to the stigma? If not, what will the implications be of revealing your situation (for you and the person)?

# 8.2. Ways to assist the person to deal with stigma

Here are some suggestions for ways to assist the person to deal with stigma:

- It is important to let the person decide how they would like to respond to stigma and discrimination from others. Only encourage the person to take a stand against stigma and discrimination, if this is not too stressful for them.
- Encourage the person to develop their abilities, interests, and a sense of purpose, as this might increase their resilience to stigma.
- Peer support groups where bipolar disorder is accepted can provide good buffers against stigma for people with bipolar disorder.
- The person's own stigma about mental illness can cause them to lose confidence and belief in their own abilities. Lack of confidence might prevent them from pursuing opportunities and goals that could enrich their lives. If this is the case, and you have a close relationship with them, it might be an idea to tactfully raise this subject.
- There may be times when you need to help the person to distinguish their personal qualities and abilities from stigmatized views of mental illness.
- When appropriate, remind the person that bipolar disorder is like other recurrent health conditions.
- If you have negative beliefs about mental illness, be careful not to pass these on to the person.

# 8.3. Disclosing the illness or your caregiving role

The issue of disclosure can be a sensitive one for people with bipolar disorder and their close family and friends. You and the person have a right to privacy. This means that you need to be cautious about who you tell about the person's illness or your own situation. However, keeping the person's bipolar disorder a secret from close family and friends, due to concerns about stigma, can eliminate potential sources of support and lead to isolation.

It can be difficult to decide who to tell and what to say about the person's illness or your situation (see Box 25 below). When you do tell someone about the bipolar disorder, help them to understand that it is a treatable illness. If friends or relatives avoid you due to stigma, develop other more supportive relationships.

# Box 25: Things to consider when working out who to tell and what to say

When working out who to tell and what to say about the person's illness or your caregiving role, it may help to ask yourself:

Who needs to know?

Who has the ability to listen, empathize or provide support? Who will respect the confidentiality of this information?

How much do they need to know (e.g. someone you are close to and trust might need to know more than a distant acquaintance)?

How much does that person know about bipolar disorder already?

How can you explain things in a way that will make sense to that particular person? For example, if children are part of the person's family, they need appropriate explanation of the person's illness, and to be allowed to ask questions. Children need to be taught what behavior is part of the illness (when they are old enough to comprehend this.

# **Chapter 9: Resources**

This section includes a selection of resources for caregivers and people with bipolar disorder. There are resources on bipolar disorder, depression, anxiety, drug and alcohol services, caregiver organizations and programs, crisis helplines, suicide prevention, support for those who are bereaved by suicide and treatment guidelines. We also encourage you to find out about local resources and helplines in your area.

Although the resources are listed under different countries, most of the organizations have international websites that you may find useful.

Not all information on the Internet is reliable and we cannot guarantee the reliability or accuracy of information on these sites. We do recommend that you check out information you are unsure of with a health professional, particularly when it comes to treatment.

# 9.1. Dealing with bipolar disorder

The organizations and websites below offer information and support for people with bipolar disorder and their family and friends. Some of these resources may also be useful for dealing with depression, anxiety or other mental health problems.

# Australia

# Australasian Society of Bipolar Disorders (ASBD):

www.bipolardisorders.com.au Ph: 03 94175468

Address: Level 8, Aikenhead Building, St Vincents Hospital, 27 Victoria parade, Fitzroy, Vic, 3065.

#### Beyondblue www.beyondblue.org.au

Info line: 1300 22 4636

Mailing address: PO Box 6100, Hawthorn West, VIC 3122. Beyondblue is dedicated to improving understanding and acceptance of depression, anxiety, bipolar disorder and postnatal depression. You can access free helpful information on these disorders and their treatment in the form of easy to comprehend online or hardcopy pamphlets. The site also has symptom checklists, advice on how to find a GP or psychologist in your area and a directory of mental health internet services. **BlueVoices** is the consumer and carer reference group for beyondblue. They offer a selection of e-groups for people with mood disorders, family members and primary support people. There is also a blueVoices representative body that provides input on national mental health policy.

# Black Dog Institute www.blackdoginstitute.org.au Info line: (02) 9382 4530

Mailing address: Hospital Road, Prince of Wales Hospital, Randwick, NSW 2031.

The Black Dog Institute offers specialist mood disorders assessment, treatment and information. It contributes to research in the area and offers education programs. There is also a list of Australian support groups for consumers and carers on their website.

#### Headspace www.headspace.org.au

Ph 03 9027 0100 (Mon-Fri 9am-5pm)

Mailing address: PO Box 473, North Melbourne, Vic 3051 Email: info@headspace.org.au

Headspace offers support, information and health services for young people (age 12-25) with mental health problems and their families at 30 centres throughout Australia.

#### HealthInsite www.healthinsite.gov.au

Ph: (02) 6289 8488 (Mon - Fri business hours).

This is an Australian Government initiative that offers quality information about health conditions including bipolar disorder and depression. The content of information is carefully assessed for inclusion on the website. They aim to provide the public with 'reliable, up-to-date information'.

# Mental Health Foundation of Australia (MHFA in Victoria)

www.mhfa.org.au

Ph: (03) 9427 0406

Address: 270 Church Street, Richmond, Vic, 3121.

MHFA raises funds for projects that will benefit people with mental health problems and their family and friends. They offer mood support groups that include both people with bipolar disorder and their family members. One of their projects is 'Look to the future', which was developed in conjunction with young people (up to age 24) and aims to enhance the positive mental health of children and youth.

## Mental Health Foundation (MHF in ACT)

## www.mhf.org.au

Ph: (02) 6282 6658 If you need urgent help contact the Crisis Assessment and Treatment Team on 1800 629 354 (24hrs) or 02 6205 1065

Mailing address: Mental Health Foundation (ACT) PO Box 78 Woden ACT 2606.

The Mental Health Foundation is a professional not-forprofit, community organisation. They offer information, peer support, a referral service, support on leaving hospital, a residential long stay program and skill development courses. MHF Canberra also offers a respite service for carers.

#### Mental Illness Fellowship of Australia (MIFA)

www.mifa.org.au

# Ph: 1800 985 944

MIFA is a non-government, not-for-profit organization aimed at supporting and advocating for people with serious mental illnesses and their families. They have developed the WellWays program for family and friends. This is a carer led group program to provide information on mental illness, helpful ways to cope and take care of themselves. It is currently being evaluated to assess its helpfulness.

# Mind www.rfv.org.au/index.htm

Central Office: Ph: 03 9455 7900, email: info@mindaustralia.org.au, mailing address: 86-92 Mount Street. Heidelberg VIC 3084 Southern Australia Office: Ph: 08 8368 7800, email: reception-sa@mindaustralia.org.au, mailing address: 19 Glynburn Road Glynde SA 5070 Mind encourages people to accept their mental illness and find individual solutions to living well with their condition. They offer a large range of programs including residential rehabilitation and transition to independent living and secure accommodation, respite for carers, volunteer and mentor programs, individual service programs and creative expression and employment programs.

#### Moodswings www.moodswings.net.au

This is a comprehensive online self help based program for people with bipolar disorder, which is currently being researched to test its effectiveness.

### SANE Australia www.sane.org

Helpline: 1800 18 SANE (9am-5pm and messages can be left after hours) Email: info@sane.org

Mailing address: PO Box 226, South Melbourne, VIC 3205. SANE offers helpful information and support for people with bipolar disorder, family and friends. They also focus on improving the overall health of people with mental illness. SANE campaigns for better services and attitudes towards people with mental illness. There is also a 'Mental Illness and Bereavement Initiative' that provides information and aims to enhance supportive services when a loved one dies by suicide.

# **United States**

#### Depression and bipolar support alliance

www.dbsalliance.org

DBSA is a not-for-profit consumer organization with satellite organizations all over the US and one in Australia. It has a scientific advisory board and offers easy to understand information on bipolar disorder and depression, treatments, recovery and research trials. There is a special section devoted to family and friends. In addition, caregivers and people with bipolar disorder or depression can access discussion forums and online or face to face support groups. They also offer training courses to assist people to live well with their illness.

# International Society for Bipolar Disorders

### www.isbd.org

This is an international organization aimed at fostering education and research to advance the treatment of all aspects of bipolar disorders to improve quality of life for those with bipolar disorder and their family member and friends.

#### Mental Health America

www.nmha.org

Ph: 1-800-969-6642

Mailing address: 2000 N. Beauregard Street, 6th Floor Alexandria, VA 22311.

This is a non-profit national mental health association. It assists people with mental illness and their families to find treatment, support groups, medication information and helps with issues such as financial concerns around treatment.

## National Alliance on Mental Illness (NAMI)

www.nami.org

Information helpline: 1-800-950-NAMI (6264). Mailing address: NAMI, Colonial Place Three, 2107 Wilson Blvd., Suite 300, Arlington, VA 22201-3042

This large organization offers information, advocacy and support in every state in the US. NAMI run a family –to family education program for caregivers of people with mental illness including bipolar disorder that is available in the USA, parts of Canada, Mexico and Puerto Rico. Initial evaluation of this program suggests that it can reduce caregiver worry and displeasure and increase caregivers' sense of empowerment.

## National Mental Health Information Center (NMHIC)

www.mentalhealth.samhsa.gov/database/ NMHIC is a database you can use to locate mental health services in your area in the US, as well as suicide prevention and substance abuse programs.

#### Bipolarbrain www.bipolarbrain.com

Juliet shares her experience of bipolar disorder and Greg, her partner, contributes a family member's perspective. They provide both a personal perspective and information and resources on topics that are relevant to people living with bipolar disorder.

#### McMan's Depression and Bipolar www.mcmanweb.com

This site presents information on bipolar disorder and related topics in a unique and interesting way. It makes the latest research in the area easy and enjoyable to read and has a number of useful resources.

**PsychEducation.org** www.psycheducation.org Psych education is run by Dr Jim Phelps, a psychiatrist who offers detailed information on bipolar disorder, causes, treatment and resources.

# WRAP (Wellness Recovery Action Plan)

http://copelandcenter.com/

WRAP is a program developed by people with mental health difficulties at the Copeland Center for Wellness and Recovery. It focuses on wellness tools and strategies and helps people to monitor and plan how to respond to symptoms and crises.

# **United Kingdom**

**Bipolar Fellowship Scotland www.bipolarscotland.org.uk** This organization is run by a dedicated team who aim to enhance self-help and education about bipolar disorder in Scotland. It provides information, a catalogue of resources and support for people with bipolar disorder and their family or friends. There is also a facility to locate support groups in Scotland.

## Bipolar 4 All www.bipolar4all.co.uk

Bipolar 4 all has a forum and chatroom for all those affected by bipolar disorder. It also provides information, and useful links to access more information and support, especially in the UK. There is a special section for friends and families.

### MDF Bipolar Organization www.mdf.org.uk

Ph: 08456 340 540 (UK Only) or 0044 207 793 2600 (rest of world). Email: mdf@mef.org.uk Mailing address: Castle Works, 21 St George's Road, London SE16ES.

This is a user-led organization that offers a range of self-help resources and support, including self help groups and illness management workshops, a 24 hours legal advice line, travel insurance and employment advice.

#### Mind

www.mind.org.uk/ Mind Info Line: 0845 766 0163 Email: info@mind.org.uk Mailing address: Mindinfoline PO Box 277 Manchester M60 3XN

Mind is a leading mental health charity in England and Wales. They aim to assist people with mental health problems to take control of their lives. Mind provides information on a range of topics including bipolar disorder, treatments and where to get help, ways to deal with a crisis and help someone who is suicidal, advocacy, and legal advice.

#### Mood Swings network

www.moodswings.org.uk

Helpline 0845 123 50 60 from 10am to 4pm Mon to Fri. Email helpline@moodswings.org.uk.

They offer free confidential advice and support for people with bipolar disorder and depression, their family and friends and health workers. In addition they run training programs to assist people and caregivers to cope with mental illness and improve their quality of life.

#### Pendulum Resources

#### www.pendulum.org/

This website has been in operation since 1994. It has accumulated a wealth of information on bipolar disorder and related topics. In addition there are chatrooms and discussion forums for people with bipolar disorder and their family and friends. You can also find a section on coping resources for family and friends.

SANE UK www.sane.org.uk SANELINE: 0845 767 8000 (12 noon until 2am 365 days year). Email helpline: SANEmail@org.uk. sMailing address: 2nd Floor Worthington House, 199-205 Old Marylebone Road, London W1 5QP SANE UK is a charitable organization aimed at raising awareness, encouraging research into mental illness and supporting users and their relatives and friends on their helpline and SANEmail. They offer help in times of crisis and information on mental health problems, treatments, local services, legal rights and the health system.

# Ireland

# AWARE www.aware.ie

Helpline: (0)1 890 303 302 (24 hours).

Aware is a voluntary organization formed by people with depression, relatives and mental health professionals to provide information, a listening helpline and support groups for people suffering from depression and their caregivers. There is an online mood dairy to help people to monitor their moods.

**Mental Health Ireland (MHI) www.mentalhealthireland.ie** MHI is a national voluntary organization that offers courses and seminars in mental health education, supports research in the area and provides information fact-sheets. It offers a befriending service to prevent the isolation sometimes experienced by people with mental disorders. MHI also offers assistance with housing problems.

#### Shine www.shineonline.ie

Information line 1890 621 631 (9am to 4pm) Shine supports people with mental ill health and their families and friends. They have Regional Development Officers based in Dublin, Kilkenny, Cork, Ennis, Galway, Tullamore and Dundalk who can provide information on support groups, local mental health services, resources, training and employment services. Some centres offer counseling, rehabilitation, personal development and social activities. Shine has an online library called www.recover.ie

# **New Zealand**

### **Balance NZ**

www.balance.org.nz Ph: 03 366 3631

Email: info@balance.org.nz

Mailing address: PO Box 13266, Armagh, Christchurch 8141 This is a charitable trust providing information, peer support training and advocacy for people with mood disorders. If you live in NZ and have bipolar disorder, it can assist you to find support groups in your area. They offer online support groups for parents, spouses and relatives.

#### **Bipolar Support Canterbury**

www.bipolarsupportcanterbury.org.nz Ph: (03) 366 581

Mailing address: PO Box 13167, Christchurch 8141, NZ. This organization provides information about bipolar disorder; peer support groups and one to one support service and holds education and information sessions. There is a focus on the needs of people within Christchurch city but they can send our pamphlets to other places in New Zealand.

### Mental Health Foundation of New Zealand

#### www.mentalhealth.org.nz

Phone Auckland: (09) 300 7010, Wellington: (09) 300 7010, Christchurch: (03) 366 6936. This foundation provides free information and training, and advocates for policies and services to support people with mental illness, their families/ whanau and friends

#### Mental Health Services Directory

www.mentalhealthservicesdirectory.co.nz

# Canada

# **Canadian Mental Health Association (CMHA)**

**www.cmha.ca** Ph: 613-745-7750

Email info@cmha.ca. This organization has information and a support centre

for people with mental health problems and their families and caregivers. They offer information on local services and everyday concerns such as financial assistance, legal information, housing, education and work.

#### Mood Disorders Association of BC (MDA)

www.mdabc.net/

Ph: 604.873.0103, 202-2250

Mailing address: Commercial Drive, Vancouver, BC Canada V5N 5P9.

This is a non-profit organization dedicated to providing support, education and hope for people affected by mood disorders and their family and friends. You will find information and ways to locate support groups in British Columbia on this site.

#### Mood disorders society of Canada (MDSC)

www.mooddisorderscanada.ca Ph: 519-824-5565

Email: info@mooddisorderscanada.ca

Mailing address: 3-304 Stone Road West, Suite 736 Guelph, ON N1G 4W4.

The MDSC is a national, not for profit health charity run by consumers. The MDSC provides information resources and links to national and provincial organizations and services that help people with mood disorders and their family and friends. They also have an online discussion forum.

#### Mood disorders Association of Manitoba (MDAM)

www.depression.mb.ca

Ph: (204) 786-0987 Toll-free:1-800-263-1460

Email: sdmd@depression.md.ca

MDAM is a non-profit organization that provides peer support, public education and advocacy. In this way it supports people affected by mood disorders and their family and friends in Manitoba.

# Mood disorders association of Ontario

www.mooddisorders.on.ca

Ph: (416) 486-8046 or Toll free 1-888-486-8236 This organization offers people with depression and bipolar disorder and their caregivers, peer support groups and telephonic support and educational programs. They have online support forums including a forum for family members.

#### REVIVRE

www.revivre.org Ph (514) 529-7552 Email: revivre@revivre.org Association québecoise de soutien aux personnes souffrant de troubles anxieux, dépressifs ou bipolaires

### Stable Moods www.stablemoods.com

This online resource for family, friends and people affected by bipolar disorder covers a broad range of topics and includes news, book reviews, and articles on bipolar disorder. There are interviews with clinical experts and people with firsthand experience of bipolar disorder such as Julie Fast and Cynthia Last (authors of books on dealing with bipolar disorder for caregivers).

The Depressive and Manic-Depressive Society of Nova Scotia: Ph: (902) 539-7179

# **The Netherlands**

#### **Dutch Association for Manic Depressives**

www.nsmd.nl

This association sponsors psycho-educational courses to provide information and teach coping skills to bipolar patients, their families and friends

# Portugal

# ADEB Associacao de Apoio aos Doentes Depressivos e Bipolares

www.adeb.pt

Adress : Quinta do Cabrinha, Av.de Ceuta, 53, Loja F/G, H/ IeJ 1300-125 LISBOA Ph: 21 8540740/8 Fax: 21 8540749 Mobile: 968982150

# Brazil

ABRATA www.abrata.org.br Stabilitas www.stabilitas.kit.net/

# Spain

**FEAFES: www.feafes.com** Confederación Española de Agrupaciones de Familiares y Personas con Enfermedad Mental

### FECAFAMM

Federació Catalana d'Associacions de Familiars i Persones amb Problemes de Salut Mental www.familiarsmalaltsmentals.org Associació de Bipolars de Catalunya: www.bipolars.org Asociación Valenciana de Trastorno Bipolar: www.avtbipolar.org Asociación Bipolar de Madrid: www.asociacionbipolar-demadrid.com Fundación Mundo Bipolar: www.mundobipolar.org

There are two websites on bipolar disorder where patients can get information and receive advice from specialists: www.puedoser.es www.forumclinic.org

# 9.2. Caregiver organizations and programs

# Australia

# Associations for the Relatives and Friends of the Mentally III (ARAFMI)

**ARAFMI NSW: www.arafmi.org.au** Ph: (02) 9887 5897 carer helpline: (02) 9805 1883

Mental Health Carers NT: www.mentlhealthcarersnt.org Ph: (08) 89481051, Fax 08 8948 2473 Mail: PO Box 40556, Casuarina NT 0811

#### ARAFMI QLD: www.arafmiqld.org

Ph: (07) 3254 188. Carers from outside the Brisbane area can access the 1800 toll free service: 1800 35 1881.

#### ARAFMI TAS: www.arafmitas.org.au

Southern region carer helpline (03) 6228 7448, PO Box 464,

Launceston, TAS 7250

Northern region befriender service (03) 6331 4486 Business Hours

Mail: PO Box 717, Moonah, TAS 7009

ARAFEMI VIC: www.arafemi.org.au

Ph: +61 3 9810 9300 carer Helpline: 1300 550 265

# ARAFMI WA: www.arafmi.asn.au

Phone number in Perth +618 9427-7100 and they have services in a number of other areas in WA including rural areas.

ARAFMI is a non-profit community based organization dedicated to supporting and advocating for family members and carers of people with a mental illness. They offer information and help with accessing supportive health services, respite, legal and financial advice. ARAFMI runs support groups and conducts education and training courses for carers about mental illness and ways to cope.

# Carers Australia www.carersaustralia.com.au

Ph: 1800 242 636.

Carers Australia and the network of carers associations in each state and territory provide services for carers including counseling, advocacy, education and training.

## The WellWays program: Mental Illness Fellowship of

Australia www.mifa.org.au Ph: 1800 985 944.

MIFA is a non-government, not-for-profit organization aimed at supporting and advocating for people with serious mental illnesses and their families. They have developed the WellWays program for family and friends. This is a carer led group program that provides information on mental illness, helpful ways to cope and take care of yourself. It is currently being evaluated to assess its helpfulness.

# National network of adult and adolescent children who have a mentally ill parent (NNAAMI) www.nnaami.org

Ph: (03) 98893095 best after 4. 30 pm EST and book a time to talk.

Mailing address: P.O. Box 213 Glen Iris Victoria Australia 3146.

The website has online forums, information and resources for young adult and adolescent caregivers, for example tips on developing a family management crisis plan. The organisation advocates for children, adults and adolescents who have a mentally ill parent to obtain services and reduce stigma.

# **COMIC (Children of Mentally III Consumers)**

www.howstat.com/comic

Mailing address: The Secretary, P O Box 310 Marleston, Adelaide, SA, 5033.

This organization was established by adult children of people with a mental illness. It advocates to improve information and supportive resources for children and young people affected by the mental illness of a parent, and to assist parents with a mental illness. COMIC offers a *family support kit* and *'child's care plan'* to help children and parents to cope with times when the parent is ill.

### Reach out www.reachout.com.au

This website has a section for young carers on supporting a family member. There is also information for young people on different mental health problems, alcohol and drugs, suicide and family issues and a section on where to get help.

## **Relationships Australia** www.relationships.com.au Ph: 1300 364 277.

This organization offers information, skills training courses, resources and online support with relationship problems.

**More for depression:** In addition to the organisations that support people with mood disorders in section 9.1 above, the following resources may be helpful if you are depressed.

### BluePages www.bluepages.anu.edu.au

It provides information on treatment, helpful resources and an online support group for people suffering from depression. This site has been evaluated and was found to help relieve depression

**depressionServices www.depressionServices.org.au** Depressiveservices offers a variety of interactive online services, such as peer support and free counselling

## Mood GYM www.moodgym.anu.edu.au

This website assists people with depression to use cognitive behavioral strategies to relieve and prevent depressive symptoms. It was found to be helpful in relieving depressive symptoms when people worked through it systematically in a research study.

## e-couch www.ecouch.anu.edu.au

e-couch has information and evidenced based online therapy for people with anxiety or depression.

# **United States**

**Bipolar Significant others mailing list www.bpso.org** Besides providing useful information and links for family, partners and friends of a person with bipolar disorder, this website gives caregivers the opportunity to communicate and share experiences with others in similar situations. Although this website is based in the USA, it has members all over the world.

**Families for Depression Awareness www.familyaware.org** Families for Depression Awareness (FFDA) assists families to recognize and cope with depressive disorders and prevent suicides. FFDA offers brochures, educational seminars, online support groups, resources, and advocacy to support families with depression.

Family to family education program for caregivers (National Alliance on Mental Illness) www.nami.org Information helpline: 1-800-950-NAMI (6264). Mailing address: NAMI, Colonial Place Three, 2107 Wilson Blvd., Suite 300, Arlington, VA 22201-3042 This large organization offers information, advocacy and support in every state in the US. NAMI run a family –to family education program for caregivers of people with mental illness including bipolar disorder that is available in the USA, parts of Canada, Mexico and Puerto Rico. Initial evaluation of this program suggests that it can reduce caregiver worry and displeasure and increase caregivers' sense of empowerment.

#### National Family Caregivers Association (NFCA)

#### www.thefamilycaregiver.org/

This is a national organization that seeks to inform, support and empower caregivers of people with all types of diagnoses. You can find information on legal and financial issues, insurance, respite and many other concerns of caregivers. They offer screening test and helpful resources for caregivers who experience depression: www.thefamilycaregiver.org/ improving\_caregiving/depression\_screener.cfm. There is also information on how stress affects people and a quiz for you to check your stress levels: www.mentalhealthamerica.net/llw/stressquiz.html

# United Kingdom

### **Bipolar Carers Trust UK-Wales**

www.bipolarcarerstrustuk.co.uk Ph: 01873 856314.

This charity was established by carers of people with bipolar disorder to provide support and offer training courses for carers and their families. They aim to assist carers and the person with bipolar disorder to work well together.

#### Carers UK www.carersuk.org

This carer advocacy organization offers information and advice to carers about their rights and how to get support.

# The Princess Royal Trust for Carers www.carers.org/

This large organization represents UK carers and offers information on carers' allowances, benefits and other relevant issues such as the Mental Health Act and confidentiality laws.

# 9.3. Crisis Help Lines

There are crisis helplines listed below. Your local phone directory will have phone numbers of emergency services and crisis helplines in your area.

# Australia

## Lifeline Ph: 13 11 14 (24 hour crisis counseling service)

www.lifeline.org.au This service is provided at the cost of a local call.

#### Salvation Army Care Line: 1300 36 36 22 (24 hour service)

If you have lost a loved one to suicide call the national hope line: 1300 467 354 or 1300 HOPE LINE

# Suicideline (Vic) Ph: 1300 651 251 (24 hour telephone counseling service)

www.suicideline.org.au

This suicideLine is for people who are suicidal or have self harming thoughts and those who are concerned about them (family and friends). The cost is that of a local call (mobiles extra). They also offer support for people bereaved by suicide.

# Suicide Call Back Service (SCBS) Ph: 1300 659 467

seven days a week, 10am – 8.30pm (EST). After hours calls are answered by SuicideLine counselors who can provide immediate support or organize counseling sessions with the SCBS counselors. SCBS offers callers up to six 50 minute telephone counseling sessions. http://www. suicidecallbackservice.org.au.

## Kids Helpline Ph: 1800 55 1800

# (24 hour counseling service for young people aged 5-25) www.kidshelpline.com.au

This service is free from a landline, but there are charges for some mobile users. The website has a link to 'parentline', a helpline service for parents that operates during certain times in different states in Australia.

# Mensline Australia Ph: 1300 78 99 78 (24 hour telephone counseling for men)

www.menslineaus.org.au This service is provided at the cost of a local call.

# National Domestic Violence and Sexual Assault Helpline: Ph: 1800 200 526 (24 hour telephone counseling).

www.fahcsia.gov.au

# **United States**

## National Suicide Prevention Hotlines Call: 1-800-273-TALK (8255) or 1800-SUICIDE. TTY: 1-800-799-4TTY (4889)

You will automatically be transferred to receive appropriate help from trained telephone counselors at a crisis centre near you. www.suicidepreventionlifeline.org or wwwhopeline.com/

# National Domestic Violence Hotline Call: 1-800-799-SAFE (7233) or TTY 1-800-787-3224.

# **United Kingdom**

NHS Direct: 0845 46 47 is a national nurse-led helpline providing 24 hour medical advice in England and Wales. In Scotland the NHS 24 phone number is 08454 242424.

# Samaritans: National helpline: 08457 90 90 90 ( 24 hour service)

www.samaritans.org.uk

Email: Jo@ Samaritans.org

Mailing address: Chris, PO Box 9090, Stirling FK8 2SA. The Samaritans offer confidential non-judgmental support (over the phone, email or face-to face) for people in the UK and Ireland who are experiencing feelings of distress or despair.

Saneline: 0845 767 8000 provides information and crisis support between 1pm to 11pm every day.

# Ireland

Samaritans Ph: 1850 609090 (24 hours service in the Republic of Ireland) or 08457909090 (UK including Northern Ireland). jo@samaritans.org (24 Hour Email Helpline) http://www.samaritans.org.

**1Life Helpline Ph: 1800 247 100** or **text HELP to 51444** (24 hour suicide prevention helpline).

# New Zealand

Family violence helpline: 0800456450

Lifeline 0800 111 777 available 24 hours

Samaritans, see your local whitepages for listings in your area

Youthline Helpline 0800 37 66 33, Free TXT 234 Email/MSN talk@youthline.co.nz

# 9.4. Suicide prevention and support for those bereaved by suicide

# International

# Befrienders Worldwide www.befrienders.org

You or the person who is suicidal can locate helplines and services for support and to help prevent suicide on this website. You can also locate support if you are bereaved by suicide. The organization has over 400 volunteer centers in 39 countries.

**Suicide.org www.suicide.org/suicide-hotlines.html** Suicide.org has extensive listings of suicide hotlines in countries all over the world. There is also information on suicide, prevention, bereavement and information for people who have survived a suicide attempt.

## **Living Works**

LivingWorks offers training to caregivers, community and professional helpers to be able to recognize suicide warning signs and help prevent suicide. These training courses can be found in:

**Canada www.livingworks.net/** Ph: +1 (403) 209-0242 Toll-Free: +1-888-733-5484

**America** www.livingworks.net/ Ph +1 (910) 867-8822

Toll-Free: +1-888-733-5484

**Australia www.livingworks.net/** Ph: +011 61 (3) 9894 1833

New Zealand www.livingworks.org.nz

Ph: +011 64 (9) 524 3080

Norway www.unn.no/vivat Ph: +011 47 (77) 62 7819 Scotland www.chooselife.net Email: info@chooselife.net

# Australia

## Living Is For Everyone (LIFE)

www.livingisforeveryone.com.au

The LIFE website is dedicated to preventing suicide and selfharm. There is a brochure on what to do if a person you know is suicidal, a variety of factsheets and links to related sites.

## Hope for life

www.suicideprevention.salvos.org.au Hope for Life offers information and training courses on suicide prevention, support groups for bereavement and other resources.

## ARBOR

www.ichr.uwa.au/prevntingsuicide/arbour Ph: (08) 9489 7717

Email: arbor-support@curtain.edu.au

Is an Australian outreach service for people bereaved by suicide. You can access peer support and counselors. This is NOT a crisis line.

## Support after Suicide

www.supportaftersuicide.org.au/home/ Ph: (03) 9427 9899.

This is a program of the Jesuit Social Services in Victoria (Australia) and offers information, counseling and support groups for bereaved children, young people and adults. They do not offer online counseling.

# American

# American Association of Suicidology (AAS)

www.suicidology.org

AAS offers comprehensive information on suicide prevention and bereavement. Family and friends in America and Canada can locate support groups in their area on the website

# American Foundation for Suicide Prevention (AFSP)

www.afsp.org

AFSP contains information about preventing suicide, current research and advocacy programs. There is also an online community of people who have lost a loved one to suicide and a directory of face- to-face support groups in America. They also offer training for caregivers who have experienced the suicide of a loved one to facilitate these groups.

# Canadia

# The Centre for Suicide Prevention

www.suicideinfo.ca

Ph: 403-245-3900 Fax: 403-245-0299

Mailing address: Suite 320, 1202 Centre Street S.E.Calgary, AB T2G 5A5.

The Centre offers information and skills workshops on suicide prevention across Canada. They do not provide crisis intervention but offer a facility on the site to locate a crisis center in your area if you live in Canada.

# **New Zealand**

### SPINZ – Suicide Prevention in New Zealand

www.spinz.org.nz Ph: Auckland (09) 300 7035 Email: info@spinz.org.nz

This website has information to support people who are suicidal and their family and friends. There is information on preventing suicide and help for the bereaved if suicide occurs.

# **UK and Europe**

### National Suicide Bereavement Support Network

www.nsbsn.org/index.htm

This is an Irish organization with links to support groups for the bereaved in Ireland and services for suicide survivors all over Europe.

#### Console www.console.ie

Helpline: 1800 201 890 (24 hour service). Email: info@console.ie This organization in Ireland aims to help prevent suicide and support those who experience bereavement by suicide.

#### Survivors of Bereavement by Suicide (SOBS)

www.sobs.admin.care4free.net

Helpline: 0870 241 3337 (Open 9am- 9pm, 7 days per week). This organization also has a website with an excellent resource library

# 9.5. Drug and alcohol services

You may find that the person uses alcohol or street drugs to try to improve their mood, but these substances make bipolar disorder and its consequences worse. They result in ongoing bipolar symptoms, more frequent relapse and hospitalization.<sup>32,47</sup> This can affect the person and families' quality of life.

Alcohol and other drug problems need to be treated in their own right and the person's clinician may be able to assist with treatment or recommendations. If the person is physically addicted to a certain substance, they may need medical assistance to break this habit. It can be very difficult to reduce or stop an alcohol or drug habit and some people try many times before managing to so. Some organizations provide information and support for people and families affected by alcohol or other drug problems or 'dual diagnosis' (i.e. when a person has alcohol or other drug problems with another disorder like bipolar disorder).

# Australia

#### Australian Drug Information Network

www.adin.com.au

This is a government funded site that aims to offer good quality internet based drug and alcohol information. They also have information specifically for family and friends and lists of helpful resources (e.g. a national directory of treatment services)

#### **Australian Drug Foundation**

www.adf.org.au

This is a non-profit organization dedicated to reducing alcohol and drug problems with information on most of these substances.

## Family Drug Support (FDS) Help Line

Call 1300 368 186. Open 24 hours seven days a week. FDS is a service for families and friends of people with drug related issues. It is a run by volunteers who provide information, referral and non-judgmental listening. They also have a website to address the support and information needs of parents and other family members of someone with problematic alcohol or other drug use: www.familydrughelp.org.au/

### Highsnlows www.highsnlows.com.au

Highsnlows has information and a discussion forum about the link between mental health problems and cannabis use.

# **United States**

#### National Council on Alcoholism and Drug Dependence (NCADD) www.ncadd.org

Helpline: 800/NCA-CALL

Mailing address: 20 Exchange Place, Suite 2902 New York, NY 10005.

This organization provides education, information and assistance with drug and alcohol related problems. It has offices in New York and Washington, and a nationwide network of affiliates.

# Substance abuse and mental health services administration health information network (SHIN)

www.samhsa.gov/shin

Ph: 1-877-SAMHSA-7 (1-877-726-4727) TTY: 1-800-487-4889

Mailing address: SAMHSA's Health Information Network P.O. Box 2345 Rockville, MD 20847-2345.

This organization includes the National Clearinghouse for Alcohol and Drug Information (NCADI) www.health.org and the National Mental Health Information Center (NMHIC) http://mentalhealth.samhsa.gov/databases/ .You can access information on treatment options for mental health and drug and alcohol problems on their website or by calling them. The database may assist you to find appropriate treatment in your area.

### Dual recovery anonymous (for people with alcohol or drug problems and another mental health problem) www.draonline.org

This organization offers 12 step programs and peer support groups for people dealing with alcohol, drug problems or dual diagnosis (alcohol or drug problem together with another mental health problem).

## Al-anon, Alteen www.al-anon.alateen.org

These organizations offer information and support for family members and friends of alcoholics who may or may not have stopped drinking (adapted for caregivers from Alcoholics Anonymous). Alteen provides support for teenagers with a parent with a drinking problem.

# Nar-Anon www.nar-anon.org

Nar-Anon members are family and friends who are concerned about the drug problem of another. Nar-Anon's group program is adapted from Narcotics Anonymous

# United Kingdom

Adfam www.adfam.org.uk Ph: 020 7553 7640 Email: admin@adfam.org.uk

Mailing address: 25 Corsham Street, London, N1 6DR Adfam lobbies on behalf of families affected by the alcohol or drug use of a family member. They have a database of support resources and offer training courses in conflict management and dealing with substance use for family members. They also offer best practice training for professionals.

#### Families Anonymous www.famanon.org.uk

Helpline 0845 1200 660

Families Anonymous is a self –help organization that provides an international fellowship of relatives and friends of people who abuse substances, or with related behavioral problems. There are Families Anonymous groups in many places in the UK. The group program is adapted from Alcoholics Anonymous

#### FRANK – National Drugs Helpline www.talktofrank.com

Ph: 0800 77 66 00 (24 hours service)

You can speak to a professionally trained advisor to get information about drugs or help with concerns about a family member or friend who is taking drugs.

#### Lifeline for Anyone Who Cares

www.lifelineforanyone.com.

Helpline 0161 832 8073 (7pm-9pm, 7 days a week) This is a registered charity that provides information and support to family and friends of a person with a substance abuse problem. They offer a family group, family mediation sessions, a telephone help-line and one to one support and assessment. Services are facilitated by qualified professionals.

#### National Alcohol Helpline Ph: 0800 918 82 82

# New Zealand (NZ)

# Alcohol and Drug Association New Zealand (ADANZ)

www.adanz.org.nz/ADANZ/Home

Helpline: 0800 787 797 for information, advice and referrals for drug and alcohol problems. Friends and family can also use this helpline. You can use the treatment directory www. addictionshelp.org.nz to find alcohol or other drug treatment services in your area.

### CareNZ www.carenz.co.nz

This organization is part of the charitable trust 'The New Zealand Society on Alcohol and Drug Dependence'. It offers people with drug and alcohol abuse and their families information and counseling. They offer assessments and can discuss treatment options and make referrals to residential care programs.

# Canada

# **Canadian Centre on Substance Abuse**

www.ccsa.ca

Ph: (613) 235-4048 Mailing address: Suite 300, 75 Albert St., Ottawa, ON K1P 5E7.

This organisation is dedicated to reducing addictions at a national level and has a comprehensive list of treatment services in Canada called the CCSA Addictions Databases. They also have information on things to consider when selecting the most appropriate treatment.

# Drug and alcohol registry of treatment (DART) Helpline in Ontario: 1-800-565-8603. Helpline for the rest of Canada: 1-519-439-0174.

DART provides information and referral to alcohol and drug treatment services.

# 9.6. Anxiety management

The experiences of anxiety ranges from a few mild symptoms now and then to a disabling condition. Anxiety may accompany bipolar episodes or be an ongoing problem for the person.

When a person is anxious they may experience:

- Increased heart rate
- Shortness of breath
- Sweating, shaking or trembling
- Feeling dizzy light heated or distant
- Concentration difficulties
- Excessive worry about things
- Aches and pains or indigestion, pins and needles, nausea, vomiting or diarrhea
- Feelings of dread or fear of losing control

Anxiety disorders can have a very disruptive effect on a person's life, they include:

- **Panic with or without agoraphobia:** Panic involves short intense periods of anxiety and can be linked to being in certain situations (e.g.in crowds or away from home).
- **Obsessive compulsive disorder:** Obsessions are intrusive thoughts, images or impulses that are hard to ignore (thoughts about the dangers of dirt). Compulsions are the actions related to the obsessions. These actions are repeated to bring relief (e.g. washing hands repeatedly).
- **Phobias:** This involves excessive, irrational anxiety about something specific (e.g. snakes or spiders). Social phobia involves fear of social situations where you need to perform and others may judge you.
- **Post-traumatic stress disorder**: This can sometimes occur when a person has experienced a traumatic event. They have flashbacks or nightmares about the event and avoid any reminders it.
- Generalized anxiety disorder: GAD involves excessive worry together with other anxiety symptoms, sleep disturbances, feeling tired or on edge and persists for over 6 months.

Finding ways to manage and treat anxiety can reduce the distress and disruption connected to anxiety disorders. We have listed a few resources below and there are some books titles on anxiety management in section 9.11.

# **Australia**

**Anxiety Online www.anxietyonline.org.au** This website offers information on anxiety and self help strategies as well as low cost on-line therapy for Australians.

**Anxiety Treatment Australia www.anxietyaustralia.com.au** This website offers information about anxiety disorders, treatment options, support groups and helpful resources.

## Panic Anxiety Disorders Association Inc. (PADA)

www.panicanxietydisorder.org.au

Ph: (08) 8227 1044 (Mon – Thur 9.30am – 2.30pm). Mailing address: PADA Inc., PO Box 83, Fullarton, SA 5063. This consumer organization provides information, resources, referral, and discussion groups for people with anxiety disorders.

# **United States**

### Anxieties.com www.anxieties.com

This is a self-help resource for people with a variety of anxiety disorders including panic attacks, obsessive compulsive disorder (OCD), post-traumatic stress, fear of flying and other phobias.

#### Anxiety Disorders Association of American (ADAA)

www.adaa.org

Ph: 240-485-1001 Mailing address: 8730 Georgia Avenue – Suite 600, Silver Spring, MD 20910.

ADAA is a national nonprofit organization that provides information on the different kinds of anxiety disorders, treatment options, finding health professionals, support groups and forums and how friends and family can help a person with an anxiety disorder.

# **United Kingdom**

#### ANXIETY UK www.anxietyuk.org.uk/

Tel: 08444 775 774

General information: info@anxietyuk.org.uk,support@ anxietyuk.org.uk

Mailing address: Zion Community Resource Centre, 339 Stretford Road, Hulme, Manchester, M15 4ZY

This registered charity is a user-led organization with a medical advisory panel. They provide information on anxiety disorders, treatment options and ways to access professional and peer support. They also try to improve anxiety services and raise community awareness about anxiety disorders.

# NO Panic (National Organization for Phobias, Anxiety, Neuroses, Information and Care)

www.nopanic.org.uk

Helpline: 0808 808 0545 (10am–10pm every day) and 01952 590005 (office Number).

E-mail: ceo@no-panic.co.uk

No panic offers advice, counseling and self-help for people with anxiety, panic attacks, phobias or compulsive disorders and related problems, including tranquillizer withdrawal. They also support family members or carers.

# Ireland

# **Ireland NO PANIC**

Helpline 01 272 1897 (10am to 1pm Monday to Friday and 7pm to 10pm on Thursdays and Fridays). Outside of these times you can access support from the No Panic UK helpline by phoning 0044 1 952 590 545 which operates 10am - 10pm, 7 days a week.

This is a voluntary charity for the relief and rehabilitation of those people suffering from panic attacks, phobias, obsessive compulsive disorders (OCD), other related anxiety disorders, including tranquillizer withdrawal. They support sufferers and their families or carers.

# Canada

#### Anxiety disorders association of Canada (ADAC)

www.anxietycanada.ca

Ph: 1-888-223-2252 or 1-514-484-0504

Email contactus@anxietycanada.ca

ADAC is a non-profit organization whose aim is to promote the prevention, treatment and management of anxiety disorders and to improve the lives of people who suffer from them. They offer information and resources with links to organizations and services that can assist with anxiety disorders throughout Canada.

# 9.7. Guidelines on bipolar disorder and its treatment

The Royal Australian and New Zealand College of Psychiatrists Consumer and Carer Guidelines on Bipolar Disorder 2009 version.

www.ranzcp.org/resources/clinical-practice-guidelines.html

Yatham LN, Kennedy SH, Schaffer A et al. Canadian Network for Mood and Anxiety Treatments (CANMAT) and International Society for Bipolar Disorders (ISBD) collaborative update of CANMAT guidelines for the management of patients with bipolar disorder: update 2009, Bipolar Disorders, 11(3) 225-255. www.ncbi.nlm.nih.gov/pubmed/19419382 or

www.ncbi.nlm.nih.gov/pubmed/19419382 or www.canmat.org/

NICE (National Institute for Health and Clinical Excellence): The management of BD in adults, children and adolescents, in primary and secondary care, NICE clinical guideline 38, 2006 version.

www.guidance.nice.org.uk/CG38

Kahn DA, Keck, P, Perlis R, Otto MW, Ross R. 2004. Treatment of Bipolar Disorder: A Guide for Patients and Families.

www.psychguides.com/Bipolar%20Handout.pdf

# 9.8. Information on medications for bipolar disorder

**DrugWatch.com** www.drugwatch.com/ DrugWatch.com offers a database of information about medications, side effects and interactions with other medications. We recommend that any concerns raised are discussed with a medical doctor.

# 9.9. Mental Health First Aid (MHFA)

www.mhfa.com.au This website offers members of the public well researched guidelines about how to help a person who is developing a mental health problem or in a mental health crisis to the point where they get appropriate treatment or the crisis resolves. They also run training courses to teach people to recognize the symptoms of mental illness and strategies to provide support. The guidelines have been adapted to different cultures and courses are available in many countries.

# 9.10. Books on bipolar disorder

### Personal accounts of bipolar disorder and coping

Duke P, Hochman G (1992). *A Brilliant Madness: Living with manic-depressive illness*. Bantam Books, New York, USA.

Eyers K, Parker G (Eds.) (2008). *Mastering Bipolar Disorder: An insider's guide to managing mood swings and finding balance.* Allen & Unwin, Crows Nest, Sydney, Australia.

Kern D (2000). *Mind Gone Awry.* Donald Kern/Isaac Nathan Publishing, Los Angeles,

Hamilton CJ N (2004). *Broken Open.* Bantam Books, Sydney, Australia.

Hollan H (2007). *Soaring & Crashing: My Bipolar Adventures.* Mill City Press.

Hornbacher M (2008). *Madness: A Bipolar Life.* Houghton Mifflin Company, New York.

Jamison K R (1995). An Unquiet Mind: A memoir of moods and madness. Vintage Books, New York.

Johnston S (2004). *The Naked Bird Watcher*. The Cairn, Scotland, UK.

Johnston S (2009). *The Snow Globe Journals: sound bites from a mental illness*. The Cairn, Scotland, UK

Kelly M (2000). *Life on a Roller-Coaster: Living well with depression and manic depression*. Simon & Schuster, Sydney, Australia.

McManamy J (2006). *Living Well with Depression and Bipolar Disorder: What your doctor doesn't tell you... That you need to know.* HarperCollins, New York.

Wigney T, Eyers K, Parker G (eds.) (2007). *Journeys with the Black Dog: Inspirational stories of bringing depression to heel.* Allen & Unwin, Crows Nest, NSW, Australia.

#### Books by family members

Fast JE, Preston JD (2004). *Loving Someone with Bipolar Disorder: understanding and helping your partner*. New Harbinger Publications, Oakland, CA, USA.

Johnston J (2005). *To Walk on Eggshells*. The Cairn, Scotland, UK

Karp DA (2001). *The Burden of Sympathy: how families cope with mental illness.* Oxford University Press, New York.

Last CG (2009). When Someone You Love Is Bipolar: Help and Support for You and Your Partner. Guilford Publication, New York.

Lyden J (1998). Daughter of the Queen of Sheba. Penguin, US.

Meehl D, Meehl M (2005). *Friends and Family Bipolar Survival Guide*. Meehl Foundation Press, Texas

Owen S, Saunders A (2008). *Bipolar Disorder - The Ultimate Guide*. Oneworld Publications, Oxford, UK.

#### Books by health professionals/researchers

Basco MR (2006). *The Bipolar Workbook: Tools for controlling your mood swings.* The Guilford Press, New York.

Berk L, Berk M, Castle D, Lauder S (2008). *Living with Bipolar: A guide to understanding and managing the disorder.* Allen and Unwin, Crows Nest, NSW, Australia.

Copeland ME (1992). *The Depression Workbook: A Guide for Living with Depression and Manic Depression*. New Harbinger Workbooks, Oakland, CA.

Fawcett J, Golden B, Rosenfeld N (2000). *New Hope for People With Bipolar Disorder*. Prima Publishing, Roseville, California.

Goodwin G, Sachs G. (2010). *Fast Facts: Bipolar Disorder*. Health Press, UK.

Jones S, Hayward P, Lam D (2003). *Coping with Bipolar Disorder: A guide to living with manic depression.* Oneworld Publications, Oxford, UK.

Miklowitz DJ (2002). *The Bipolar Disorder Survival Guide: What you and your family need to know.* The Guildford Press, New York.

Miklowitz DJ, George EL (2007). *The Bipolar Teen: What you can do to help your child and your family.* The Guildford Press, New York.

Mountain J (2003). Bipolar Disorder: *Insights for Recovery,* Chapter One Press, Denver, Colorado.

Parker G, Eyers K (2008). *Bipolar II Disorder: Modelling, Measuring and Managing.* Cambridge university press, New York.

Russell S (2005). *Lifelong Journey: Staying well with manic depression/bipolar disorder*. Michelle Anderson Publishing, Melbourne, Australia.

Scott J (2001). Overcoming Mood Swings: A self-help guide using cognitive behavioral techniques. NYU Press, New York.

# 9.11. Books on dealing with anxiety

Anthony M M, McCabe R (2004). *10 Simple Solutions to Panic: How to overcome panic attacks, calm physical symptoms, and reclaim your life.* New Harbinger Publications, Oakland, CA, USA.

Bourne E J (2005). *The Anxiety & Phobia Workbook*. New Harbinger Publications, Oakland, CA.

Copeland M E (1998). *The Worry Control Workbook.* New Harbinger Publications, Oakland, CA, USA.

Fox B (2001). *Power Over Panic 2nd ed.* Pearson Education Australia, Frenchs Forest, Australia.

Hyman B M, Pedrick C (2005). *The OCD Workbook: Your guide to breaking free from obsessive compulsive disorder 2nd ed.* New Harbinger Publications, Oakland, CA.

Rapee R M (1998). Overcoming Shyness and Social Phobia: A step-by-step approach. Lifestyle Press, Killara, NSW. Australia.

Williams MB, Piojula S (2002). The PTSD Workbook: Simple, effective techniques for overcoming traumatic stress symptoms. New Harbinger Publications, Oakland, CA, US.

# References

- Merikangas KR, Pato M. Recent developments in the epidemiology of bipolar disorder in adults and children: magnitude, correlates, and future directions. *Clin Psychol-Sci Pr* 2009; 16(2): 121-133.
- 2. Kelsoe JR. Arguments for the genetic basis of the bipolar spectrum. *J Affect Disord* 2003; 73: 183–197.
- 3. McManamy J. Living well with depression and bipolar disorder: What your doctor doesn't tell you...that you need to know. NY: HarperCollins; 2006.
- 4. Berk L, Berk M, Castle, D, Lauder S. *Living with bipolar: A guide to understanding and managing the disorder.* NSW: Allen and Unwin; 2008.
- Smith LA, Cornelius V, Warnock A, et al. Effectiveness of mood stabilizers and antipsychotics in the maintenance phase of bipolar disorder: a systematic review of randomized controlled trials. *Bipolar Disord* 2007; 9(4): 394-412.
- Baldessarini RJ, Tondo L, Davis P, et al. Decreased risk of suicides and attempts during long-term lithium treatment: a meta-analytic review. *Bipolar Disord* 2006; 8: 625-639.
- Biel MG, Peselow E, Mulcare L, Case BG, Fieve R. Continuation versus discontinuation of lithium in recurrent bipolar illness: a naturalistic study. *Bipolar Disord* 2007; 9: 435-442.
- Baldessarini RJ, Calabrese JR, Tohen M, Bowden CL. Bipolar depression: Overview and commentary. *Harvard Rev Psychiat* 2010; 18(3): 143-157.
- Payne NA, Prudic J. Electroconvulsive therapy: Part I. A perspective on the evolution and current practice of ECT. J Psychiatr Pract 2009; 15: 346-368.
- Kraguliac NV, Montori VM, Pavuluri M, et al. Efficacy of omega-3 fatty acids in mood disorders - a systematic review and meta-analysis. *Psychopharmacol Bull 2009*; 42(3): 39-54.
- Barnard K, Colón-Emeric C. Extraskeletal effects of vitamin D in older adults: cardiovascular disease, mortality, mood, and cognition. *Am J Geriatr Pharmac* 2010; 8(1): 4-33.
- 12. Barbour KA, Edenfield TM, Blumenthal JA. Exercise as a treatment for depression and other psychiatric disorders: A review. *J Cardiopulm Rehabil* 2007; 27(6): 359-367.
- 13. Ng F, Dodd S, Berk M. The effects of physical activity in the acute treatment of bipolar disorder: A pilot study. *J Affect Disord* 2007; 101: 259-262
- Berk M, Copolov DL, Dean O, et al. N-Acetyl Cysteine for depressive symptoms in bipolar disorder—A doubleblind randomized placebo-controlled trial. *Biol Pychiat* 2008; 64(6):468-475.

- Zarate C, Rodrigo MV, Ioline H, Glutamatergic modulators: the future of treating mood disorders? *Havard Rev Psychiat* 2010; 18(5): 293-303.
- Colom F, Vieta E, Sánchez-Moreno J, et al. Psychoeducation for stabilized bipolar disorders: 5-year outcome of a randomized clinical trial. *Brit J Psychiat* 2009; 194 (3): 260-265.
- 17. Lam DH, Watkins ER, Hayward P, et al. A randomized controlled study of cognitive therapy for relapse prevention for bipolar affective disorder. *Arch Gen Psychiatry* 2003; 60: 145–152.
- Castle D, White C, Chamberlain J et al. Group-based psychosocial intervention for bipolar disorder. Randomised controlled trial. *Brit J Psychiat* 2010; 196: 383-388.
- 19. Scott J, Paykel E, Morriss R, et al. Cognitive-behavioral therapy for severe and recurrent bipolar disorders: a randomized controlled trial. *Brit J Psychiat* 2006; 188: 313–320.
- 20. Frank E, Kupfer DJ, Thase ME, et al. Two-year outcomes for interpersonal and social rhythm therapy in individuals with bipolar I disorder. *Arch Gen Psychiatry* 2005; 62:996-1004.
- 21. Bauer MS, McBride L, Williford WO et al. Collaborative care for bipolar disorder: Part II. Impact on clinical outcome, function, and costs. *Psychiatr Serv* 2006; 57: 937-945
- 22. Simon GE, Ludman EJ, Bauer MS, Unutzer J, & Operskalski B. Long-term effectiveness and cost of a systematic care management program for bipolar disorder. *Arch Gen Psychiatry* 2006; 63: 500–508.
- 23. Miklowitz DJ, George EL, Richards JA, Simoneau TL, Suddath RL. A randomized study of family-focused psychoeducation and pharmacotherapy in the outpatient management of bipolar disorder. *Arch Gen Psychiatry* 2003; 60: 904-912.
- 24. Miklowitz DJ, Otto MW, Frank E, et al. Intensive psychosocial intervention enhances functioning in patients with bipolar disorder: Results from a 9 month randomized controlled trial. *Am J Psychiatry* 2007; 164: 1340-1347.
- 25. Reinares M, Vieta E, Colom F, et al. Impact of psychoeducational family interventions on caregivers of stabilized bipolar patients. *Psychoth Psychosom* 2004; 73(5): 312-9.
- 26. Reinares M, Colom F, Sanchez-Moreno J, et al. Impact of caregiver group psychoeducation on the course and outcome of bipolar patients in remission: a randomized controlled trail. *Bipolar Disord* 2008; 10: 511-19.
- 27. Perlick DA, Miklowitz DJ, Lopez N et al. Family-focused treatment for caregivers of patients with bipolar disorder. *Bipolar Disord* 2010; 12: 627-637.

- Reinares M, Colom F, Rosa AR et al. The impact of staging bipolar disorder on treatment outcome of family psychoeducation *J Affect Disord* 2010; 123(1-3) :81-86.
- 29. Johnson S L. Life events in bipolar disorder: towards more specific models. *Clin Psychol Rev* 2005; 25: 1008-27.
- Plante DT, Winkelman JW. Sleep disturbance in bipolar disorder: Therapeutic implications. *Am J Psychiatry* 2008; 165: 830-843.
- Frank E, Gonzalez J M, and Fagioloni A. The importance of routine for preventing recurrence in bipolar disorder. *Am J Psychiatry* 2006; 163(6): 981-985.
- 32. Johnson S L, Sandrow D, Meyer B et al. Increases in manic symptoms following life events involving goal attainment. *J Abnorm Psychol* 2000; 109: 721–727.
- 33. Cassidy F, Ahearn E, & Carroll B. Substance abuse in bipolar disorder. *Bipolar Disord* 2001; 3: 181-188.
- Miklowitz DJ. The role of the family in the course and treatment of bipolar disorder. *Curr Dir Psychol Sci* 2006; 14(4): 192-196.
- 35. Lam D, and Wong G. *Bipolar relapse: the importance of early warning signs and coping strategies.* In: The psychology of bipolar disorder: New developments and research strategies, S.H. Jones and R.P. Bentall (Eds.). NY: Oxford University Press; 2006.
- 36. Sierra P, Livianos L, Arques S, Castello J, Rojo L. Prodromal symptoms to relapse in bipolar disorder. *Aust N Z J Psychiatry* 2007; 41(5): 385-391.
- 37. Mantere O, Suominen K, Valtonen HM, Arvilommi P, Isometsä E. Only half of bipolar I and II patients report prodromal symptoms. J Affect Disord 2008; 111: 366–371.
- 38. Miklowitz D J. *The bipolar disorder survival guide*. NY: The Guilford Press; 2002.
- 39. Dias V, Brissos S, Carita A. Clinical and neurocognitive aspects of lack of insight in euthymic bipolar patients. *Acta Psychiatr Scand* 2008; 117(1): 28-34.
- Brissos S, Dias VV, Kapczinski F. Cognitive performance and quality of life in bipolar disorder. *Can J Psychiat* 2008; 53: 517-524.
- 41. Suto M, Murray G, Hale S, et al. What works for people with bipolar disorder? Tips from the experts. *J Affect Disord* 2010; 124(1-2): 76-84.
- 42. Johnson SL. Meyer B, Winett C. Social support and self-esteem predict changes in bipolar depression but not mania. *J Affect Disord* 2000; 58: 79-86.
- 43. Rudd MD, Berman A, Joiner TE et al. Warning Signs for Suicide: Theory, Research, and Clinical Applications. *Suicide Life Threat Behav* 2006; 36(3): 255-262.

- 44. Rihmer Z. Suicide risk in mood disorders. *Curr Opin Psychiatry* 2007; 20: 17-22.
- 45. Sajatovic M, Ignacio RV, West JA et al. Predictors of nonadherence among individuals with bipolar disorder receiving treatment in a community mental health clinic. *Compr Psychiatry* 2009; 50: 100-7.
- 46. Scott J, Pope M. Nonadherence with mood stabilizers: prevalence and predictors. *J Clin Psychiatry* 2002; 63: 384–390.
- Miklowitz DJ. Adjunctive Psychotherapy for Bipolar Disorder: State of the Evidence. *Am J Psychiatry* 2008; 165(11): 1408-19.
- 48. Miklowitz DJ, Otto MW, Frank E, et al. Psychosocial treatments for bipolar depression. *Arch Gen Psychiatry* 2007; 64: 419-27.
- 49. Morin CM, Hauri PJ, Espie CA, et al. Nonpharmacologic treatment of chronic insomnia. *Sleep.* 1999; 22: 1134–1156.
- 50. Ryan MP. The antidepressant effects of physical activity: Mediating self–esteem and self–efficacy mechanisms. *Psychol Health.* 2008; 23(3): 279-307.
- 51. Strakowski S, DelBello M, Fleck D, Arndt S. The impact of substance abuse on the course of bipolar disorder. *Biol Psychiatry.* 2000; 48: 477-485.
- 52. Perry A, Terrier N, Morris R, McCarthy E, & Limb K. A randomized controlled trial of the efficacy of teaching patients with bipolar mood disorder to identify early symptoms of relapse and obtain treatment. *BMJ*. 1999 ; 318 :149-153.
- 53. Anthony WA. Recovering from mental illness: The guiding vision of the mental health service system in the 1990's. *Psychosocial Rehabilitation Journal.* 1993; 16: 11-23.
- 54. Tranvag O & Kristoffersen K. Experience of being the spouse/cohabitant of a person with bipolar affective disorder: a cumulative process over time. *Scand J Caring Sci.* 2008; 22 (1): 5-18.
- 55. Miklowitz DJ. *Bipolar Disorder. A Family Focused Treatment Approach.* New York: The Guilford press; 2008.
- 56. Arseneault L, Moffitt TE, Caspi A, Taylor PJ, Silva PA. Mental disorders and violence's in a total birth cohort: results from the Dunedin study. *Arch Gen Psychiatry.* 2000; 57:979-86.
- 57. Jamison K R. An *Unquiet Mind: A memoir of moods and madness*. NY: Vintage Books: 2005.