CARING FOR A LOVED ONE WITH BIPOLAR

A Carer's Guide to Understanding the Illness and Keeping Well

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Authors' Note

Whilst bipolar disorder is a condition that requires long-term management, it is important to remember that with effective treatment and support the majority of individuals lead full and active lives. Enjoying meaningful relationships, caring for a family, holding down a job and contributing to the local community can all be a part of your loved one's life.

The term "patient" is used throughout this booklet to denote those who have been diagnosed with a mental illness, and the term "bipolar disorder" is used to describe the mental illness that is diagnosed according to criteria found in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV TR).

There are points throughout this booklet where statements or stories from our contributors have been included. The names of all individuals have been changed to protect the identity and respect the privacy of those who have shared so thoughtfully.

Cover Art: "With These Arms" Artist: Ingi

"With These Arms" is a celebration of 'carers' – those that support and care for their loved ones with bipolar disorder everywhere. These are people who so often, are overlooked and undervalued... In this picture, the relationship is between a mother and her son with bipolar. The bipolar spectrum is depicted like the symbol of the yin and yang, the blue pole for depression and the red pole for mania. Her arms hug and encircle this spectrum, arms strong enough to contain a storm.

Arms that pull down when he's too high and bold...

Arms that pull up when he's heavy and cold...

Her love is shown by the little hearts she literally wears on her sleeve.

DISCLAIMER

The information contained in this booklet is not intended to be a substitute for medical care. Decisions regarding treatment are complex medical decisions requiring the independent, informed decision of an appropriate health care professional. Reference to any medication or substance does not imply recommendation by the authors who accept no responsibility for any clinical untoward event that may arise from following the recommendations contained herein.

Contents

| Introduction: Why Should I f | 5 | |
|---|--------------------|----|
| What Is Bipolar Disorder? | | 6 |
| Why Is Diagnosis Important? | ? | 10 |
| What Isn't Bipolar Disorder? | , | 11 |
| What Causes Bipolar Disorde | er? | 14 |
| What Can Accompany Bipole | ar Disorder? | 16 |
| Alcohol and other Drugs | | 16 |
| Anxiety | | 17 |
| How Is Bipolar Disorder Treat | ated? | 18 |
| Medications | | 20 |
| Psychological Therapies | | 22 |
| Lifestyle Considerations | | 24 |
| Electro-Convulsive Thera | ру | 27 |
| Preventing Relapse | | 29 |
| Mood Monitoring | | 30 |
| What Are the Early Warn | ing Signs? | 32 |
| The Importance of Sleep | | 35 |
| Safety | | 38 |
| Communication Skills | | 39 |
| Suicidal Thoughts | | 42 |
| Crisis Plan | | 44 |
| Consent and Privacy | | 48 |
| Employment and Taking Time | ne Off Work | 49 |
| Family Planning | | 50 |
| Caring for Yourself | | 51 |
| Carer Support Groups an | d Respite Services | 56 |
| Further Resources | | 57 |
| References | | 58 |

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We would like to extend sincere thanks to all of the carers and individuals who contributed to the process of developing this booklet. Thank you for sharing your personal stories so generously and graciously. Your expertise in this area is unique and priceless and your loved ones are so fortunate to have you in their lives.

Introduction: Why Should I Read This Booklet?

This booklet has been put together to help the carers of those individuals diagnosed with bipolar disorder. You may be reading this booklet because your child, parent, partner, sibling, relative or friend has been diagnosed with bipolar disorder. The information provided here is aimed to give you a better understanding of what the disorder is, the different presentations and problems it may come with, and ways to help manage it over the course of your loved one's illness journey.

A very important aspect of this booklet is that it is written for *you*, the carer. You are invaluable in the care of your loved one, but your well-being is also invaluable. Caring for yourself is first and foremost when caring for your loved one. Though it may not feel like you have the time or energy to think about yourself, especially when your loved one is very unwell, your mental and physical health and emotional well-being are just as important.

Knowing about your loved one's illness is one way of reducing stress through reducing uncertainty, but allowing yourself time and space away from your loved one's illness is equally necessary. It may be difficult for you to pull away at times, you may feel guilty or undeserving of prioritising yourself when it is your loved one who has a mental illness. These are common reactions and reasons why caregivers are vulnerable to feeling overwhelmed, anxious or depressed. That's why it is so important that you do put yourself first, so that you can be in the best emotional and physical state to be there for others.

If you don't look after yourself, you won't be able to look after anyone else.

Hopefully, this booklet will help you become more aware of this. It aims to answer the common questions you might have about bipolar disorder, but also aims to be a working document where you are encouraged to write down information related to your loved ones' and your well-being. You might like to photocopy the pages where there are blank lines and forms to fill in. Keep multiple copies in a folder to make it easier to access. Whether you choose to write in this booklet, or just use it as a prompt to think about certain areas, please do keep them in mind.

Throughout these pages, you'll also find information that is highlighted and put in boxes like this one. These are the take-home messages that are incredibly important to remember. When lives are busy and reading time is limited, these messages may be the easiest to flick to and use as quick reminders.

If you have any thoughts or questions that arise from reading this booklet, please approach your doctor or a mental health professional who is involved with the care of your loved one to gain more information or understanding.

What Is Bipolar Disorder?

Bipolar disorder is an illness which results in someone experiencing extreme mood changes. This is accompanied by significant changes in an individual's thinking, feeling, and behaviour which can sometimes result in serious concerns about the safety or themselves or others.

It is only human to experience ups and downs as we go through life, but a person living with bipolar disorder suffers these to extremes and may be unable to make clear decisions about getting the professional help they need.

This used to be called manic depression, but is now termed bipolar disorder, or sometimes, bipolar affective disorder.

Mood Episodes

The mood episodes that your loved one may experience in bipolar disorder include depression, mania, hypomania or mixed states. Occasionally, they may also suffer with psychotic symptoms mixed in with their mood episodes.

The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV TR) is the clinical tool that is commonly used to assist with the diagnosis of a mental illness. It distinguishes between the following types of mood episodes:

1. A Major Depressive Episode

This is when your loved one's mood is excessively low and depressed or they have lost interest in the activities they usually enjoy for at least two weeks. This is accompanied by a cluster of at least five of the following changes to their usual character:

- A lack of energy or constantly feeling tired
- Sleep disturbance sleeping too little or sometimes too much
- Appetite disturbance eating too little or sometimes too much, and may be accompanied by a noticeable change in weight.
- Persistent restlessness or little movement at all nearly every day
- Reduced concentration, sometimes with memory difficulties
- Feelings of worthlessness or excessive guilt
- Recurrent thoughts about death and/or suicide

2. A Manic Episode

This is when your loved one's mood is either excessively happy or elevated, or irritable, for at least one week (or shorter if they require hospitalisation). This is accompanied by a cluster of at least three of the following changes to their usual character:

- Requiring less sleep
- Talking more than usual or feeling a pressure to keep talking
- Feeling like thoughts are racing
- More distractable than usual
- Excessive confidence or increased self-esteem.
- Increase in goal-directed activities eg. work, school, relationships, physical intimacy
- Excessive involvement in pleasurable activities without considering the risks or dangers involved eg. spending or shopping sprees, gambling, sexual promiscuity, reckless driving.

3. A Hypomanic Episode

Where there are noticeable changes in mood that are similar to mania, but of a lesser intensity and not requiring hospitalisation. The changes in your loved one's character that may occur are from the same list as for a manic episode but only need to be present for a minimum of four days. The individual is usually able to carry out their usual work but may well be more argumentative and irritable than usual.

4. A Mixed Episode

Where your loved one experiences a mixture of mania and depression at the same time. The criteria for both a manic and depressive episode are fulfilled simultaneously for at least one week with significant disruptions to their usual functioning or work. Prompt hospitalisation may be required to manage this state.

Bipolar Disorder Types

Depending on the combination of mood episodes your loved one experiences, they may be diagnosed with different types of bipolar disorder.

The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV TR) distinguishes between the following types:

1. Bipolar I Disorder

Where at least one manic or mixed episode has occurred in their life, usually (but not necessarily) accompanied by a major depressive episode at another point in time.

2. Bipolar II Disorder

Where at least one major depressive episode has occurred with a history of at least one hypomanic episode (but none meeting full criteria for a manic episode).

3. Cyclothymic Disorder

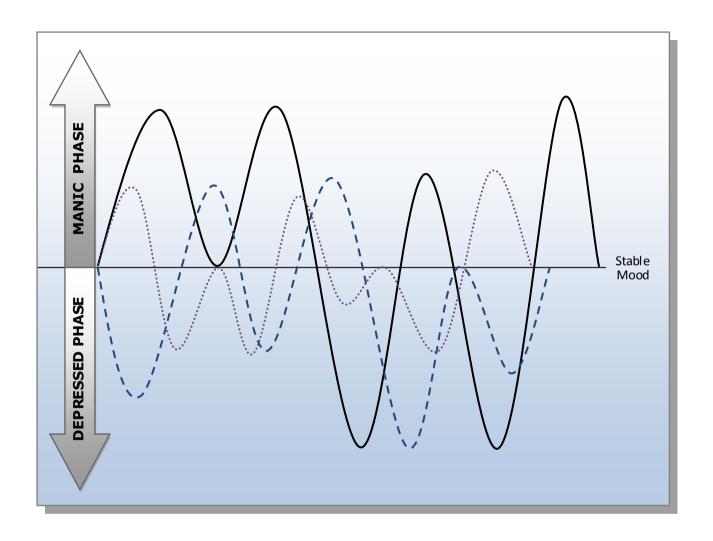
Where they have experienced fluctuating episodes of hypomania (but none meeting full criteria for a manic episode) and mild depression (but none meeting full criteria for a major depressive episode) over at least two years.

4. Bipolar Disorder Not Otherwise Specified

Where there is very rapid change between manic and depressive states (lasting days) that meet criteria based on symptoms but not on the minimum time course required to qualify as a manic or depressive episode. This diagnosis may also be applied if your loved one has experienced recurrent hypomanic episodes without a history of depression.

It may be easier to appreciate the different patterns of bipolar disorder by following the lines on the figure on the next page.

The different types of bipolar disorder are represented below.



Key:

Bipolar I Disorder

– – Bipolar II Disorder

···· Cyclothymic Disorder

There are also other descriptions based on the timing of the mood changes. You might hear mental health professionals refer to the below terms.

1. Rapid Cycling

Where there have been at least four different mood episodes occurring in a 12 month period. The individual will rapidly swing from depression to mania to depression to hypomania and so on. It is important to recognise whether your loved one is suffering from this frequently changing pattern, as the treatment may need to be specifically altered. Rapid cycling bipolar disorder appears to be more common in younger females, or those who have developed the illness later in life. Thyroid abnormalities, substance abuse and anti-depressant therapies may sometimes contribute to your loved one developing this pattern.

2. Seasonal Pattern

Where an individual appears to get unwell at a particular time of the year in a predictable pattern. A common manifestation of this is depression in the winter months, and hypomania or mania in the spring or summer months. If this is occurring for your loved one, protective measures can be taken in anticipation of the seasonal change. With advanced planning, it may be possible to prevent or reduce the intensity of the mood state during certain times of the year.

Why Is Diagnosis So Important?

Even though bipolar disorder is a recognised medical disorder, there aren't any simple blood tests or investigations that can be used to diagnose it. The diagnosis often relies on getting a story of bipolar symptoms from the individual and their loved ones over time. And sometimes it may take years to see a pattern of bipolar mood episodes emerge.

If this is the case, an individual might have an incorrect diagnosis and be treated with medication that is not suited to bipolar disorder. This can cause unnecessary distress with ongoing symptoms for the individual and frustration and feelings of helplessness for those that are trying to help them.

A prompt clinical assessment with a view to diagnosis is critical. It will mean tailoring the right treatment to the individual and stabilising the illness as quickly as possible. If you suspect a loved one may be suffering with bipolar disorder, encourage them to see their GP or a mental health specialist as soon as possible.

What Isn't Bipolar Disorder?

Not everyone who suffers from mood swings has bipolar disorder. Most of us have 'good days' and 'bad days' but wouldn't experience these to such extremes as an individual with bipolar disorder. Depending on what may be happening in an individual's life, they may have different reactions and changes in their mood that sound a bit like bipolar disorder, but overall wouldn't meet the full criteria for a diagnosis.

If your loved one has only ever experienced major depressive episodes, without a hypomanic or manic or mixed episode, a diagnosis of bipolar disorder cannot be made. This would be considered a *unipolar* depression, as opposed to a bipolar depression.

Sometimes, psychotic features present prominently in an individual's mood state. These might include paranoia, delusions and hallucinations like hearing voices. Mood episodes can co-occur with psychotic symptoms in bipolar disorder. But if the psychotic symptoms are present in isolation to mood changes, then a primary psychotic illness such as schizoaffective disorder or schizophrenia needs to be considered.

Similarly, if your loved one is using *recreational substances* and experiencing changes in their mood which look like bipolar disorder, it is important to see whether these changes persist after they have become substance-free for at least one month. If their mood state returns to normal within this time, it is more likely that they were experiencing a temporary substance-induced mood disorder.

Remember though that people with bipolar disorder are particularly vulnerable to the effects of drugs.

Some *medical conditions* or the side effects of certain medications may also mimic bipolar disorder. Therefore it is always important that an individual has a comprehensive medical assessment, including blood tests and CT scans when they experience their first mood episode.

Finally, reactive changes in mood are also seen for some individuals who have a borderline personality structure. These are due to difficulties with emotional regulation in response to personal stressors and may only last a short amount of time. Their moods tend to fluctuate from minutes to hours, rather than days to weeks as in bipolar disorder.

'It took me a long time to realise that's what it was. I just thought it was part of his 'big personality'. I had to find an explanation, I had to understand what was going on – in order to find a solution, to know how to handle and accept him.' (Helen, carer)

| when they occur. |
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| Depressive episode symptoms: |
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| Hypomanic episode symptoms: |
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So, what are some of the symptoms that the person you care about experiences during different mood episodes? It may be helpful to list them so you can spot them more easily

| Manic episode symptoms: |
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| Mixed episode symptoms: |
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What Causes Bipolar Disorder?

Like diabetes or high blood pressure, bipolar disorder is an illness. This means that an individual's genes and changes in certain chemicals in their brain influence whether or not they will develop bipolar disorder. An individual who has a biological relative with bipolar disorder does have an increased chance of inheriting the vulnerability, but this is only seen in a small fraction of people who eventually develop the disorder. Basically, there is still a lot to be discovered about how bipolar disorder starts in the first place and no single proven cause has yet been found.

Whilst a person's genes can increase their vulnerability to developing the disorder, it is not the only factor that contributes. Environmental factors that impose physical, emotional or psychological stress on the individual can tap into this vulnerability and trigger the first and following bipolar mood episodes.

'Stress' can be a hard thing to define, and is very different for each individual. What might stress you may not stress your loved one and vice versa.

Also, be aware there are 'good' stressors (eg. going on holidays) just as there are 'bad' stressors (eg. losing a job). <u>Both</u> kinds of stressors can affect mood, especially in bipolar disorder.

Some of the more common reasons that the mind and body of an individual with bipolar disorder might feel 'stressed' includes:

- Major losses such as the death of a loved one, or the breakdown of a meaningful relationship
- Lots of interpersonal conflict with family or friends, or even workmates
- Physical illness
- Disruption to regular sleep patterns
- Disruption to usual activity levels
- Using recreational drugs or alcohol
- Stopping helpful medications that were stabilising mood states
- Changes to circumstances such as unexpected unemployment, loss of stable accommodation or financial hardship

Not every person with a diagnosis of bipolar disorder who faces the above will become unwell, but it is a guide to help keep in mind so you can increase your alertness around these times. See 'Early Warning Signs' for more detail.

'It was clear to everyone that he was not able to focus on anything. Anything! Very accelerated behaviours, more irrational, more chaotic, more risk-taking. Not relative to drugs or drink. Just the brain. Neurotransmitters in the brain were firing in every direction. But we certainly had no idea of a mental illness being in the mix. His speech was accelerated, his actions, no sleep. Amazing! Just amazing and extraordinary, almost as if you were seeing a play or film or something, it was just unreal.' (Natalie, carer)

What Can Accompany Bipolar Disorder?

Not uncommonly, bipolar disorder can co-exist with other conditions. You may hear these referred to as *co-morbidities*. Two areas of difficulty that can commonly co-occur with bipolar disorder are problems with the use of alcohol and other drugs, and problems with anxiety.

Alcohol and Other Drugs

A proportion of individuals who live with bipolar disorder, also suffer with alcohol or other drug problems alongside of this. Alcohol is the most common substance that is used from this group, but some individuals may use illicit substances such as marijuana, amphetamines, hallucinogens, cocaine or heroin. The harmful use of these substances is a separate condition which warrants treatment in itself; however, periods of intoxication or withdrawal from these substances can severely affect someone who is already vulnerable to serious mood changes.

It is well-known that the continuous use of alcohol or other drugs in people with bipolar disorder increases the risk of relapse of their illness.

For example, alcohol is most commonly implicated in triggering depressive episodes, whereas amphetamines and hallucinogens are commonly associated with triggering manic episodes. Using these substances can also increase the risk of a mixed mood episode emerging, a switch to a rapid cycling illness, feelings of suicidality and aggressive or violent behaviours.

'It's important to reduce drugs and alcohol, otherwise you're just throwing kerosene onto the fire.' (Elizabeth, patient)

Whilst the individual who uses alcohol or other drugs may find it reduces some of their bipolar symptoms in the short term, the consequences of harmful patterns of substance use will only intensify their bipolar disorder in the longer term.

Also, most substances, and especially alcohol, are incompatible with the medications used to treat bipolar disorder. It can make the medications feel like they are working too heavily or not working at all — when they are really working in competition with any recreational substances that are also in the body.

'It seems to me that they do drug take and they do drink a lot because if they're feeling down, of course they're going to want to do that. Or if they're hyper, and all their mates are partying, it makes sense in a way that they want to do those things. I can understand that. So then it's about getting to that point where they realise, 'Whoa, this makes me really sick. I'm not going to drink any more, I'm not going to take any more drugs, because there's a strong correlation between doing that and me going back to hospital.' (Nicholas, carer)

There are effective treatments for difficulties with alcohol or drug addiction. Getting help does take a lot of motivation and courage but can make an incredible difference to the stability of an individual's bipolar disorder. Sensitively encouraging your loved one to keep an open mind about talking to their doctors about their options to reduce or quit can start the process of addressing this very common problem.

Anxiety

Another frequently distressing experience for individuals with bipolar disorder is difficulties with anxiety. The anxiety issues may have been present before the bipolar illness emerged, or may have evolved since the diagnosis. Different people will experience anxiety in different ways and due to many different reasons.

The experience of anxiety is usually a combination of physical and psychological symptoms including: intense fear or worry, feelings of dread, a pounding heartbeat, shortness of breath, sweating, dizziness, and shaking. The fears or worries themselves may be related to going out to public places, social situations, worries about germs or contamination, generalised distress about a number of things constantly, or a personalised distress that has a particular meaning to the individual.

Anxiety symptoms may be so severe that they impact on the individual's mood stability. Effective treatments are readily available. So, once again, encouraging your loved one to talk to their doctor about the difficulties they're experiencing with anxiety can make a big difference to their overall well-being.

How Is Bipolar Disorder Treated?

If we consider diabetes again, there is an underlying biological vulnerability in the body of a person with diabetes that first leads to the expression of their diabetic illness. They might first present to their doctor feeling physically unwell due to extremely high blood sugar or extremely low blood sugar. This needs urgent treatment, and once their diabetic illness is diagnosed, treatment and medicines need to be used to keep their blood sugars stable throughout the day, every day.

Similarly in bipolar disorder, an individual may initially present with an extremely high mood or an extremely low mood. So, once the immediate distress is treated, and bipolar disorder is diagnosed, treatment and medicines need to be used to keep their mood states stable throughout the day, *every day*.

This might be a useful comparison to keep in mind - to help you understand the importance of mood stability and help explain it to your loved one who has the diagnosis of bipolar disorder. Just like severe changes in blood sugar levels in diabetes may be life threatening, severe changes in mood states in individuals with bipolar disorder can also be life threatening. Sticking to a combination of recommended treatments is vital to optimising mood stability and keeping your loved one as well as possible.

Broadly, the treatment of bipolar disorder can be considered across two different stages.

- 1. There is the *acute phase*, where treatment is aimed at providing quick relief for an active manic, depressive, hypomanic or mixed episode.
- 2. And there is the *maintenance phase*, where treatment is aimed at providing longer-term mood stability to prevent relapses of severe mood episodes.

The treatments used at these different stages will almost always involve a combination of biological therapy (medications mainly), ongoing education, psychological therapy and continued support.

Just like outside stress (physical, emotional, psychological) can cause blood sugars to change, they can certainly cause moods to change – so keeping stress to a minimum will give your loved one the best chance of keeping well.

'It's actually a living nightmare, it just never goes away.

It's there all the time, even when your loved one is well, there's still that anxiety you know that... He hasn't had an admission to hospital for about five years.

No drugs. No drugs and the illness is actually contained with the medication, because there are no illicit drugs involved. My son would know when he was becoming manic. He would sense it. He was in touch with his illness by the time he was in his thirties. He knows when he's becoming a bit too high, and he'll slow himself down a bit... That's all you want. You don't want them to be anything but well.' (Samantha, carer)

Medications

The medications used to treat bipolar disorder fall into three different classes:

- 1. Mood stabilisers eg. Lithium, Epilim
- 2. Anti-depressants eg. Prozac, Zoloft, Cipramil, Effexor
- 3. Anti-psychotics eg. Seroquel, Zyprexa

A brief overview will be given here, but please see the *Psychiatric Medication Information Handbook* published by the St Vincent's Mental Health Service for more detailed information. Copies can be obtained through St Vincent's Hospital and the contact details are provided at the end of this booklet.

1. Mood Stabilisers

These are incredibly important medications that are used to keep an individual's mood level and prevent any rapid swings to higher or lower extremes. They include Lithium, and the anti-epileptic medications Sodium Valproate, Lamotrigine and Carbamazepine. Because they work in a dose-sensitive way, regular blood tests are required to ensure the correct amount of medication is in the blood stream. You may need to assist your loved one in remembering to have their blood test when monitoring is requested.

2. Anti-depressants

These medications are sometimes used to treat depressive episodes and may also be helpful if your loved one is suffering a very severe anxiety disorder. Caution needs to be taken when prescribing these medications in bipolar disorder, as there is a risk of lifting a depressed mood into a hypomanic, manic or mixed state. For this reason, they are usually prescribed alongside of mood stabilisers in bipolar depression to buffer against this risk.

3. Anti-psychotics

These medications can be used to treat psychotic symptoms, such as hallucinations or delusions, that might accompany a bipolar mood episode. Even when there are no psychotic symptoms, some of these medications also have mood stabilising properties, and can help reduce agitation or distress and aid with sleep.

Different individuals respond to different medications in different ways.

It is not uncommon to see someone with bipolar disorder on a combination of the above medications, and sometimes on more than one from the same class. In fact, sometimes adding a low dose of one mood stabiliser can boost the effect of another one. Other types of medication may also be added from time to time if the individual is having a lot of difficulty with sleep, anxiety or restlessness.

Medication Issues

'Medication issues have been a big problem for me, I didn't realise she would put on so much weight.' (Jim, carer)

Unfortunately, even the most helpful medications often come with some unwanted side effects. Sometimes these are minor, but other times they may impact on the lifestyle you and your loved one share together.

Your sensitivity and understanding, whatever the issue, will help ease the personal difficulties they may be facing because of the medication side effects.

For example, if your loved one gets *very sleepy* when they take their nightly medication, you may need to consider adapting the timing of your evening social activities. Making earlier plans to avoid them feeling over-tired, may only be a small change to your night, but can make an enormous difference to their well-being.

Also keep in mind that certain medications may affect your loved one's *ability to drive*. If medication changes are being made, talk to the prescribing doctor about any impact they might have on driving and adhere to any precautions that are recommended.

It's important to always remind your loved one to take their medication as it has been prescribed, and not to experiment with stopping or changing the dose.

If they are experiencing side effects, encourage them to see their doctor as soon as possible.

'If medication means bringing quality to your life and preserving your relationships, then you need to accept the trade-offs. But if you want to cease meds, you need to be responsible with other strategies.' (Elizabeth, patient)

To help your loved one remember to take their medication regularly, here are some tips that might help:

- Take the medication at a set time every day.
- Set a daily alarm to remind the person to take their medication each day.
- Link it to a regular activity, such as brushing their teeth.
- Keep a simple medication diary or mark it on a daily calendar.
- Use a blister pack or dosette box that can be pre-filled by the local pharmacy.

Psychological Therapies

Whilst medications are the cornerstone of maintaining wellness in bipolar disorder, psychological therapy is also invaluable.

Psychological therapy is sometimes referred to as 'talking therapy' and helps individuals reframe their experiences in more helpful ways. It can improve your loved one's quality of life and assist recovery by helping them better understand themselves and overcome challenges they might face because of their illness.

During an *acute mood episode*, psychological therapy can be difficult to utilise, and is best aimed at treating depressive symptoms rather than manic. As you can imagine, if your loved one is experiencing acute mania, it may be difficult for them to focus and take on board psychological strategies. This is a more realistic opportunity for times of acute depression, although sometimes may still be difficult due to problems with fatigue and concentration. However, during the maintenance phase of bipolar disorder, psychological techniques may be taken up more easily and stand a better chance of providing long-term relief through recovery and relapse prevention.

Different psychological therapies have gained different types of results in terms of their usefulness. Outlined below are some of the more common types of therapies offered to individuals with bipolar disorder. It is important to find a style that your loved one feels the most comfortable with, as this will hold the greatest interest and provide the most beneficial outcome.

- Cognitive Behavioural Therapy (CBT) is one of the most common and well-researched types of psychological therapy. The 'cognitive' part involves identifying and altering unhelpful thoughts and beliefs that frequently occur in mood or anxiety disorders. And the 'behavioural' part focuses on actions that individuals take because of these thoughts that result in distress and prolongation of symptoms. The therapist works with the individual over a set amount of time to address the main difficulties that they are encountering. CBT also requires the individual to complete homework on their own in between therapy sessions, and may also involve the carers in some of the home-based exercises that might be prescribed.
- Interpersonal Psychotherapy (IPT) is another commonly used therapy in mood disorders, especially depressive conditions. It targets the individual's difficulties in important relationships, and aims to improve the way they relate to and communicate with their loved ones and significant others. IPT is also conducted over a set time frame with homework recommendations for the individual to get the most out of the therapy.

- Interpersonal and Social Rhythms Therapy (IPSRT) or sometimes just Social Rhythms Therapy (SRT) is a type of therapy which builds on the principles of IPT described above. Therapists help individuals understand how changes in daily routines, their social relationships and personal roles can affect their moods. With this in mind, strategies are developed to better maintain regular sleep-wake cycles, stable mood states and positive relationships.
- Family-Focussed Therapy involves working with the individual and their family together to help strengthen the existing support within the family unit. It helps resolve underlying conflicts that might be contributing to distress within the family or their loved one. This therapy can offer a safe space for members of the family to voice their concerns or fears to each other with the sensitive guidance of a trained family therapist.

'We've got three other children, and one of the best things we did was to listen to them, in a forum where they felt safe and heard. That was really good. They actually felt that we were more mindful then of the things that were affecting or worrying them. And then they became part of this team that was caring for someone that was less well than they are.'

(Nicholas, carer)

There are many more types of psychological therapy that you may be interested in helping your loved one look into. When they're ready, encourage them to approach their doctor or mental health practitioner about finding a compatible style to start the therapeutic work.

Keep in mind that these therapies take commitment and *ongoing* work outside of sessions to really be effective. Try to help them integrate what they learn into their daily life.

Your loved one might be tempted to stop attending in the first few weeks if they feel like they're not getting much out of it.

If they are losing faith, encourage them to persevere.

It's very normal to feel stressed or run down in your caring relationship from time to time. If there are periods where you feel overwhelmed or experience symptoms of depression or anxiety, let your own doctor know. They may recommend a short course of individual psychological therapy to help support you through a rough patch. You may also find value in regularly attending a Carer Support Group. See the 'Carer Support Groups and Respite Services' section for further information on this.

Lifestyle Considerations

As you already know, stress can play a major role in triggering initial mood episodes or relapses in bipolar disorder. Whilst medications and additional psychological therapies can help your loved one keep their mood symptoms under control, paying close attention to their lifestyle habits is also important for illness stability. Most often, it is the delicate balance of healthy lifestyle habits, regular helpful medication and beneficial psychological strategies that give your loved one the best chance of maintaining a balanced mood.

Lifestyle habits collectively refer to how individuals choose to live their lives. This involves activities and behaviours that may either have a negative or a positive impact on your loved one and their well-being. You can encourage them to adopt healthier lifestyle habits if you've identified areas that may be creating stress or more vulnerability for ongoing symptoms or clear relapse.

By paying attention to the following areas, your loved one's mood can remain better controlled and relapses may be minimised in the longer-term.

- Maintain stable sleep patterns. This is vital when your loved one has a bipolar illness.
 Please read more about it in 'The Importance of Sleep' section further on.
- Maintain stable activity patterns. Encourage your loved one to keep daytime activity levels to a similar amount and frequency each day. It can be very disruptive to the mind and body's natural rhythms to change suddenly from a casually-paced day to a fast-paced, high energy day. Keep a check on the intensity of activity levels and gently remind your loved one to slow down if you feel they're taking on too much.
- Remind your loved one about the negative effects of alcohol, nicotine and other drugs on their moods and on the helpful medications they are taking to keep their illness stable. This will help them with their mental health and well-being, but also their physical health if they can avoid using these harmful substances in the long-run.
- Nutritious diets are important for all of us. Eating several healthy meals regularly each day is also an important part of keeping the mind and body's natural rhythms stable. Try to help your loved one remember the importance of a healthy balanced diet, and try to discourage them from relying on high carbohydrate or fatty meals and fast food options. Again, this will not only help with mood stability, but also help prevent the longer-term physical complications of unhealthy diets.
- Regular exercise is another way to ensure beneficial balance to the mind and body. It's important to help your loved one find a form of exercise that they enjoy doing, so they may keep doing it regularly over time. You may also use it as a good opportunity to make exercise a regular part of your life. For example, you may decide to go for walks

together every day or several times a week, as a pleasurable way of spending time together with a healthy benefit for both of you.

 Minimise stressful situations whenever this is possible. Whether the source of stress is relationships, work, money, housing or another area of their lives, help your loved one work through the difficulties they're having.

It might help to use a therapeutic exercise called 'Structured Problem-Solving.' With your loved one, write down the problems they're experiencing and then break up each problem into smaller components that can be addressed one at a time. Help your loved one think about solutions and actions they can take to start lessening their stress in these separate areas and encourage them to make these initial steps with or without your help.

- Of course, there are times when stressful situations just arise out of the blue and attention should be directed at helping your loved one cope with the stress. After the initial shock has settled, remind your loved one that you are there for them and the difficult emotions they're experiencing are very understandable, but may be harmful to their psychological health. Once the immediate stress has passed, try to adopt the 'Structured Problem Solving' approach described above to help them work through realistic solutions. If your loved one's reactions or the stressors they are facing seem too overwhelming, remember to involve their doctor or mental health practitioner who may be able to help stabilise the situation quickly.
- Remember the good things! Help your loved one identify activities or hobbies that they enjoy doing, that can help restore purpose and meaning to their lives. Encourage them to take time out and regularly insert these activities into their week. For example, they might enjoy playing a musical instrument, singing, watching television or movies, practising yoga, drawing, gardening etc. Depending on what it is, their chosen activity can also help improve their confidence and social skills, especially if they participate in a group setting.
- Spirituality may also help. If your loved one adheres to a particular faith or draws strength from a particular spiritual philosophy, encourage them to continue these connections. It is a very individual thing, but many benefit greatly from the support of a greater spiritual community.

'Knowing how to manage myself overall, regular sleep, having a daily routine, getting sunshine, pacing myself, managing my medications... has made all the difference.'

(Claudia, patient)

| What are some of the lifestyle considerations that are important for your loved one's mental health and physical well-being? It might be handy to keep a list and check every now and then whether these are being given enough attention. |
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| now and then whether these are being given enough attention. |
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| What are some fun things you can do together with your loved one to help you both? Committing to going for a morning or evening walk together might be a start? List some potential activities you could do together here and try to keep to them regularly. |
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Electro-Convulsive Therapy

Electro-Convulsive Therapy or ECT is another medical treatment for very severe mood episodes. It is often reserved for life-threatening crises where an individual has not responded to the usually helpful medications, or where an immediate life-saving response is required. This is usually reserved for severe depression where the individual is no longer eating or drinking, is profoundly suicidal, or is floridly psychotic. Sometimes it is used for severe mania where physical exhaustion is imminent. There are a number of other situations where ECT may be the preferred treatment of choice in bipolar disorder, such as pregnancy or concurrent medical illnesses that may also benefit from this treatment.

ECT is also sometimes referred to as "shock therapy" and has unfortunately received a lot of bad press because of its history and inaccurate information that occasionally gets circulated in the general media. It is never a treatment decision that is made lightly, and the individual and their family are always involved in discussing this option whenever possible.

ECT has very clear benefits above many other treatment strategies when an individual is critically unwell.

If ECT is suggested as a helpful treatment for your loved one, ask the prescribing doctor as many questions about the procedure as possible. Inform yourself about aspects that are unclear.

Modern medical sophistication has allowed ECT to be administered in a controlled and safe hospital environment with very close monitoring for any physical stress on the body whilst the treatment is being given. A *course* of ECT usually involves at least six individual treatment sessions spaced over a few weeks. It is common to see a rapid improvement in your loved one's mental and physical state after the first few treatments.

Sometimes, your loved one may be able to remain at home and undergo a course of ECT as an *outpatient*, but other times a hospital admission may be necessary. Once your loved one's illness has been stabilised with ECT, it may be beneficial for them to continue having *maintenance* ECT treatment every month or so.

Whatever the recommendation, make sure you have all the information you need to help your loved one make the right decision for the ongoing stability of their bipolar disorder.

'I think bipolar is just one of those illnesses where there's the mania and the grandiose, and the thoughts and everything that you get swept up in. And then there's the huge shift into the depression. I don't know, I sometimes try and work out what's easier to manage. The really highs or the really lows. And I think, I don't really know, they're both exhausting. I think the highs are probably a bit more exhausting but then you worry when they're so down, that it just gets too much, too hard for them, and there's no point to life.

I think for us, you could sort of see it creeping up on us, but we weren't really sure what was happening until he brought himself to hospital. He's had five admissions, and it has gotten easier, but when we first took him home after the first admission, it was like 'Now what?' You know, we felt so unprepared and had no idea what we were meant to do. But the longer you're caring for someone like that, you do learn things along the way.' (Mary, carer)

Preventing Relapse

Maintaining mood stability and preventing relapse is the key to living well with bipolar disorder. The best way to ensure this is to help your loved one continue their prescribed medications, particularly their mood stabilisers. Some may not experience any further mood symptoms whilst on these medication, though some might. Your loved one may experience occasional mood symptoms that remain difficult to eliminate entirely.

It's important to continue to encourage them to stick to their treatment including the recommendations that are made in addition to medication.

Sometimes, there may be a temptation for your loved one to stop taking their medication altogether because they feel it isn't useful or they feel well again. It is important to gently explore their thoughts around this and suggest that they talk to their doctor before making any decision to change their medication.

Research shows that stopping maintenance medication in bipolar disorder almost always results in relapse, within days, weeks or months of stopping. You might like to remind your loved one that bipolar disorder is a long-term vulnerability, and needs long-term treatment to best control it. It might be helpful to express your concern that they may become unwell again if they were to stop their medication.

Whilst medication is a vital part of keeping well, it is not the only part. As described in the 'How Is Bipolar Disorder Treated?' section above, there are other important aspects to management that can keep your loved one's illness stable. Sticking with psychological therapies if these have been suggested, and following recommendations for a well-balanced lifestyle are just as vital to preventing relapses as medications are. These strategies work with the medication for the best outcomes.

It is also very useful to have a plan for times when your loved one's mood may begin to change again, so that action can be taken as quickly and safely as possible. To help with this, knowing your loved one's *early warning signs* is critical to minimising the intensity of a crisis. These areas are covered more specifically in 'What Are the Early Warning Signs' and 'Crisis Plan' a little further on.

Mood Monitoring

'When she's going through a lot of swings, I'm not sure who I'm going to wake up next to.'
(Roger, carer)

Mood monitoring is a very helpful first step when encouraging your loved one to identify their feelings and moods. By getting to know these and the natural fluctuations they may experience on a day to day basis, you will all be in a better position to identify when their moods are out of the ordinary for them.

Mood monitoring is best done as a daily routine, towards the end of the day, at a similar time each day.

You might like to sit down with your loved one and ask them, 'So how did you feel today? Was your mood on the lower side, higher side, or even?' Try to then rate the mood out of 10 - where 0 is the rating for an awful, severely depressed mood, 10 is the rating for a wonderfully elevated, manic mood, and 5 is the middle where their mood feels the most normal.

Make a note of the date and time, and any important factors that might have contributed to that rating. This might include your loved one forgetting to take medication, having a very stressful interaction with someone, receiving unexpected news, using alcohol or recreational substances, and so on. It is also important to keep a track of how much *sleep* they have been getting over this time.

This method of documenting moods and their changes helps your loved one get to know themselves better, and also helps you. It is also a useful tool for the doctor or mental health practitioner involved in their care to look over and identify *patterns* that might need to be addressed. So keep these weekly records on hand when your loved one next visits their mental health professional so that important information is communicated and appropriate changes to treatment can be recommended.

'Mood monitoring, and knowing my triggers and early warning signs has been so important in maintaining my wellness.' (Claudia, patient)

An example of a daily mood monitoring diary has been included on the following page. You can photocopy it to use at home with your loved one, or think of your own version together. By using it, or something like it, mood monitoring provides invaluable information. Once your loved one gets used to this exercise, it becomes easier and quicker, and just another part of their day.

| | DAILY MOOD MONITORING DIARY | | | | |
|-----|-----------------------------|------------------|------------|-------------|--|
| DAY | DATE & TIME | MOOD * (0-10) | COMMENTS** | SLEEP (Hrs) | |
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^{*} Rate the mood out of 10 - where 0 is "awful", 10 is "wonderful" and 5 is "normal."

^{**}Comment on anything significant that may have happened on this day such as important life events, medication changes, major stressors or use of alcohol or other drugs.

What Are the Early Warning Signs?

'Early Warning Signs' refer to the changes to an individual's thoughts, behaviours and feelings that might typically signal the beginning of a serious mood episode. It is very important to work out what the early warning signs are for each individual living with bipolar disorder. Being able to identify these and act on them quickly can provide relief and prevent a severe relapse.

'Carers need to be aware of early warning signs for depression and mania, and point them out to the patient. It's important to ask others to point out when you're not yourself.'

(Laura, patient)

Some of the common early warning signs for hypomania or mania include:

- An uncharacteristically upbeat mood
- Sleeping or eating less
- Having more to say or feeling unable to stop talking
- Feeling uncharacteristically more confident and sociable
- Getting irritated or impatient more easily
- Feeling like thoughts are racing
- Feeling more easily distracted or having difficulty focussing
- Using alcohol or other drugs more frequently
- Engaging in risky behaviours

| What are some of the early warning signs that your loved one might display when they entering a <i>hypomanic or manic</i> phase? | | | | |
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When this occurs, encourage them to rest, get regular sleep, continue their prescribed medication and see their treating doctor as soon as possible.

Some of the common early warning signs for *depression* include:

- Expressing little interest in doing things that previously made them happy
- Looking sad, worried or crying more
- Changes in appetite
- Difficulties with sleep
- Feeling more tired than usual
- Feeling like there are problems with their memory
- Neglecting themselves and possibly their home eg. not interested in showering, personal grooming or tending to their home
- Complaining more of physical aches or pains

| What are some of the early warning signs that your loved one might display when they a entering a depressive phase? | | | | |
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When this occurs, encourage them to establish a routine to their day involving some physical exercise and small goals they can work at every day. Also remind them of the importance of regular sleep and nutrition. And encourage them to see their treating doctor as soon as possible.

The possible warning signs of a *mixed episode* may look like a combination of the above. It is incredibly important that the person sees their treating doctor as soon as they can.

'Learning to observe my own symptoms and knowing how to control them has been empowering. I learned that I needed to manage my illness, otherwise it would manage me.' (Claudia, patient)

Sometimes it can be difficult *communicating* with a loved one about their early warning signs. Because of the bipolar disorder, they may not want to hear it, or perhaps just can't. Or they may feel ashamed, embarrassed, defeated or more sensitive to perceived criticism during these times. They may also feel like they've let their carer down. This can be a frustrating situation for both you and your loved one. The approach should be one of gentle care and sensitivity.

Some initial communication strategies that may be helpful include:

- First asking them if they have noticed any changes in themselves.
- Express your concerns about the changes you have noticed in a caring and non-judgmental way, eg. "I've noticed that you haven't quite been your usual self lately."
- Be open if you're not sure whether what you've noticed is actually an early warning sign.
- It may also be useful to have discussions when your loved one is well about how they would prefer you to approach them when you are concerned about early warning signs.
- Remind them that you care for them and only want them to be as well as possible.

The Importance of Sleep

Maintaining a *regular sleep-wake cycle* is important for everyone's general health and well-being. Sleep is critical to survival, just like oxygen, water and nutrition. It can be easy to forget about the importance of sleep when lives become busy and other things take priority. Unfortunately, it's not usually until sleep patterns becomes terribly disturbed that we realise how much they impact on our physical, mental and emotional health. This is especially true for your loved one who is living with bipolar disorder.

A regular and consistent sleep-wake cycle can become critically important in maintaining wellness in bipolar disorder.

You may have already noticed that your loved one's moods and behaviours are highly sensitive to small changes in their sleep pattern. This is especially true of sleep deprivation or broken sleep, which may occur for many different reasons including lifestyle choices, work commitments, short-term stressors, medications, alcohol or other drug use, or travel and jet lag. For many individuals diagnosed with bipolar disorder, loss of sleep is a well-known *trigger* for a mood relapse, usually along the hypomania or mania end. Sometimes it may only be a few bad nights of sleep in a row that can tip the balance.

'That sleep deprivation can be a nightmare.' (Nicholas, carer)

In order to prevent this from happening, it is important to encourage your loved one to maintain regular sleep patterns. The phrase 'sleep hygiene' is used when talking about ways to promote healthy sleeping habits. Here are some good sleep hygiene tips to try with your loved one, or yourself, if either of you are suffering from disturbed sleep.

- Go to bed at around the same time every night and encourage waking at the around the same time each morning, even if this means having to set a regular alarm. This means every day, including weekends. The mind and body will feel much more regulated with a predictable sleep-wake cycle.
- Avoid over-sleeping and day-time napping. These habits will disrupt the cycle you've achieved above.
- Refrain from lying in bed for long periods of time if you're not actually sleeping. So, if your loved one complains of difficulty falling asleep, suggest that they get up, leave their bedroom and engage in an activity to mentally tire them out, such as reading or watching television on low volume. Once they begin to feel sleepy again, they should return to bed and hopefully fall asleep. If they remain awake again for more than half an hour, suggest that they leave and repeat the same steps, as many times as they need until they fall asleep.

- Engage in regular exercise, preferably daily, such as walking. This should be done well before bedtime, preferably during the day. It will allow the body to feel physically tired and crave sleep to re-energise itself for the next day.
- Keep the bedroom free of distractions such as electrical equipment that might unnecessarily stimulate your loved one. This means no televisions, computers or gaming devices in the bedroom that might tempt them to continue usage into bedtime hours.
- Good quality sleep is best achieved in a quiet dark room with minimal audio or visual interference. Sometimes eye masks or ear plugs can help with this if your loved one is sensitive to outside noises and lights.
- Train the mind and body to associate the bedroom with only sleep and intimacy. So minimise the amount your loved one spends in their bedroom outside of these times. Even if they prefer their own company at times, suggest they do so in the common living area, or use a separate room for independent wakeful activities.
- Sometimes a warm bath or shower just before bedtime can help the mind and body unwind and ready itself for bed. Consider whether this might be included as a regular pre-bedtime routine for your loved one.
- We all know how hard it can be to get a restful sleep if the room is too hot or cold, or if the bed is too uncomfortable. Check that none of these other issues are affecting your loved one's sleep. Encourage them to let you know if they're not feeling physically comfortable in their bedroom or bed. Help them find a solution if this is a problem, for example, a new pillow or an extra blanket.
- Occasionally a light snack or warm milk drink can also help the mind and the body feel sleepy. Certain foods are thought to trigger particular chemicals in the brain that are important for sleep. These sleep-inducing chemicals are tryptophan, serotonin and melatonin. The foods that trigger them include milk, oats, yoghurt, bananas and honey. A teaspoon of honey can be a useful addition to a glass of warmed milk to help ready the mind for sleep. Remember that chocolate contains caffeine and will only waken the mind, so should not be added to milk if insomnia is a problem.
- Minimise alcohol and other drug intake. Alcohol is especially disruptive to the natural sleep architecture and your loved one may be tempted to use it to assist with sleep difficulties in the short-term, but it will only make it harder to regain a natural sleep cycle in the longer-term.
- Refrain from drinking caffeinated beverages after lunchtime. The amount of caffeine found in tea, coffee and cola drinks can vary, but all can interfere with sleep induction. Consider non-caffeinated or herbal beverages as a safer substitute.

Similarly, refrain from smoking nicotine several hours before bed as this will also make it difficult to wind down. Encourage your loved one to have their last cigarette several hours before going to bed. It may also be a good opportunity to encourage them to consider quitting smoking for the sake of their overall health and well-being.

Of course, every now and then, there may be nights when it might take a long time to get to sleep or it might be difficult to fall back asleep after waking up in the middle of the night. The most important thing is to try and regulate sleep for the next few nights as strictly as possible, to prevent it from snowballing and becoming an ongoing problem with serious impact on mood. If sleep patterns become recurrently disturbed, alert your loved one's doctor to the problem quickly so that action can be taken before they experience a bipolar relapse.

| What are some of experiencing difficult | | that | are | useful | for | you | or | your | loved | one | when |
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Safety

Some carers can feel frightened or unsafe when their loved one with bipolar disorder is unwell. Whilst physical aggression is not a common feature of this illness, it can sometimes occur if the person is very angry and manic, experiencing a mixed mood state or psychotic. Aggression can also be amplified during times of intoxication with alcohol or other drugs. Following general principles around safety is vital.

The important things to remember include:

- Remain alert to the issues of safety and tune in to your instincts which will also guide you on whether the situation is safe or not.
- Follow the *principles of communication* when your loved one is very unwell. See 'Communication Skills' further on.
- Learn to identify the early warning signs of aggression for your loved one. Let them
 know that their behaviour is beginning to scare you and you will have to leave if they
 don't stop.
- Try to have an action plan already worked out what you will do if safety becomes a critical issue. For example, remove dangerous items that may be used as weapons.
- If you feel unsafe or threatened, remove yourself from the situation and call the Crisis
 Team or the police.
- If you are *unable to leave*, keep yourself close to a door or an exit.
- Don't continue to try and reason with your loved one, as their illness may prevent them from responding rationally.

After the crisis has passed, if you continue to feel traumatised or fearful — seek medical advice and consider psychological support to help you come to terms with the episode of aggression.

'Always be aware that you may be talking to a person who is affected by an illness – not the 'real person' who is being aggressive or abusive.' (Roger, carer)

Communication Skills

Sometimes it can be difficult to know how to talk to someone who is unwell with bipolar disorder. It can be difficult to know what to say or how to say it. You know you don't want to upset them, but how do you talk to your loved one when they're very depressed or very elevated? A big part of communication is actually non-verbal.

'Communication is so important.' (Angela, carer)

When the person you care about is unwell, it is often a stressful time for you, too. It is important that you try and remain calm so you can communicate in an effective manner.

The following points might be useful when speaking with your loved one in a time of acute distress:

- Be understanding and compassionate.
 - For example, "It must be frightening to feel like you're so alone right now."
- Remain *calm* and speak in a soft voice.
 - Try to keep your tone of voice low and steady to minimise further frightening the person.
- Be non-judgmental.
 - Keep in mind that the person is behaving or speaking in a particular way because they are unwell and cannot control this at the moment.
- Use open-ended questions to start conversations.
 - Give the person an opportunity to explain what's going on for them in their own words. For example, "What's going through your mind?"
- Actively listen to what is being said.
 - You may find it's more helpful to listen more than talk, but listen *actively* so the person knows that you're really hearing what they're saying.
 - It may feel comfortable to offer soothing responses such as, "I can understand why you're feeling that way" during their talk.
- Directly challenging unusual thoughts is not useful.
 - Remember not to directly challenge the person on what they believe, even if you feel it doesn't make any sense. This may only anger them more, and escalate a tense situation.

'I definitely felt a loss of trust in my own sanity, but having your sanity questioned by your carer is awful.' (Claudia, patient)

 Indicate that you have noticed a change in them or their behaviour, and that you are worried about it.

'It's important to ask others to point out when you're not yourself.' (Laura, patient)

- Don't take things personally.
 - A lot of things may be said that are not meant, or not meant as harshly. Be aware that you are talking to someone affected by their mental illness.

'Be patient and stand back – acknowledge it's the mental illness and not the person.'
(Roger, carer)

- Use non-verbal behaviour to demonstrate your support.
 - Try to maintain eye contact, although sometimes it might be more comfortable to avoid direct eye contact or physical touch. The person may feel more comfortable just knowing you are there, sitting beside them, in silence.

'There needs to be a balance between action and inaction, a carer also needs to know when to do nothing.' (Laura, patient)

- Be clear about what you will tolerate, if the behaviour is becoming unacceptable.
 - Express you will be there for them, but if they begin to threaten or frighten you you will have to contact the crisis team or police.
- If you have said or done something wrong, admit it.
 - Be honest and clear about your mistakes.
 - Acknowledge that you may have upset the person, but that you didn't mean it.
- Look for topics of discussion that aren't related to the illness.
- Minimise stimulation from the outside when your loved one isn't feeling well.
 - Reduce exposure to television, radio, the internet.
- Give them space.
 - Fear is common when someone is acutely unwell.
 - Give them enough space so they don't feel trapped.
- Be open about any concern regarding serious self harm or suicide.
- You may need to suggest they see their usual doctor or a health professional.
 - Assist them in making an appointment. Attend the appointment with them if you're able to, or suggest another family member or friend that could instead.

Certain ways of responding when your loved one is unwell may be more *harmful to their* mental health, as well as your relationship with them.

For example, try to *avoid*:

- Insisting that they "snap out of it."
- Accusing them of exaggerating their reactions or not being genuinely unwell.
- Reacting to them in an aggressive or frightening manner.
- Encouraging them to forget about their difficulties and continue using alcohol or recreational substances.
- Providing all the answers for them or feeling like you can save them.
- Assuming the problem will pass.
- Undermining their independence and attempts at making their emotional well-being a priority.

Suicidal Thoughts

Unfortunately, individuals living with bipolar disorder are sometimes vulnerable to experiencing suicidal thoughts during mood episodes. Whilst this doesn't always mean that your loved one will act on them, they need to be taken seriously. They should alert you to the fact that the individual is still suffering and needs help.

If you do think your loved one may be feeling suicidal, be open about it. Ask them. Encourage them to discuss it with you. You may feel anxious or overwhelmed even just thinking about this, which is understandable and common. But there are a number of things you can do that can help you help them.

- Ask if they've been thinking about taking their own life.
 - By asking, you are communicating your concern and support. And giving them an opportunity to talk about their feelings.
 - This won't make them more likely to act on their plans.
- Tell them you are concerned.

Communicate that you are worried about them and want to help.

- Ask if they have made any plans.
 - Check if they have access to the means with which they intend to carry out their plan (eg. tablets, blades, weapons, rope) and remove these from their possession if you're able to.
 - Contact the local Crisis Team and let them know your concerns.

Having a plan does increase the risk of suicide, so don't hesitate to get professional help.

- Be open and clear about getting help.
 - Gently reassure your loved one that you are trying to do what's best for them and you don't want to see them continue to suffer, but there other options apart from suicide.
 - Politely refuse to agree with any desire they may express to keep this a secret: it is too much of a burden for you to carry alone and involving a health professional is critical.

Sometimes your loved one is able to let you know directly that suicide has been on their mind. But other times, it may be difficult for them to admit that they're feeling this way. You may suspect they are having these thoughts by picking up on other warning signs.

Signs or signals of suicidality include:

- Referring to death or dying in a casual or indirect manner.
- Writing or talking more generally about suicide or death.
- Appearing more depressed and hopeless.
- Isolating themselves from you or friends and becoming more withdrawn.
- Becoming more *agitated and anxious* with great difficulty sleeping.
- Increasing alcohol or recreational substance use as a means of coping with very troubling feelings or thoughts.
- Demonstrating less and less regard for their future, so they might be displaying dangerous behaviour that is out of character as the consequences don't matter to them.
- Or expressing a *sudden change in mood*, appearing more uplifted and in brighter spirits.

Sometimes, when an individual has worked out a plan of suicide, their mood can temporarily improve. If they had recently been talking about suicide, then their mood unexpectedly lifts, ask them if they have a plan to end their lives.

If you are worried that your loved one is suicidal, ask for professional help; it is too much of a burden for you to carry alone.

Tragically, sometimes there just aren't any obvious warning signs. It can be extremely hard to accept, but there are times when an individual will complete their plan despite all of your efforts to help them find another way. It's important to maintain a realistic attitude if this happens, and not fall into the trap of blaming yourself, or others.

Blame can't bring your loved one back and acts as a constant reminder of the pain of losing them. If you are in this situation, it is important that you find someone you can talk to openly. Working through your grief and emotions, like sorrow, anger, guilt or resentment, can be very helpful when trying to recover your life after losing someone you love to suicide.

Crisis Plan

A bipolar crisis is a situation when the person is so acutely unwell that they are at risk of seriously hurting themselves or someone else. This may involve direct thoughts of wanting to end their lives or suicidality. It may also include the potential negative consequences of their mood episodes such as neglecting to care for themselves due to the illness, creating significant financial debt in a short amount of time, driving recklessly or targeting someone else aggressively.

Having a plan of action in times of crisis can be very useful to help the person feel safe and give you a structured approach to dealing with the acute risks related to their illness.

A crisis plan is usually a sheet of paper that has specific details of care on it, including:

- Name and contact details of the patient
- Name and contact details of the carer
- Diagnosis
- Current medications and doses
- Names and contact details of the health professionals who are involved in the person's care, such as their treating specialist doctor, case manager, GP and psychologist.
- Who to contact in times of crisis during business hours
- Who to contact in times of crisis after hours, including the local Crisis Team, emergency numbers and police.
- The *precise actions to be taken* in different situations of crisis, and especially when the patient is expressing ideas of harm towards themselves or others.
 - Eg. don't remain alone if feeling at risk, contact a family member or close friend, make an agreement on who you will contact if feeling overwhelmed or distressed.

These plans should be devised in collaboration with the individual living with bipolar disorder, their carer and the treating doctor or case manager.

As your loved one's treatment may change from time to time, these plans should be updated regularly to ensure all the information is accurate.

'When your loved one relapses, back-up is so important. You need to know firstly that there is someone there that you can call and you're going to have an immediate response from.'

(Samantha, carer)

A time of crisis can be awfully overwhelming for both you and your loved one. The situation might feel especially daunting when immediate help is required after hours or during times when you can't get in touch with the mental health practitioners who are more familiar to you both. If this occurs and you need to call the Psychiatric Triage or the local Crisis Team, you can expect to talk to a trained mental health clinician who will explore the current concerns you have for your loved one. They will then give you advice based on the level of urgency of the situation. Sometimes, they may ask you to wait at home with your loved one until the Crisis Team arrives to speak with you both directly. Other times, they may ask you to take your loved one into the emergency department of your local hospital for a medical assessment, or help you call an ambulance or the police.

'We called the Crisis Team one Sunday morning, and these two girls came out, and I'll always remember that sense of relief that they were there. They were talking to our son, and they got on the phone, and they spoke to a doctor, and the doctor said, 'Yep, give him a bit more medication so he can sleep.' Now, it kept him out of hospital that time. But it was just so comforting. That's what I mean by having things in place. Maybe there needs to be more of that so we're not getting to that desperation where they end up having to go into hospital.' (Mary, carer)

Note down these details for a crisis plan on the following pages as a guide. You may never need to use the information, but it's always handy to have ready, just in case.

| CRISIS PLAN | | | | | |
|----------------------------------|------------------------------|--|--|--|--|
| | Date of Completion: | | | | |
| Details of Patient | | | | | |
| Name | | | | | |
| Date of Birth | | | | | |
| Address | | | | | |
| Phone Number | | | | | |
| Carer or Next of Kin | | | | | |
| Contact Details | | | | | |
| (name, phone number, address) | | | | | |
| Healthcare Professionals inv | volved in the Patient's Care | | | | |
| (name, phone number, place where | e treatment is received) | | | | |
| General Practitioner | | | | | |
| Mental Health Clinic | | | | | |
| Case Manager | | | | | |
| Psychiatrist | | | | | |
| Psychologist | | | | | |
| Counsellor | | | | | |
| Others | | | | | |
| Clinical Information | | | | | |
| Diagnosis | | | | | |
| | | | | | |
| Current Medications and | | | | | |
| Doses | | | | | |
| 2000 | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| | | | | | |
| Allergies or Serious Side | | | | | |
| Effects from Previous | | | | | |
| | | | | | |
| Medications | | | | | |

| Crisis Information | |
|--------------------------------------|---------------|
| Triggers of a Crisis | |
| (eg. stopping medication, stress, | |
| sleep disturbance, drugs, | |
| alcohol) | |
| Frequency of a Crisis | |
| Safety Concerns during a | |
| Crisis (eg. serious relapse, | |
| putting self at risk, putting others | |
| at risk, suicidality, aggression, | |
| vulnerability) | |
| Pathways of Action in Mana | ging a Crisis |
| Communication Skills that | |
| may be helpful in a Crisis | |
| (eg. calm, empathic responses, | |
| active listening, non-judgmental | |
| approach) | |
| Who to call during | |
| business hours, 9-5 Mon- | |
| Fri (eg. case manager, clinic, GP, | |
| Psychiatrist) | |
| Who to call after hours or | |
| on weekends | |
| (eg. Crisis Team, Emergency | |
| Dept, Ambulance or Police) | |
| Additional Important Conta | cts |
| Local Psychiatric Triage | |
| Crisis Assessment and | |
| Treatment (CAT) Team | |
| Emergency Department of | |
| Local Hospital | |
| Police or Ambulance | |
| Services | |
| Other | |

Consent and Privacy

Many individuals with bipolar disorder benefit greatly from *admission to hospital* if they are suffering with very severe mood relapses. Admissions are usually encouraged by the doctor or mental health practitioner when these episodes appear no longer responsive to community-based approaches.

Whenever possible, admissions with your loved one's *consent and co-operation* are preferred, so that hospital-based treatment can be provided as collaboratively as possible. Sometimes, however, your loved one may be so unwell with a bipolar relapse, that they are *no longer able to provide informed consent* or make rational decisions about their own health and safety. In these instances, doctors and mental health practitioners may need to facilitate a hospital admission under the *Mental Health Act*.

This means your loved one is placed under an 'involuntary treatment order' which medicolegally insists that they receive life-saving psychiatric treatment immediately, before their safety or possibly others' is any further jeopardised.

Whether your loved one is receiving mental health care in the community or in a hospital setting, there will be times when you would like to discuss their progress directly with their treating mental health team. This can be a frustrating situation for carers when consent has not been obtained, or cannot be obtained, from their loved one to disclose their medical information. Laws surrounding *disclosure of health information* to immediate family or caregivers can be complex and difficult to understand. It is best to check with the mental health team who is providing medical care for your loved one about the information that can be discussed in different situations.

To help avoid this complexity, and the frustration that can accompany it, it might help to discuss this hypothetical situation with your loved one when they are well. A brief letter stating they would like you to have full knowledge of their health information whether they are receiving treatment voluntarily or involuntarily can be a useful document should they become very unwell in the future.

There may also be times when your loved one would like *direct access to their own medical records* for their own personal reasons. Under the Australian Commonwealth's *Freedom of Information Act 1982*, they can apply for access by making a Freedom of Information (FOI) request. You can help them contact the FOI Officer of the particular health service they are involved with to start the process of making this request.

Employment and Taking Time Off Work

'One of the things that would have been really valuable to me on numerous occasions was some sort of recognition that life is still ticking over in every other aspect.' (Angela, carer)

If your loved one becomes unwell when they are employed, they may need to take some time off work until they're feeling better in themselves again. You may also find yourself needing take time off your usual work to provide extra care and support during these periods. This might be to spend more time with your loved one or to help them get to extra medical appointments or sessions that will help their recovery. This can be a very unpredictable situation where your work and important responsibilities in your own life may get unexpectedly delayed because of your loved one's urgent mental health needs.

These times of acute unwellness may often be intensely emotional, so if possible, try to share the responsibility of providing the care and support to your loved one. This is important to reduce the stress and impact that their condition has on your own life and emotional well-being, and to preserve the positive relationship that exists between you and your loved other. This might mean communicating your need to share the caring responsibilities to other friends or family and delegating certain tasks to these others when you are feeling over-committed.

Let your loved one's mental health practitioner know that you also need extra support. They can help come up with solutions you may not be aware of. This may also be a good time to consider attending a carer support group if you haven't had the chance to yet. See 'Carer Support Groups and Respite Services', further on.

'I had one professional at one point say to me, 'You may not be able to continue your employment right now. You may have to drop your job and put all of your focus over there, and that's your reality.' Something's gotta ease off, and that's okay. That is okay to say that and admit it to everyone. Instead of beating yourself up over the fact of 'Oh my gosh, I can't maintain the whole family, and my work, and this crisis.' Otherwise everyone walks around going 'Why can't I manage all of this? I should be able to manage all of this.' (Natalie, carer)

Carer's leave is an additional type of paid leave that employers may provide for these situations. When you need to take the time off work, enquire as to whether you are eligible to utilise carer's leave in preference to your own sick leave. Medical staff are also able to provide you with a carer's certificate of attendance for medical appointments that you attend with your loved one. In some instances, you may need to negotiate more flexible working hours with your employer in order to continue caring for your loved one whilst you continue working.

When your loved one is ready to resume employment after a bipolar relapse, it is usually best to encourage them to take this slowly until their recovery is complete. Their mental health practitioner can help them decide on a suitable 'Return To Work' plan which moves from shorter working hours to progressively longer working hours each week following their rate of recovery.

Sometimes, your loved one may need extra help deciding what sort of employment they would like, or are capable of resuming. This is called 'Vocational Rehabilitation' and can be arranged through their mental health practitioner when they are ready to return to the workforce.

If your loved one is returning to, or wants to commence, further academic study – a similar plan can be thought through and put in place for them.

Family Planning

If your loved one with a diagnosis of bipolar disorder is female and interested in starting a family of her own, it is very important that she discuss certain aspects of her treatment with her doctor. This is to ensure the absolute safety and stability of her wellness throughout her pregnancy. Some of the *medications* that treat bipolar disorder, especially the mood stabilisers, carry certain *physical risks for a developing baby*. There are a variety of treatment options for mothers-to-be in this situation who might need to change their usual medication temporarily during this time of their lives.

Understandably, experiencing a bipolar relapse during this important time in your loved one's life can also place stress on the pregnancy and the developing baby. This is another reason why getting the treatment right during this phase of a woman's life is so critical. The health and safety of her and her newborn is the main priority. To ensure that this time is as stable and rewarding as possible, encouraged your loved other to have close antenatal and post-natal medical care.

It is preferred that if a pregnancy in this setting can be planned, it really *is* planned. However, if pregnancy is a surprise, encourage your loved one to continue her treatment and see her doctor as soon as possible to discuss the risks and benefits of continuing helpful medications.

Caring for Yourself

During your care for someone with bipolar disorder, you might feel a range of different emotions. Some of these will be difficult and may impact on *your* emotional well-being. It isn't unusual to experience anger, guilt, grief or fear at various points in time.

It is vital that you look after yourself, as much as you're looking after the individual with a mental illness. There is always a risk that the pressures and demands of caring for another with a serious illness can lead to feelings of anxiety and depression in those who are providing the care.

Your own mental health needs must be tended to in order for you to be able to provide the best quality care for someone else's.

'Carers need to look after themselves, take time out, and have respite. They need to hold onto their identity outside of the caring relationship.' (Elizabeth, patient)

It might be useful to keep some practical strategies in mind:

- Educate yourself generally.
 - Learn about bipolar disorder, so you can understand and help others understand what it is and why someone with this illness might react in a certain way.

'It's important for carers to read up on bipolar. The first step is to get educated about what it is and what's going on. Get savvy with the area of mental illness and this will reduce fears, prejudice and stigma.' (Elizabeth, patient)

- *Educate* yourself specifically.
 - Learn about the way bipolar disorder presents in the person you are caring for. What is particular to their lows or highs? What changes first when they are close to relapse? What are their triggers? What are their early warning signs?

'It's individualistic — it's about knowing the person you're caring for with bipolar disorder — what they need when they're low or high or mixed. It's different for each individual who suffers with the illness.' (Elizabeth, patient)

- Be open and inquisitive.
 - Getting to know what a person with bipolar disorder needs requires an open conversation with them. Between the two of you, you are the experts in that individual's illness.

- Try asking them what they notice in themselves when they first start to feel unwell, what makes them feel better and what makes them feel worse.
- Knowing what your loved one needs from you when their illness does relapse will help you provide them with the care they have identified as most valuable during these difficult times.

'Informing yourself is empowering yourself.' (Elizabeth, patient)

- Take the time to adjust and grieve.
 - When coming to terms with the person's illness or a new diagnosis, give yourself time to grieve. You might experience sadness about the changes and losses you perceive for the person you are caring for. This is natural, and will come to pass.

'That's the sad part, mourning the loss of what you hoped they could be.' (Mary, carer)

- Make your own health a priority.
 - Eat nutritiously, exercise regularly and sleep soundly. Develop balanced routines that support you in maintaining a healthy lifestyle.
 - Create times in your week that are just for you, where you can relax and rejuvenate your own emotional strength. This may mean spending time with friends, spending thoughtful time alone or participating in regular activities that add meaning to your life. It's different for different people, but pursuing what you need will benefit you, your care and your ability to cope in difficult times.

'If you can't reclaim some joy in your own life along the way, then you're going to be sunk.' (Natalie, carer)

- Have your own GP.
 - Make sure you are linked in with a general practitioner for your own physical and mental health needs. It is not uncommon to be so focussed on your loved that you forget about the importance of addressing your own health. This might mean routine check-ups or a doctor to see when you are beginning to feel persistently stressed.
 - Signs that you might be experiencing more stress than usual include: disturbed sleep, disturbed appetite, feeling easily irritated or impatient, feeling more tired, experiencing minor physical niggles, drinking more alcohol or using other drugs more heavily.
 - Looking after your own mental health is no less important than looking after your loved others'. Don't leave it until it is too late.

- Keep healthy boundaries.
 - This can help ease the tension in your relationship with the person you are caring for, and prevent cycles of anger, frustration or resentment from repeating.
 - Consider strategies such as:
 - Delegating certain duties of care to other family members or friends.
 - Arranging your own time out so you continue to maintain your interests and relationships outside of your relationship of care.
 - Stick to a general *daily routine* as best as possible.
 - Find someone you can talk to about your feelings.
 - Join a *carer support group* to share experiences and tips with others who are in the same position as you.
 - Be clear on the *limits of your care* and communicate these sensitively to the individual with bipolar disorder during times of wellness. Be comfortable with saying 'No' sometimes.
 - Don't expect that you can fix everything for your loved one. Bipolar disorder is a chronic, complex illness with a relapsing pattern. Try to remain realistic about the influence of your support, which may, at times, be in conflict with the influence of the illness.

'It's important to be conscious of your limitations as a carer.' (Elizabeth, patient)

- Learn to receive support from the person you care for.
 - Be open to their efforts to repay your kindness or express gratitude.
 - Acknowledge the incredible support and care you provide on a daily basis.
 - Thank yourself, and allow yourself to be thanked.

'The patient needs to give something back - be generous to their carer after episodes and replenish their relationship.' (Laura, patient)

- Maintain hope.
 - When the person you care for continues to suffer with ongoing symptoms of a bipolar illness, you may feel defeated. It's important that you maintain optimism and hope. That you continue to believe the person will get better, and you will see better days together.
 - Each episode of illness may continue for different lengths of time, so bear in mind that you may not experience the same course as the last one.

'Remaining optimistic is so important, you have to see the glass as half full. You have to believe there will be better days.' (Helen, carer)

| What are some important things about your own health and emotional wellbeing that might be accidentally forgotten when the focus is on caring for your loved one? Write them down here so you can remind yourself from time to time. |
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| 'People need to understand that mental illness is a lifelong illness, but that you can still have a life.' (Elizabeth, patient) |
| An example of a weekly planner has been included on the following page. Use it as a guide to think about how much time in the week you spend actively caring for your loved one, and how much time in the week you spend actively caring for you. |
| Is there a big difference? Are there any opportunities to create some more time and space for yourself? To enjoy an activity alone, or with others who are also important to you? |

| | SUN | | | |
|--------------------------|-------|---------|-----------|---------|
| | SAT | | | |
| | FRI | | | |
| TY SCHEDULE | THURS | | | |
| WEEKLY ACTIVITY SCHEDULE | WED | | | |
| Λ | TUES | | | |
| | MON | | | |
| | | MORNING | AFTERNOON | EVENING |

Carer Support Groups and Respite Services

'You just feel like you're so out on a limb and on your own, and no one else is going through this... You need support and people that can understand a little bit of what you're going through.' (Mary, carer)

The demands of caring for your loved one may leave you feeling *emotionally drained* and *socially isolated* at times. The difficult feelings that can accompany different points in your caring relationship might feel less understood by those who have not had similar experiences. *Carer Support Groups* are regular gatherings of people who are interested in hearing and sharing mutual experiences to help with feelings of connectedness and support. These groups are typically run by a mental health professional, who will guide discussions and help group members share experiences and knowledge, to give and receive support. They are usually arranged through local community organisations.

Many carers experience relief through sharing their stories, feelings and information on caring for a loved one with bipolar disorder. A lot of strength and hope can be gained from *sharing experiences* with others who are in familiar situations.

'The stories that are shared are educational. And they do give you that sense of, okay, you're not like Robinson Crusoe, you're not on your own. Some of the simplest little tales that are told, and stories that are passed on can be enormously helpful, in a practical way.'

(Nicholas, carer)

Along with carer support groups, you may like to consider seeking support in the form of *individual counselling sessions*. There may be times when you're seeking a private outlet to talk through the feelings and impact that your caring relationship is having on your life. There are a range of services available through various carer organisations which can be explored as needed. See 'Further Resources' for the details.

You're so consumed by it all that you put your whole life on hold.' (Mary, carer)

Carer respite is another area of support that may be able to provide you with opportunities to make your own health and well-being a priority and be assured that your loved one is in safe and professional hands. This might involve having a community-employed carer come to your home and provide care for your loved one whilst you attend to your own personal obligations. Or it might involve your loved one attending a community day program outside of the home, or staying short-term in supported residential accommodation, to help improve their skills of independence and provide you with a short break from your caring responsibilities.

Further Resources

Carers Australia is the national peak body representing carers in Australia. *Carers Australia* works with the Carers Associations in each of the state and territories to deliver carer programs and services and advocate on behalf of all carers. The services provided will vary according to where you and your loved one are living, but can all be accessed and explored via the national website at: www.carersaustralia.com.au

Information is also available via a free call to the *Carer Advisory and Counselling Service* on **1800 242 636**.

ARAFEMI (Association for the Relatives and Friends of the Mentally III) is a non-profit community based organization dedicated to supporting and advocating for family members and carers of people with a mental illness. They organize many groups and services that can be helpful for both you and your loved one. They have branches in most states and territories throughout Australia and also offer a valuable Carer Helpline service. Get more information on the Victorian ARAFEMI organization at: www.arafemi.org.au or phone **+61 3 9810 9300.**

The Carer Helpline service is available on 1300 550 265.

MIFA (Mental Illness Fellowship of Australia) is a non-government, not-for-profit organization aimed at supporting and advocating for people with serious mental illnesses and their families. They offer many different services, including Well Ways a family educational program that provides information on mental illness, helpful ways to cope and practical ways to take care of yourself. Information on this program and other services provided by MIFA can be accessed at: www.mifa.org.au

Or contact the National Helpline to be directed to the right service on 1800 985 944.

SANE Australia is a national charity that conducts innovative programs and campaigns to improve the lives of people living with mental illness, their family and friends. They offer useful resources and guides to help you and your loved one with their mental health needs. The section entitled 'Snapshots' on the website contains inspiring personal accounts of what it means to live, and live well, with a mental illness. The importance of sharing, recovering and connecting is highlighted through meaningful real-life stories.

Access this information at: www.sane.org

The SANE Helpline can also offer information and advice on 1800 18 SANE (7263).

Information obtained via the internet can sometimes be inaccurate or misleading. Keep an open mind about what you are reading, particularly if you are unsure about the credibility of the source. Try to check what you've read with your loved one's doctor or mental health practitioner to ensure you are getting the correct information.

Listed below are some additional websites that provide accurate information and might be of further help:

www.bipolarcaregivers.org

www.beyondblue.org.au

www.blackdoginstitute.org.au

Most community mental health clinics will have a Carer Consultant who can provide specific advice and pathways to assistance if you're experiencing any difficulties in your caring role. Check with your loved one's mental health practitioner to find out more about this service.

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| 'While there is life, there is hope.' (Samantha, carer) |
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| 'It's a matter of hanging in there with them.' (Nicholas, carer) |
| 'Don't try to fix it, just get through it. Persevere.' (Natalie, carer) |
| 'Learn to reprioritise your expectations and be realistic about what to let go.' (Helen, carer) |
| 'To be able to move forward in their lives - that's all you want for them.' (Mary, carer) |
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| |
| 'And how lucky are our loved ones, in one way, that they have us?' (Samantha, carer) |

Copies of this booklet and the Psychiatric Medication Information booklet can be requested through:

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