

The development of guidelines for caregivers of people with bipolar disorder

List of survey items that were endorsed by three panels of experts

Below are tables of survey items with information and suggestions endorsed by at least 80% or more of the three panels (caregiver, clinician and consumer panels) as either “important” or “essential” to include in the guidelines. The term “should” is used to obtain unequivocal ratings of items (e.g. the caregiver should not arrange some time out to replenish their energy). Panel members pointed out that due to the diversity of bipolar disorder and caregiving situations, certain items may only be relevant to some caregivers. In the guidelines items are presented in context as suggestions and the caregiver is encouraged to select what may be appropriate in their situation.

Items marked with two asterisks ** were endorsed by 100% of all panels. Those with one asterisk * were endorsed by between 95%-99% of all panels. Re-rated items have the letters (RI) next to them.

Contents

GENERAL INFORMATION ON BIPOLAR DISORDER AND CAREGIVERS	2
Table 1: Bipolar disorder, treatment and management	2
Table 2: Bipolar disorder and the caregiver	3
WAYS THE CAREGIVER CAN LOOK AFTER THEMSELVES	4
Table 3: Constructive coping and healthy boundaries	4
Table 4: Caregiver health and wellbeing	6
Table 5: Self-care in challenging caregiver situations	8
WAYS TO SUPPORT THE PERSON WITH BIPOLAR DISORDER	9
Table 6: Working out how to help	10
Table 7: Helping with triggers and keeping well	12
Table 8: Helping with warning signs	13
Table 9: Communicating when the person is ill	16
Table 10: Helping when an episode occurs	17
Table 11: Helping to get the best from treatment	18
Table 12: Dealing with an illness-related crises	20
Table 13: Helping to prevent suicide	21
Table 14: Dealing with risky or inappropriate manic or very hypomanic behavior	22
Table 15: Support after an episode of illness	24
Table 16: Adjusting to wellness	25
Table 17: Ways to encourage the person’s confidence	26
Table 18: Ways to respond if the person refuses to treat or manage their bipolar disorder or refuses the caregivers help	26
STIGMA, DISCRIMINATION AND DISCLOSURE	28

Table 19: Suggestions for dealing with stigma, discrimination and disclosure 28

GENERAL INFORMATION ON BIPOLAR DISORDER AND CAREGIVERS**Table 1: Bipolar disorder, treatment and management**

Item	Survey
Caregivers should be informed about the following:	
▪ Symptoms and patterns of bipolar disorder** including:	1
○ People with bipolar disorder can have different patterns of illness (e.g. some people may be ill most of the time and others remain well for a long time).*	2
○ Patterns of illness can change (e.g. the person who was ill a lot of the time can become well for long periods of time).	2
▪ The way that bipolar disorder is diagnosed (RI).	3
▪ The prevalence of bipolar disorder (RI).	3
▪ Biological causes of bipolar disorder (chemical imbalances and genetic factors).	1
▪ Environmental and personal factors that may trigger bipolar moods (e.g. lack of sleep can trigger hypomania or mania). **	1
▪ Factors that help to protect people from relapse (e.g. effective treatment, receiving appropriate support or responding to warning signs). **	1
▪ Treatments that help to prevent and reduce symptoms of bipolar disorder. **	1
▪ Treatments that are supported by research evidence.	1
▪ Bipolar disorder commonly involves recurrent episodes and needs long-term treatment.	1
▪ The person needs to continue to manage their illness even when they are not experiencing an episode. *	1
▪ There are ways in which the person's personality differs from their bipolar disorder.	1
▪ Other conditions that are experienced by a number of people with bipolar disorder (e.g. substance use and anxiety disorders).	1
▪ The risks involved in some of the extreme behaviours connected with bipolar disorder (e.g. suicide risk, spending savings and reckless driving).	2
▪ The risks involved in abusing drugs or alcohol for people with bipolar disorder.	2
▪ If the person is abusing drugs or alcohol, this needs to be addressed as a problem in its own right, in addition to the bipolar disorder.	2
▪ Health services and other resources available to support the person.	1
▪ Resources to assist caregivers to deal with the illness.	1
▪ The person may need to try different treatments and personal illness management strategies to find what helps them to keep well.	1
▪ Some illness management strategies are helpful and others are unhelpful or harmful (e.g. drinking too much alcohol to reduce depressed mood can make depression worse). *	1
▪ Be aware that bipolar disorder is a complex illness, and episodes sometimes occur despite good treatment and personal illness management strategies. **	1
▪ Managing the illness and engaging in life enables many people to live well	1

despite their bipolar disorder. **	
<ul style="list-style-type: none"> ▪ Caution is required when obtaining information about bipolar disorder and its treatment from the Internet, as some information may be inaccurate or misleading (e.g. certain advertisements about treatment). 	2
<ul style="list-style-type: none"> ▪ When obtaining information about treatments for bipolar disorder, the family member should confirm its accuracy by discussing it with a knowledgeable clinician. 	2

Table: 2 Bipolar disorder and the caregiver

Item	Survey
<p>When dealing with bipolar disorder in the family, as a couple, or in a close friendship, the caregiver should be aware that:</p> <ul style="list-style-type: none"> ▪ It is normal for both the person and the caregiver to feel stressed at times when dealing with the challenges of bipolar disorder. * ▪ Certain patterns of illness may be more stressful or disruptive to the lives of people with bipolar disorder and caregivers ▪ It is important to normalize family or couple life as much as possible. ▪ The close friend should try and normalize the friendship as much as possible. ▪ The caregiver should try not to make the person or their illness the centre of the family's attention all the time (if the person is part of the family). ▪ Relationships that involve even a little reciprocation (give and take) of support can be less stressful (e.g. the caregiver could ask the person to help out at times and accept their support when it is offered). ▪ Sometimes it is easier for the person to discuss what stresses them with someone outside the family, even when they care deeply for the family members. ▪ Caregivers often go through specific stages after the person's first bipolar episode, ranging from initial shock, disbelief and emotional turmoil to gradual understanding and acceptance, and then hope that there are ways to deal with bipolar disorder and live well. ▪ The stages of emotional turmoil, new acceptance and hope may re-occur over the years (RI). ▪ Certain individuals in the family might deny that the person has bipolar disorder or needs treatment, as it can be very difficult to accept that a loved one has bipolar disorder. ▪ Bipolar disorder can cause conflict in relationships. ▪ If it is hard to sort out conflict in the relationship, they can consult an objective counsellor or therapist who has good knowledge of bipolar disorder, and experience working in this area. 	<p>1</p> <p>2</p> <p>2</p> <p>2</p> <p>2</p> <p>2</p> <p>2</p> <p>2</p> <p>2</p> <p>2</p> <p>3</p> <p>2</p> <p>2</p> <p>2</p>
<p>When dealing with bipolar disorder and providing support, the caregiver should be aware that:</p> <ul style="list-style-type: none"> ▪ Primary caregivers can differ in how much and what type of support they provide (e.g. some help when there is an emergency, and others assist the person in trying to prevent relapse as well). ▪ People with bipolar disorder can differ in how much, and what type of help they need and prefer from caregivers. ▪ Caregivers who care for a person with bipolar disorder are at increased risk of becoming emotionally worn out, depressed and having health problems. 	<p>2</p> <p>2</p> <p>2</p>

<ul style="list-style-type: none"> ▪ Finding what helps to make things easier often takes time and involves trial and error. 	2
<ul style="list-style-type: none"> ▪ While it is useful to have information on the illness and ways to deal with it, finding what works for the caregiver is an individual process. 	2

WAYS THE CAREGIVER CAN LOOK AFTER THEMSELVES

Table 3: Constructive coping and healthy boundaries

Item	Survey
To make it easier to cope the caregiver should:	
<ul style="list-style-type: none"> ▪ Find someone to talk to whom they can trust, or join a support group. 	1
<ul style="list-style-type: none"> ▪ Not expect to “fix” everything. * 	1
<ul style="list-style-type: none"> ▪ Arrange to share or delegate certain caregiving tasks and other demands. * 	1
<ul style="list-style-type: none"> ▪ Adopt a problem solving approach to deal with difficulties. 	1
<ul style="list-style-type: none"> ▪ Arrange some time out to replenish their energy, even when the person is ill (e.g. if the person cannot be left alone, the caregiver should arrange for someone else to be with them for a while or for respite care). * 	1
<ul style="list-style-type: none"> ▪ Find ways to nurture themselves (e.g. doing something relaxing or plan something to look forward to). * 	1
<ul style="list-style-type: none"> ▪ Accept support from others when it is offered. 	1
<ul style="list-style-type: none"> ▪ Prioritize essential tasks and postpone or cancel other tasks. 	1
<ul style="list-style-type: none"> ▪ Learn to say “no” to demands that are unreasonable or unmanageable.** 	1
<ul style="list-style-type: none"> ▪ Find out about possibilities for leave and flexible work hours, and if necessary, discuss this with their employer if it is hard to manage work and the demands of the illness. 	1
<ul style="list-style-type: none"> ▪ Find out about financial assistance for themselves and the person with bipolar disorder, especially if they need to cut down on their work commitments. 	1
<ul style="list-style-type: none"> ▪ Acknowledge the tasks that they manage to do and the support they provide. 	1
<ul style="list-style-type: none"> ▪ Consider what they have learnt from their caregiving situation (e.g. they may have learnt to deal with a crisis or become more independent). 	1
The caregiver should be aware that:	
<ul style="list-style-type: none"> ▪ They will not be able to provide optimal support if their own health is compromised. 	2
<ul style="list-style-type: none"> ▪ The caregiver will increase their chance of developing health problems, if they neglect their own health. 	2
<ul style="list-style-type: none"> ▪ To protect their own health and wellbeing, the caregiver should set healthy boundaries when supporting the person. 	2
To maintain healthy boundaries the caregiver should:	
<ul style="list-style-type: none"> ▪ Acknowledge that they have needs too. * 	1
<ul style="list-style-type: none"> ▪ Be aware that, while they can help, it is the person’s illness and the person needs to find ways to deal with it. 	1
<ul style="list-style-type: none"> ▪ Devote some time to outside interests. * 	1
<ul style="list-style-type: none"> ▪ Pursue personal goals, even if at times they need to focus on actively providing support. 	1
<ul style="list-style-type: none"> ▪ Support the person’s efforts to maintain their own identity and interest. 	1
<ul style="list-style-type: none"> ▪ Use the time when the person is well to focus on things that are important to 	1

<p>them, besides the person's illness. *</p> <ul style="list-style-type: none"> ▪ Maintain contact with friends and family. * ▪ Set realistic limits on what they can do to help. ** ▪ When confronted with behaviour that threatens the caregiver's personal boundaries, the caregiver should consider responding in a way that protects the boundaries that are important to them (RI) (see Table 14: Dealing with risky or inappropriate illness behaviour). 	<p>1 1 3</p>
<p>When considering how to provide support within healthy personal boundaries, the caregiver should:</p> <ul style="list-style-type: none"> ▪ Be aware that they might not need to provide the same level of active help all the time (e.g. if the person is symptom free between episodes). 2 ▪ Be aware that constantly doing things for the person that they are able to manage at that time might put an unnecessary burden on the caregiver and make the person feel very dependent and undermined. 2 ▪ Let the person do as much as they can for themselves, as this may help them to develop confidence and independence (RI). 2 ▪ Encourage the person to do as much as they can for themselves providing the person is not hypomanic or manic (doing too much when hypomanic/manic can be overstimulating, and risky behaviour may have negative consequences). 2 ▪ Give up unrealistic expectations that exhaust and undermine the caregiver (e.g. that the caregiver should cure the illness, or never feel angry or stressed). 2 ▪ Not try to be the person's therapist or doctor. 2 ▪ If the caregiver feels out of their depth when trying to help the person, they should say something supportive that acknowledges the need for extra help (e.g. "I really care about you, but I think we need extra help here"). * 2 ▪ Encourage the person to develop a support network involving professionals, friends and community networks. ** 2 ▪ Be aware that if the person has recently been diagnosed with bipolar disorder, it can take time to establish good clinical and community supports, and the caregiver may need to provide more support initially. * 2 	<p>2 2 2 2 2 2 2 2</p>
<p>In summary, if the caregiver is not sure how involved to be in helping the person, some things to consider include:</p> <ul style="list-style-type: none"> ▪ The different ways to support the person (e.g. helping them to access treatment in an emergency or to monitor warning signs). * 2 ▪ The severity of the person's illness (e.g. more support may be needed in an emergency or if the person relapses frequently). 2 ▪ The caregiver's preference (e.g. how comfortable the caregiver feels about helping in certain ways, given their relationship with the person, their other duties and their own health). 2 ▪ What other support, besides the caregiver is available to the person. ▪ The caregiver should include a consideration of the person's preference (what support the person wants/does not want) when working out how involved to be in helping the person with their illness (RI). 2 3 ▪ The likely consequences (for the caregiver and the person), if the caregiver does NOT support the person in a certain way (e.g. the consequences of not helping in an emergency, or not helping with warning signs). 2 	<p>2 2 2 2 3 2</p>

<ul style="list-style-type: none"> ▪ The likely consequences of supporting the person in these ways (e.g. helping in an emergency, or with warning signs). 	2
---	---

Table 4: Caregiver health and wellbeing

Item	Survey
<p>To attend to their own health and wellbeing the caregiver should:</p> <ul style="list-style-type: none"> ▪ Maintain a healthy lifestyle (e.g. regular sleep, exercise and a healthy diet). 1 ▪ Try to find ways of coping that are not destructive to their health (e.g. drinking too much alcohol). 1 ▪ Be alert to signs that they are becoming stressed (e.g. a bit more irritable and tired than usual) or depressed (e.g. sleep problems, persistently flat or sad mood and loss of interest in things). ** 1 ▪ Develop a plan for coping if the caregiver notices they have signs of stress or depression (e.g. delegate more duties and take time off). * 1 ▪ Contact their doctor for an assessment and to discuss treatment options if they have symptoms of depression. * 1 ▪ Be aware that counseling can assist with the changes and problems that sometimes arise from dealing with bipolar disorder. 1 	
<p>The caregiver should be aware that when dealing with bipolar disorder in someone they care about:</p> <ul style="list-style-type: none"> ▪ It is normal to feel upset, angry or uncertain at times. * 1 ▪ The caregiver should not blame themselves for how they feel. 1 ▪ The caregiver should acknowledge the way they feel and try to work out how best to deal with the situation. 1 	
<p>If the caregiver is experiencing a sense of grief about the losses and changes connected to the illness, he/she should:</p> <ul style="list-style-type: none"> ▪ Be aware that it is understandable that they may feel a sense of grief and this is experienced by many people in similar situations. * 1 ▪ Make contact with other people in similar situations so they are not alone. 1 ▪ Be aware of what the grief process involves. 1 ▪ Allow themselves to grieve. 1 ▪ Reassure themselves that while the changes and losses connected to the illness are real, there are still ways of living well and enjoying relationships despite bipolar disorder. 1 	
<p>When experiencing anger related to the challenges of bipolar disorder and the caregiving situation, the caregiver should:</p> <ul style="list-style-type: none"> ▪ Find a constructive release for their anger (e.g. going for a walk, painting, and writing in a journal or talking things through with someone they trust). * 1 ▪ If they are feeling burnt out and resentful, they should devote more time to their own needs and put more limits on the support they provide. 1 ▪ Wait until they have calmed down to discuss a specific behaviour they are angry about with the person. 1 ▪ If possible, delay discussing their angry feelings with the person until the person is well and more able to deal with these issues. 1 ▪ Consider if their frustration or anger with the person is related to factors that the person cannot control (e.g. the person's symptoms or times when treatments take a long time to work). 1 	

<p>If the caregiver is feeling hurt or rejected by the person they should:</p> <ul style="list-style-type: none"> ▪ Consider whether the hurtful things the person did or said are part of the illness (e.g. when the person has symptoms such as irritable or is withdrawn). 1 ▪ Separate the "bipolar talk and actions" from the person and not take them personally. 1 ▪ Be aware that there might be times when the person is too ill to respond to them in the way the caregiver would like them to (emotionally, or where partners are concerned, sexually). ** 1 ▪ If the person has lost interest in sex due to depression, the partner should offer companionship and slowly start to rebuild an intimate relationship once the depression subsides. 1 ▪ Try to sort out the problem with the person, if the hurtful things the person says or does are not connected to the illness. 1 ▪ Talk about their feelings of hurt or sadness with someone they trust. 1 ▪ Do something they enjoy to distract them from these feelings. 1 	
<p>Sometimes caregivers blame themselves for the bipolar disorder and feel guilty about it. The caregiver should:</p> <ul style="list-style-type: none"> ▪ Be aware that there are many causes of bipolar disorder and the illness is nobody's fault. 1 ▪ Be aware that about one in nine first degree relatives of the person with bipolar disorder will have the illness, which means that genetics is not the only determining factor. 1 ▪ Not blame themselves if their child has bipolar disorder as none of us can control the genes we have. 1 ▪ Not feel guilty about their occasional emotional outburst, as dealing with bipolar disorder can be difficult and stressful at times. 1 ▪ If the caregiver is feeling stressed and burnt out, they should explain this to the person and take some time out, rather than blame themselves or the person. 1 	
<p>There may be times when the caregiver needs to withdraw. At such times the caregiver should be aware that:</p> <ul style="list-style-type: none"> ▪ It is common to feel a bit withdrawn from the person when they have been behaving strangely due to the illness, but this often subsides as the person recovers. 1 ▪ Feeling the need to withdraw may be a sign that they are exhausted and need some time out. 1 ▪ The caregiver should try to find ways to provide less support and focus more on their own wellbeing if the caregiving situation is affecting their health. 1 <p>Before deciding to leave the relationship, the caregiver should:</p> <ul style="list-style-type: none"> ▪ Discuss what they are going through with the person, as they may be able to find ways to resolve some of the difficulties together. 1 ▪ Address problems with the help of a counselor or relationship or family therapist 1 	
<p>Finding hope:</p> <ul style="list-style-type: none"> ▪ The caregiver should be aware that it is common to be anxious about the possibility of relapse, but there are ways to prevent relapse and to make things easier if it occurs. 1 ▪ If the person has been ill for a long time, the caregiver should be aware that 1 	

getting well can be a slow process and they should not give up hope. *	
▪ If the person relapses frequently, the caregiver should be aware that with time people commonly find ways to get the illness more under control.	1
▪ The caregiver should be aware that people with bipolar disorder and their caregivers report finding ways to live well with the illness (e.g. McManamy, 2006; Jamison, 1997 and Fast and Preston 2004). *	1
▪ Caregivers may find new hope and direction once they have adjusted to the changes and losses brought about by the illness.	2

Table 5: Self-care in challenging caregiver situations

Item	Survey
To take care of themselves in a bipolar-related crisis, the caregiver should (see Table 12: Dealing with an illness-related crisis):	
▪ Be aware that it is common to feel exhausted and upset when going through an illness-related crisis.	1
▪ Talk to people in their social network or contact a helpline.	1
▪ Keep in mind that crises are temporary.	1
▪ If the person is in hospital, take time to rest and recover	2
▪ Schedule a bit of time to relax and unwind after the crisis, even if they are very busy.	1
▪ Try to restore their usual routine as soon as possible.	1
▪ Be aware that caregivers can be traumatized by a crisis, and professional counselling can assist them to recover from the trauma (RI). *	3
If the person is ill most of the time due to frequent or lengthy episodes, the caregiver should be aware of the following options when trying to take care of themselves. The caregiver could:	
▪ Find out what resources are available to support them and the person (e.g. financial assistance, support groups, respite). *	2
▪ Reassure themselves that it is common to feel very stressed in a challenging situation.	2
▪ Find ways to relieve stress (e.g. talk to someone they trust, watch a funny movie, go for a walk). *	2
▪ Make lifestyle changes to cope with the persistent illness or recurring episodes (e.g. have a strict budget, change jobs, and arrange for others to take over more tasks).	2
▪ Maintain as much of a routine as possible.	2
▪ Not isolate themselves socially, as this can increase the caregiver's risk of depression.	2
▪ Suggest that the person gets a second opinion from an expert clinician (RI).	3
▪ If the caregiver can't change the situation, focus on doing things that they can control (RI). *	3
▪ Keep in mind that even small changes may provide some relief (RI).	3
If the person is ill, irritable, and very critical of the caregiver, the caregiver should:	
▪ Establish a personal boundary regarding the person's verbal abuse (e.g. say something like "I understand you're upset but I'm not going to tolerate being spoken to in this way" and walk away).	2

<ul style="list-style-type: none"> ▪ Consider taking some time out to help maintain their perspective, and not be drawn into reacting to the irritability or believing the criticism. 2 ▪ Not try to defend themselves by arguing logically with the person if the person is not rational (RI). 3 ▪ If the caregiver finds it hard not to take things personally, they should consider checking out with someone they trust to confirm that what the person said was not rational (RI). 3
<p>If negative consequences due to manic behaviour occur, the caregiver should (see also Table 14: Dealing with risky or inappropriate manic or hypomanic behavior):</p> <ul style="list-style-type: none"> ▪ Seek legal or financial advice if required (e.g. if a contract is signed or a large purchase made when the person is manic). 1 ▪ Consider if the illness and not the person is to blame for the negative consequences 1 ▪ If possible, wait until the person is well before discussing ways to sort out negative consequences or rebuild relationships. 1 ▪ Talk to the person about ways to reduce the chances of negative consequences in the future. 1 ▪ Be aware that after an episode of illness, people often feel a deep sense of shame and guilt about their inappropriate or risky illness-related behaviour.* 1 ▪ If they have engaged in risky sexual behaviour, the caregiver should encourage the person to see their doctor in case they need treatment for a sexually transmitted disease. 1
<p>If the caregiver is concerned about the risk of physical aggression when the person is manic they should (see also Table 12: Dealing with an illness related crisis):</p> <ul style="list-style-type: none"> ▪ Be aware that not all people who are manic become aggressive. 2 ▪ Be aware that people who are manic are more likely to act out on their emotions, and if they are angry, they could become aggressive. 2 ▪ If the caregiver experiences fear when the person is manic, angry and does not have much control over their emotions, the caregiver should not deny the possibility of danger. 2 ▪ Not compromise their own or others safety due to concerns about hurting the person's feelings, as later the person might feel very relieved that they were prevented from hurting their loved ones. * 2 ▪ If aggressive behaviour has occurred previously, the caregiver should be especially alert to the possibility of it occurring again. 2
<p>If the person has previously become aggressive the caregiver should:</p> <ul style="list-style-type: none"> ▪ Take even casual threats of violence seriously. 1 ▪ Learn to recognize the warning signs of impending aggression. 1 ▪ Work out in advance how to ensure their (the caregiver's) safety and that of others (e.g. have locks on rooms, leave the house and get help when warning signs of aggression appear). 1 ▪ Remove objects that could be used as weapons if the person is likely to become aggressive. 1

WAYS TO SUPPORT THE PERSON WITH BIPOLAR DISORDER

Table 6: Working out how to help

Item	Survey
<p>Things the caregiver should consider when working out how to help include:</p> <ul style="list-style-type: none"> ▪ Adapting their support to the type of symptoms or mood episode the person is experiencing. 1 ▪ Taking into account their (the caregiver's) other commitments and demands. 1 ▪ What other support is available to the person. 1 ▪ Taking a more active role in providing support when the person is severely ill. 1 ▪ What practical help (e.g. lifts to the doctor or help with the housework) and emotional support (e.g. let the person know that they care) they can provide. 1 ▪ Discussing with the person when they are well: <ul style="list-style-type: none"> ○ What help the person needs in specific circumstances (e.g. what they can do to help when the person struggles to get up in the morning, as they are becoming depressed). 1 ○ How they can assist them with their plans to prevent relapse. 1 ○ If the support the caregiver has been providing is appropriate. 1 ▪ The need to be as consistent as possible in the support they provide (RI), that is: 2 <ul style="list-style-type: none"> ○ The caregiver should try to be consistent in their support, but accept that this will not always be possible due to unpredictable demands and circumstances. 2 ○ If possible the caregiver should arrange with the person for a back-up support person or organization to step in, if the caregiver cannot provide their usual support. 2 	
<p>When communicating with the person about the illness and its management the caregiver should:</p> <ul style="list-style-type: none"> ▪ Not feel obliged to use psychiatric jargon, as many families have their own ways of talking about the illness (e.g. feeling really down or very high). 2 ▪ Invite the person to share their views on what helps people to manage bipolar disorder, and keep the lines of communication about the illness open. 2 ▪ If appropriate in their situation, discuss with the person who is relatively well that the caregiver would like to help with the illness, but does not want to be intrusive or get in the way of the person's own illness management strategies. 2 ▪ Be aware that not all communication has to be verbal; sometimes just sitting with the person can be supportive. 2 ▪ Be aware that it is not always necessary to mention the illness when encouraging illness management strategies (e.g. they could invite the person to go for a walk with them because the dog needs walking, not because it might help the person's depression). 2 ▪ If the person is having difficulty carrying out their illness management strategies and the caregiver has suggestions about what might help, they should discuss their ideas tactfully with the person (providing they have the type of relationship where they can discuss such things). 2 ▪ Be aware that repeatedly telling the person what they should be doing to manage their illness might come across as nagging. 2 ▪ Not constantly intervene in the person's life, as the person might experience 2 	

<p>this as an intrusion, and refuse to ask the caregiver for help when they really need it.</p> <ul style="list-style-type: none"> ▪ If appropriate in their situation, make an agreement with the person when they are well that the caregiver will provide support when it is needed, and the person will endeavour to let the caregiver know if they notice symptoms or need help. 2 ▪ If the caregiver asks the person how they can help with the illness, consider if what the person requests is realistic for the caregiver to do under the circumstances. 2 ▪ Be aware that sometimes when the caregiver asks the person how they can help, the person may not know. 2 ▪ There might be times when the person is too ill to discuss what help they need. 1 ▪ The person might not be ready to discuss illness management plans, as it can take time for them to accept the illness and the need to manage it. 1 ▪ If the person does not want to discuss illness management strategies with the caregiver, the caregiver should still make plans in so far as the illness affects them (e.g. who to call in an illness-related emergency and how to manage if the person goes to hospital). 1 	
<p>When developing illness management plans, the caregiver should:</p> <ul style="list-style-type: none"> ▪ Keep the plans simple so they are easy to follow. 2 ▪ Select what aspects of illness management are most useful to include in their plans (e.g. dealing with triggers of illness, warning signs, dealing with episodes, crisis, preventing suicide, and what to do after the crises or episode is over). 2 ▪ Be aware that due to circumstances, it is not always possible to implement exactly what is specified in a plan, but having a plan provides direction and a basis from which to work. 2 ▪ Write the plans down and keep them in an easily accessible place (RI). 3 ▪ Review their plans as circumstances change or they acquire new information. 2 	
<p>When making plans with the person about what to do if the person becomes severely ill, the caregiver should discuss the following:</p> <ul style="list-style-type: none"> ▪ When the person is well, the caregiver should ask them about what treatments and hospital they would prefer if they become severely ill. 1 ▪ WHEN to intervene (e.g. when certain specific symptoms/ illness behaviour is present), and HOW to intervene on their behalf. 2 ▪ WHO does WHAT (i.e. if possible assign different support people to different tasks) (RI). 3 ▪ If necessary, discuss Power of Attorney agreements to arrange for the caregiver to temporarily, and in specific situations, make urgent decisions on the person's behalf (RI). 2 ▪ Ask the person in advance about information that they may need to provide to clinicians on the person's behalf (e.g. information about the history of their illness and treatment and about their health fund and concessions). 1 ▪ Reassure the person that the caregiver recognizes the sensitivity and confidentiality of the information about their illness that the person has trusted them with. 2 ▪ If the person has been very severely ill in the past, the caregiver may need to discuss under what conditions to consider involuntary hospitalisation. 2 	

<ul style="list-style-type: none"> ▪ Confirm that actions that have been agreed upon by the person and the caregiver about obtaining involuntary hospital admission are acceptable to the person, and will not damage their long-term relationship (RI). 	3
<p>If the person is having difficulty carrying out their illness management strategies, the caregiver should:</p> <ul style="list-style-type: none"> ▪ Gently encourage them to persevere. ▪ Take a more active role in assisting the person (e.g. help them to plan an activity when they are becoming depressed, or offer to call their clinician). 	1 1
<p>If the person is disappointed because they relapse although they have been trying to manage their illness, the caregiver should be aware that they can:</p> <ul style="list-style-type: none"> ▪ Listen if the person wants to discuss how disappointed they are. ▪ Reassure the person that they did their best; bipolar disorder is a complex illness and sometimes symptoms occur despite good illness management strategies. ▪ If the person has been well for a while, mention that sometimes medications and other illness management strategies that worked previously need to be adjusted. ▪ Encourage the person not to give up hope, as finding what works to manage the illness is a trial and error process. * 	2 2 2 2

Table 7: Helping with triggers and keeping well

Item	Survey
<p>When it comes to assisting the person to deal with triggers and stress, the caregiver should be aware that:</p> <ul style="list-style-type: none"> ▪ Dealing with triggers can help both to prevent relapse when the person is well, and to prevent symptoms from getting worse when the person is ill. ▪ Although certain triggers might need to be avoided, not all stress is avoidable. ▪ The caregiver should not expect to be able to shelter the person from all stress. * ▪ The person needs to find ways to manage stress (e.g. exercise, talk things over with someone, write or paint). * ▪ Most people with bipolar disorder need to make some adjustment to their lifestyle and goals to stay well, but the extent of this adjustment can differ from person to person. ▪ If the person needs to make changes to their job or study plans in order to keep well, the caregiver should take time to listen and to discuss alternatives, as this can be a challenging time for the person. ▪ Some people with bipolar disorder are very sensitive to interpersonal stress (e.g. conflict, distressing criticism), and this can contribute to relapse. ▪ The caregiver should support the person's strategy to do things when they are well that they (the person) enjoy, and that are not overstimulating or too stressful, in order to keep well (RI). 	2 2 2 2 2 1 1 2
<p>The caregiver should ask the person:</p> <ul style="list-style-type: none"> ▪ About the factors that trigger their bipolar moods and what helps them to stay well. ▪ How they can support the person's strategies to deal with triggers, and to develop a lifestyle that helps them keep well. 	1 1

<p>The person's strategies for keeping well that the caregiver should support include when the person:</p> <ul style="list-style-type: none"> ▪ Follows regular sleep patterns. * ▪ Maintains a basic routine. ▪ Takes ongoing medication prescribed for bipolar disorder. ▪ Regulates the stimulation they receive (e.g. support the person's decision to have quiet times between social arrangements or restore sleep habits after celebrations). ▪ Avoids setting unrealistic or excessively demanding goals. ▪ Sets manageable goals when they are well that are in harmony with their interests, talents, skills and values. ▪ Avoids or reduces their use of substances that make bipolar moods worse (e.g. caffeine, alcohol or ecstasy). * ▪ Exercises regularly. ▪ Eats a healthy diet. ▪ Finds ways to relax and unwind. ▪ Adopts a problem solving approach to difficulties that arise. ▪ Accepts that not all problems can be solved and make the most of things the way they are. 	<p>1</p> <p>1</p> <p>1</p> <p>1</p> <p>1</p> <p>1</p> <p>1</p> <p>1</p> <p>1</p> <p>1</p> <p>1</p> <p>1</p> <p>1</p>
<p>When stressful events occur the caregiver should:</p> <ul style="list-style-type: none"> ▪ Encourage the person to try and maintain their routine and sleep habits. ▪ Offer to listen if the person needs to talk. ▪ Offer to discuss solutions to a problem the person is finding stressful, without solving the problem for them. ▪ Ask what practical assistance they can provide. 	<p>1</p> <p>1</p> <p>1</p> <p>1</p>
<p>In order to help reduce interpersonal stress, the caregiver should:</p> <ul style="list-style-type: none"> ▪ Find out about good communication skills. ▪ Learn to express their grievances towards the person in ways that are not critical or hostile and help to bring about positive change. ▪ Initiate positive ways to sort out conflict between them, if it arises. ▪ If there is conflict between them, invite the person to join them in thinking of ways to try and sort out the problem. ▪ Communicate about the things they appreciate about the person. ▪ Talk about everyday experiences, not just about problems. 	<p>1</p> <p>1</p> <p>1</p> <p>1</p> <p>1</p> <p>1</p>

Table 8: Helping with warning signs

Item	Survey
<p>When considering whether to assist the person with their warning signs, the caregiver should be aware that:</p> <ul style="list-style-type: none"> ▪ There is evidence that recognizing and responding to warning signs can prevent or at least reduce relapse. ▪ People with bipolar disorder and caregiver's can be trained to identify and respond to warning signs of illness. ▪ If the caregiver or/and person would like to learn how to identify warning signs to help reduce relapse, they should seek out information and training (if available) on the topic. ▪ Although many people get warnings signs, some people develop certain types of bipolar episodes without any warnings. ▪ Even if the person does not get warning signs of impending depression, 	<p>1</p> <p>2</p> <p>2</p> <p>2</p>

recognizing early symptoms of depression, and implementing illness management strategies may help to reduce the intensity of the episode.	2
<p>If the family does want to help the person with their warning signs or early symptoms they should be aware that:</p> <ul style="list-style-type: none"> ▪ The caregiver should ask the person about how they can help with their warning signs, early or subsyndromal symptoms. 1 ▪ If the person does not want assistance with their signs or symptoms, the caregiver should still notice when they occur to enable them to better understand the person's behaviour, and plan how to respond to it (e.g. rather than retaliating when irritability is a warning sign, the caregiver can plan how to cope with the developing illness). 1 ▪ When the person is well, the caregiver should discuss with the person how they would like them to communicate that they have noticed changes that might be warning signs or early symptoms. 1 ▪ When the person is well, the caregiver should not constantly question everything the person says and does for signs of illness. * 2 	
<p>To identify warning signs or early symptoms the caregiver should:</p> <ul style="list-style-type: none"> ▪ Be aware of the common warning signs of bipolar episodes. * 1 ▪ Ask the person about their typical warning signs or early symptoms. 1 ▪ Be alert to changes in the person's usual behaviour and thinking. 1 ▪ Distinguish joy and sadness from bipolar moods. 1 ▪ Be aware that ongoing mild symptoms (subsyndromal symptoms) are connected with an increased risk of relapse and be alert to the possibility that mild symptoms can get worse. 1 ▪ If the person already has a few mild ongoing symptoms between episodes (subsyndromal symptoms) the caregiver can see if these mild symptoms get worse or if the person develops other signs or symptoms. 2 	
<p>When communicating with the person about changes that could be warning signs or early symptoms, the caregiver should:</p> <ul style="list-style-type: none"> ▪ Be aware that misinterpreting mood fluctuations and behaviour that are common to us all as part of bipolar disorder can be hurtful and frustrating for the person. 1 ▪ Let the person know what they have noticed as soon as possible, as there is a greater chance of preventing relapse if the person deals with their warning signs early. 1 ▪ Inquire if the person has also noticed these changes, and if they could be signs of illness. 1 ▪ Express their concerns in a way that is non-judgmental and unthreatening (e.g. I have noticed that you have been a bit down lately). 1 ▪ If the behaviour the caregiver has noticed occurred in a previous episode, they should remind the person about this, and explain that this is the reason for their current concern. 1 ▪ Communicate their uncertainty to the person if they are unsure whether something is a warning sign. 1 <p>In order to help the person who is experiencing warning signs or early symptoms the caregiver should:</p> <ul style="list-style-type: none"> ▪ Maintain their equilibrium and not get caught up in the person's bipolar mood state (e.g. in the excitement or irritability of the person's growing hypomania). 1 	

<ul style="list-style-type: none"> ▪ Be aware of how hard it can be for the person who has signs or symptoms to act contrary to their mood to prevent or reduce relapse (e.g. to get out of bed when depressed or to rest when becoming manic). * ▪ Do things that make it easier for the person to prevent or reduce relapse (e.g. make sure the house is quiet if the person who is becoming manic needs to rest). ▪ Be aware of ways of coping with warning signs that have been found to be helpful and those that may be unhelpful. ▪ Assist the person to monitor their mood and activities to help stabilize their mood, if the person wants this assistance. 	<p>1</p> <p>1</p> <p>1</p> <p>1</p>
<p>When assisting the person with their warning signs, the caregiver should be aware that:</p> <ul style="list-style-type: none"> ▪ Some people with bipolar disorder and their caregivers find it helpful to have a list of the person's warning signs. ▪ Anxiety about becoming ill often accompanies warning signs (RI). ▪ If the person is anxious about becoming ill, the caregiver should reassure them about the person's ability to deal with the illness and the availability of the caregiver's support. ▪ If the person who has warning signs is not keen to see a clinician, the caregiver should negotiate with them to agree to get clinical help if things don't improve or get worse within a set time. ▪ If the caregiver knows the persons' patterns of illness well, they should trust themselves when they notice changes in the person's mood and behaviour. 	<p>2</p> <p>3</p> <p>2</p> <p>2</p> <p>2</p>
<p>When dealing with warning signs of MANIA or HYPOMANIA, the caregiver should be aware that:</p> <ul style="list-style-type: none"> ▪ Some people find that taking medication prescribed to assist them to relax, rest and sleep when they have warning signs, helps to prevent a full manic episode. ▪ The caregiver should not be side tracked from supporting the person to manage their illness by the often positive signs of hypomania (e.g. more friendly, more confidence or increased libido), as hypomania can cycle into depression or mania (RI). 	<p>2</p> <p>3</p>
<p>If the person has warning signs or early symptoms of MANIA or HYPOMANIA the caregiver should encourage the person to:</p> <ul style="list-style-type: none"> ▪ Contact their clinician to get medical treatment early. ▪ Take medication that has been prescribed specifically for times when warning signs appear. ▪ Rest, with the help of prescribed medication if necessary (RI). ▪ Reduce stimulation. 	<p>1</p> <p>1</p> <p>2</p> <p>1</p>
<p>The caregiver should be aware that when the person has signs or symptoms of DEPRESSION:</p> <ul style="list-style-type: none"> ▪ These symptoms can make it hard for the person to communicate verbally what they are feeling, or what they need. ▪ What comforts one person who has symptoms of depression might not comfort another (e.g. while some people like to be reminded that they will feel better in time, others cannot relate to this). ▪ The person who is becoming inactive should try to maintain some level of activity, as inactivity can make things worse. 	<p>2</p> <p>2</p> <p>1</p>
<p>If the person has warning signs/early symptoms or a few ongoing symptoms of</p>	

<p>DEPRESSION, the caregiver should be aware that they could:</p> <ul style="list-style-type: none"> ▪ Tell the person that they care about them (RI). 2 ▪ Not try to get the person to do something they find very stressful or overwhelming (RI). * 2 ▪ If the person does things very slowly, not take over and do everything for them. 2 ▪ Encourage the person to: <ul style="list-style-type: none"> ○ Contact their clinician. 1 ○ Restore or maintain a basic routine, even if they are not able to do too much. 1 ○ Restore or maintain regular sleep habits (e.g. use sleep hygiene or prescribed medication if necessary). 1 ○ Set small manageable goals to do things. 1 ○ Divide these goals into smaller steps if they are hard to achieve. 1 ○ Acknowledge small achievements, as experiencing a sense of achievement can have a positive influence on mood. 1 ○ Persist with whatever regular exercise the person can manage. 1 ○ Do something that involves some physical activity (e.g. ask them to help take parcels in from the car) (RI). 3 ○ Recognize positive events and experiences when they occur (e.g. talk about an experience they both enjoyed or acknowledge good news the person has received). 1 	
<p>If the person who is ill is ruminating (thinking over and over again or preoccupied) about a problem and constantly tells the caregiver about these worries, the caregiver should be aware that they could:</p> <ul style="list-style-type: none"> ▪ Discuss with the person that problems are magnified due to the illness, and suggest that they postpone trying to sort out the problem until they feel a bit better (RI). 3 ▪ If the person is not too ill, brainstorm solutions to the problem with them, and assist them to do something small towards these solutions (RI). 3 ▪ Invite the person to do something that will distract them from the rumination. 2 	

Table 9: Communicating when the person is ill

Item	Survey
<p>The caregiver should:</p> <ul style="list-style-type: none"> ▪ Be aware that being supportive does not mean they have to agree with what the person says. * 1 ▪ Acknowledge that what the person says is very real to the person (e.g. “I know you are convinced that you should resign, but I am not so sure”). 1 ▪ Validate the feeling behind what the person says when they are ill (e.g. “I can see you are feeling disillusioned with your job right now, but maybe you need to wait until you are feeling better before making a decision about resigning”). 1 ▪ Limit their expectations and the demands they make on the person when the person is ill or under a lot of stress. 1 	
<p>The caregiver should not:</p> <ul style="list-style-type: none"> ▪ Communicate with the person in ways that are highly emotionally charged or reactive (e.g. by shouting or emotional expressions of concern). 1 	

<ul style="list-style-type: none"> ▪ React impulsively to what the person says or does (e.g. the caregiver should not retaliate when the person is irritable as this is part of the illness). 	1
<p>When communicating with the person who is hypomanic or manic, the caregiver should:</p> <ul style="list-style-type: none"> ▪ Remain calm and relaxed so they can be a calming influence on the person. * ▪ Answer questions briefly, quietly and honestly. ▪ Avoid being drawn into long conversations or arguments with the person. ▪ Consider that people who are hypomanic or manic might take offense easily. ▪ Understand that people with elevated moods are vulnerable despite their apparent confidence. * 	1 1 1 1 1
<p>When communicating with the person who has symptoms of depression, the caregiver should:</p> <ul style="list-style-type: none"> ▪ Be ready to initiate discussion if the person is withdrawn, without trying to force them to talk. ▪ Offer the person kindness and attention even if this is not reciprocated. ▪ Avoid telling the person to “snap out of it” or to “pull themselves together”. ▪ Continue to be patient and encouraging even if the caregiver’s suggestions and support do not seem to help, as depressed mood can be persistent. ▪ Express care and concern for the person, but not to the extent that it makes the person feel overwhelmed and helpless. 	1 1 1 1 1
<p>To defuse an argument with the person who is ill, the caregiver should:</p> <ul style="list-style-type: none"> ▪ Try to remain detached and remind themselves that it is the illness talking. ▪ Consider postponing the discussion (e.g. I can see this means a lot to you and we need to discuss it, but I am upset and tired now. Let's discuss it in the morning when my head is clearer.). ▪ Consider trying to find some common ground with the person (e.g. Spring has started and it might be an idea to go for a walk in the park sometime)(RI) 	2 2 3

Table 10: Helping when an episode occurs

Item	Survey
<p>When a bipolar episode occurs the caregiver should:</p> <ul style="list-style-type: none"> ▪ Support the person’s strategies to stabilise their mood (e.g. medical treatment, help them manage triggers i.e. helpful strategies). ▪ Encourage the person to contact their clinician if the person has not already done so. ▪ Offer to assist the person to access treatment. ▪ Keep an eye on their symptoms to see if the person becomes more ill. * ▪ Encourage the person to focus on getting well, and temporarily postpone or increase the timeframes on other goals. ▪ If necessary, help cancel or postpone the person’s commitments, and assist them with other practical tasks (RI). ▪ Once the person has accessed treatment, be available, listen and observe (within personal limits), rather than tell the person what to do (RI). 	1 2 2 2 1 2 3
<p>If the person requires medical treatment but they are too ill to contact their clinician, the caregiver should contact the person’s clinician on their behalf (e.g. if the person is psychotic).</p>	1

If the person has severe symptoms and is finding it hard to function, the caregiver should encourage them to talk to their clinician about whether hospitalisation may be helpful.	1
If the person's clinician recommends hospitalisation, the caregiver should:	
▪ Help the person to be admitted voluntarily	1
▪ Help the person to see that going to hospital is an opportunity to take time off and get well, away from stressful demands.	1
▪ Maintain regular contact with the person when they are in hospital.	1
▪ Tailor their contact with the person who is in hospital to what the person is comfortable with, as the person may feel vulnerable about social contact.	1
If the person has severe symptoms and is finding it hard to function, and they are too ill or refuse to discuss hospitalisation with their clinician, the caregiver should act in the interests of the person's wellbeing and discuss hospitalisation with the person's clinician (and see dealing with an illness related crisis on page).	1
If the person is depressed (see dealing with warning signs for more items):	
▪ They might be unable to respond to the caregiver's suggestions, and the caregiver should just give them loving care.	2
▪ The caregiver should keep up some of the things they enjoy and not isolate themselves from their friends when the person is depressed, or the caregiver might become depressed too.	2
▪ If the person does not maintain basic hygiene, the caregiver should encourage them to do something small in this regard (e.g. to brush their teeth, shower/bath).	2
If the person is hypomanic or manic the caregiver should (see dealing with warning signs for more items):	
▪ Adjust the environment to reduce stimulation, if they live with the person (e.g. reduce clutter, noise or social gatherings).	2
▪ Not believe that they have to participate in the persons numerous projects and goals.	2

Table 11: Helping to get the best from treatment

Item	Survey
The caregiver should:	
▪ Support the person in taking medications to treat their illness that have been agreed on by the person and their clinician. *	2
▪ Get information about the person's medication (e.g. the side effects, required changes in diet and how long the medication takes to work).	1
▪ Tell the person if they see any improvement in the person's bipolar disorder since commencing treatment.	1
▪ Consider offering to assist the person to keep a record of the medications they have been on and their positive and negative effects.	2
The caregiver should be aware that:	
▪ Some medications take time to work.	1
▪ It can take time to find the right medication to help maintain wellness.	1
▪ Medications that have helped to keep bipolar mood stable may need to be adjusted if the person develops new symptoms.	1
▪ If treatments take time to work, or the person needs to try new treatments, the caregiver should encourage the person to persevere and not give up hope.	1

<ul style="list-style-type: none"> ▪ Some side effects from medications are temporary, or can be overcome by adjusting the dose or changing medications in consultation with the clinician. ▪ If the person is very ill in hospital and has been asked to consent to trial a new drug, the caregiver should request information about the research. 	2 2
<p>To get the most benefit from treatment the caregiver should encourage the person to:</p> <ul style="list-style-type: none"> ▪ Find out about the range of treatments that have been shown to be helpful in bipolar disorder. ▪ Use treatments that have been shown to be effective. ▪ Take an active role in making treatment decisions with their clinician (e.g. by getting information on their treatment, monitoring its effect and discussing options with their clinician). ▪ Discuss treatment problems openly with their clinician. * ▪ Have regular appointments with their clinician to help monitor their progress. 	1 1 1 1 1
<p>When trying to help the person get the most benefit from treatment the caregiver should:</p> <ul style="list-style-type: none"> ▪ The caregiver should encourage the person to manage their own medications and only take over if the person is too ill or unable (e.g. due to age) to control their own treatment ▪ The caregiver should find out about confidentiality laws that may restrict clinicians from being able to provide information and discuss the person's treatment with the caregiver. ▪ Ask the person to let their clinician know they are the person's primary caregiver and their contact details, in case the clinician needs to contact them in an emergency. * ▪ If the caregiver would like to collaborate with the person and their clinician in supporting the person's treatment, the caregiver should discuss this with the person. ▪ Be aware that caregivers have the option of contacting the clinician if they are concerned about the person's wellbeing. ▪ If due to confidentiality laws the clinician cannot share information about the person with the caregiver, the caregiver should ask the person to give their clinician prior permission to share specific information with the caregiver in certain circumstances (e.g. when the person is very ill, or information to assist the caregiver's ongoing care of the person after discharge from hospital). ▪ If the caregiver would like to accompany the person to an appointment with their clinician, they should offer to do this. ▪ While the person is severely ill, the caregiver should try and keep in contact with the person's therapeutic team. ▪ When communicating with the person's clinician, not be afraid to ask questions about bipolar disorder and its treatment, or to ask for clarification if the information provided is confusing (e.g. "What are the possible side effects of that treatment?"). 	1 1 2 2 2 2 2 2 2 2 2
<p>When the person stops their medication or takes it erratically:</p> <ul style="list-style-type: none"> ▪ The caregiver should be aware that there are many reasons why people stop medications. ▪ The caregiver should enquire about the person's reasons for wanting to stop 	1 1

<p>their medications or for taking them erratically.</p> <ul style="list-style-type: none"> ▪ If the caregiver is concerned about the person not taking their medication, they should discuss the reasons for their concerns with the person. * ▪ The caregiver should discuss their concerns using “I statements” and without blaming the person (e.g. “I am concerned that stopping your medication may increase your chances of relapse”). ▪ If the person is manic/hypomanic or depressed and wants to stop their medication, the caregiver should suggest that they wait until they are well to make such important decisions. ▪ The caregiver should encourage the person to discuss their reasons for wanting to stop taking their medications with their clinician. ▪ If the person wants to stop taking medication (to treat a current episode), the caregiver should mention that the medication may relieve the symptoms the person finds particularly unpleasant (e.g. agitation, racing thoughts). ▪ If the person is experiencing a bipolar episode and stops taking their medication, the caregiver should call the person's clinician and express their concerns (RI). ▪ The caregiver should encourage the person to consider the pros and cons of taking medication, and what is at stake if they relapse. ▪ If the person wants to stop their medication in order to experience elevated moods, the caregiver should remind them that elevated moods do not come without depression or the negative consequences of mania. ▪ If the person does not want to take medications due to concerns about stigma, the caregiver should tell them that taking charge and using medication to deal with an illness is nothing to be ashamed of. ▪ The caregiver should be aware that sometimes people only recognise the importance of ongoing medication once they have relapsed a few times after having stopped their medication. ▪ If the person intends to stop taking their medication, the caregiver should encourage them to discuss how to stop their medication with their clinician, as certain medications need to be stopped gradually. ▪ If the person often forgets to take their medication, the caregiver should suggest strategies that might help (e.g. using a pill organiser or taking medication at the same time as doing another routine activity). ▪ If the caregiver is concerned about the consequences of the person's decision to stop using medication, the caregiver should negotiate an agreement with the person to resume medication if signs of relapse appear (RI) 	<p>1</p> <p>1</p> <p>1</p> <p>1</p> <p>2</p> <p>2</p> <p>1</p> <p>1</p> <p>1</p> <p>1</p> <p>1</p> <p>1</p> <p>3</p>
---	--

Table 12: Dealing with an illness-related crises

Item	Survey
The caregiver should be aware of the illness-related crises that sometimes occur in bipolar disorder. **	2
When dealing with an illness-related crisis the caregiver should:	
<ul style="list-style-type: none"> ▪ Communicate calmly and clearly. * ▪ Have a list of contact numbers of people that they can call for help in an emergency. * ▪ Call the person's clinician, if they think that things may be reaching a crisis point. 	<p>1</p> <p>1</p> <p>1</p>

<ul style="list-style-type: none"> ▪ Call the mental health crisis team or an ambulance, if there is an immediate risk that the person might do something with severe negative consequences (e.g. gambling the family finances or harming themselves). 1 ▪ Call the mental health crisis team or an ambulance, if the person is severely ill, dysfunctional and unable to access medical care. 1 ▪ Call the police, if the person urgently needs to be restrained to stop them from harming themselves or others. 1 ▪ Put safety first (e.g. If their safety is threatened, leave the house before calling emergency services). 2 ▪ Not argue, criticise or behave in a threatening way towards the person. 1 ▪ Not hurry the person or give them lots of instructions. ▪ Where possible, give the person choices to reassure them that they have some control over the situation (e.g. “Should we go for a walk in the garden or would you prefer to watch a movie?”). 1 ▪ If the person is very ill and unable to provide much information when admitted to hospital, provide information to assist with treatment (e.g. information on recent symptoms or medications). * 2 ▪ If the emergency service does not provide the help expected, contact another clinician (e.g. the GP), or take the person to the hospital emergency department. 2 ▪ Not be afraid to ask for assistance to prevent negative consequences (e.g. assistance from clinicians, appropriate family and friends or a lawyer if necessary). * 1 	
<p>Before an illness related crisis occurs, the caregiver should find out:</p> <ul style="list-style-type: none"> ▪ About realistic local service options to assist the person in a crisis (e.g. mental health crisis team, ambulance). ** 2 ▪ If emergency services will assist a person with bipolar disorder when they are very ill, but not in immediate danger of harming themselves or others. 2 ▪ Where to get help if there are no emergency services available (e.g. if the person lives in a remote area). ** 2 ▪ What hospitals will admit the person, as in certain places hospitals might only accept people with specific medical insurance, or who have been referred by affiliated doctors. 2 ▪ The caregiver should find out about involuntary hospitalisation procedures in case they need to use them. 1 ▪ Directions to the hospital if they need to help the person to get there. 2 	

Table 13: Helping to prevent suicide

Item	Survey
<p>When dealing with suicide risk the caregiver should:</p> <ul style="list-style-type: none"> ▪ Take even casual or occasional mentions of suicidal thoughts seriously, as there is a high risk of suicide in bipolar disorder. 1 ▪ Not treat suicide risk as a taboo topic (topic to avoid mentioning), as the person might feel unable to discuss their suicidal thoughts or intentions with them. 2 ▪ Be aware that the person may not express their suicidal thoughts directly or verbally. * 1 ▪ Learn to recognize warning signs that the person is becoming suicidal. * 1 	

<ul style="list-style-type: none"> ▪ Ask the person directly if they have any thoughts about suicide, if the caregiver suspects they may be suicidal. 	1
<ul style="list-style-type: none"> ▪ Be aware of factors that increase the person's risk of suicide (e.g. having depression or mixed symptoms, using alcohol or drugs and having a plan to commit suicide). * 	2
<ul style="list-style-type: none"> ▪ Be aware that if the person is suicidal, the clinician/mental health team should always be contacted. 	2
<ul style="list-style-type: none"> ▪ If the person has occasional vague, passing suicidal thoughts and none of the risk factors that increase their risk (e.g. no current or recent episode, no substance abuse, no plan to kill themselves or previous attempt), the caregiver should encourage the person to discuss these thoughts with their clinician, and keep an eye on them to see if they get worse. 	2
<ul style="list-style-type: none"> ▪ If the caregiver is uncertain about the extent of the suicide risk, they should assist the person to get an assessment of the risk from their clinician or mental health service. 	2
<ul style="list-style-type: none"> ▪ Not let the possibility of resentment from the person get in the way of taking action to help prevent the person from killing themselves. 	1
<ul style="list-style-type: none"> ▪ Not leave the person who is suicidal alone. 	1
<ul style="list-style-type: none"> ▪ Remove the means to suicide (e.g. lock away medicines, guns). 	1
<ul style="list-style-type: none"> ▪ Discuss ways that they can help the person to get through the times when the person feels suicidal. 	1
<ul style="list-style-type: none"> ▪ Assist the person to develop a plan to prevent suicide that they can both rely on if the person becomes suicidal. 	1
<ul style="list-style-type: none"> ▪ Be aware that there is only a limited amount a caregiver can do to prevent a suicidal person from killing themselves, and they should not blame themselves if this occurs. 	2

Table 14: Dealing with risky or inappropriate manic or very hypomanic behavior

Item	Survey
<p>To help prevent risky or inappropriate behavior the caregiver should:</p> <ul style="list-style-type: none"> ▪ When the person is well, discuss precautions the person can take to reduce the chance of negative consequences when they are manic or very hypomanic (e.g. give their credit cards to the caregiver temporarily, to prevent reckless spending). 	1
<ul style="list-style-type: none"> ▪ If severe negative consequences have occurred previously, take more extreme measures to prevent possible negative consequences (e.g. require co-signatures for large expenditures). 	1
<ul style="list-style-type: none"> ▪ Be aware that there may only be a brief opportunity to reason with the person to reduce risky behaviour before they become too manic and lose insight into their condition. 	1
<ul style="list-style-type: none"> ▪ Be aware that if the person is offended because the caregiver does not agree with their risky ideas or plans, tell them that they care about them and are concerned about the consequences. 	1
<p>BEFORE the person becomes too manic, the caregiver could encourage the person to:</p> <ul style="list-style-type: none"> ▪ Postpone important decisions until they are well. 	1
<ul style="list-style-type: none"> ▪ Recognize the link between their bipolar mood and the risky ideas or activity. 	1
<ul style="list-style-type: none"> ▪ Avoid alcohol and drugs, as these substances increase the risk of acting 	1

<p>impulsively. *</p> <ul style="list-style-type: none"> ▪ Consider whether their thinking has become so over optimistic that it is difficult to see risks or negative consequences. ▪ Postpone acting on a risky idea until they are well, by defining a specific wellness goal (e.g. “You could postpone acting on this idea until you have confirmation from your doctor that your mood is stable”, or “until you have managed to sleep through the night for a week”) (RI). 	<p>1</p> <p>2</p>
<p>If negative consequences are likely due to the risky or inappropriate projects or behaviour of the person who is HYPOMANIC or MANIC, the caregiver should be aware of the following options. The caregiver could:</p> <ul style="list-style-type: none"> ▪ Say something tactful to stall decisions about the risky project (e.g. "I need to give that idea more thought."). ▪ Make a positive request that the person does not pursue the risky behaviour, and mention the benefits this will have (e.g. if the person is hypomanic: "I would like us to stay home rather than going to the party, as we can have a nice quiet evening together and you might find it easier to fall asleep and get well") (RI). 	<p>2</p> <p>3</p>
<p>The caregiver should be aware that:</p> <ul style="list-style-type: none"> ▪ The person’s symptoms and behaviour when ill are not intentional or under the person’s immediate control. ▪ However, people with bipolar disorder are responsible for their behaviour except when they are very ill (e.g. psychotic, manic, or depressed). ▪ Although the person might not be in control of their behaviour when very ill, in the long term they are responsible for trying to manage their illness and its consequences. ▪ The caregiver needs to find their own balance between understanding and tolerating certain illness behaviour, and establishing boundaries to protect themselves from illness behaviour they find unacceptable. * ▪ If the caregiver is unsure if the inappropriate, hurtful or damaging behaviour is part of the bipolar disorder or not, they should seek clarification (e.g. from the person, a knowledgeable clinician or reputable text), as not all negative behaviour is due to the illness. ▪ If the person has a drug or alcohol problem in addition to bipolar disorder, this can also negatively affect their behaviour (due to intoxication and the lengths they may go to maintain these habits). ▪ The caregiver cannot control the person's behaviour, but they can control how they (the caregiver) deal with the situation. ▪ Where to set boundaries to protect themselves (or the family) from negative illness related behaviour is a personal decision, and the caregiver should decide what behaviour they will and won't accept. ▪ The caregiver should not feel obliged to accept abuse from the ill person, whether verbal, emotional, physical or financial because the person has bipolar disorder (RI). 	<p>1</p> <p>2</p> <p>2</p> <p>2</p> <p>2</p> <p>2</p> <p>2</p> <p>2</p> <p>2</p> <p>3</p>
<p>When working out how to respond to illness behaviour they find unacceptable, the caregiver should be aware of the following:</p> <ul style="list-style-type: none"> ▪ Caregivers commonly find it difficult to respond to illness behaviour they find unacceptable in as calm and caring a way as they would like to respond. ▪ It may help to detach from the situation a little by reminding themselves that the person is ill and irrational. 	<p>2</p> <p>2</p>

<ul style="list-style-type: none"> ▪ They should address the specific illness related comments or behaviour that are unacceptable, without criticizing or blaming the person as an individual. 	2
<ul style="list-style-type: none"> ▪ The caregiver should be aware of constructive ways to affirm personal boundaries (e.g. request that the person changes the behaviour and specify the BENEFITS this will have, or let the person know what boundary the caregiver needs to protect and the CONSEQUENCES that will result if this boundary is not respected). 	2
<ul style="list-style-type: none"> ▪ If the caregiver mentions consequences that will arise if the unacceptable behaviour occurs (when setting boundaries), they must be prepared to follow through with those consequences if necessary. 	2
<ul style="list-style-type: none"> ▪ If the caregiver sets a boundary about specific behaviour, the person will know where they stand and have the option of doing what they can to try to prevent this behaviour from occurring again (RI). 	3
<ul style="list-style-type: none"> ▪ If the person tries hard to prevent the behaviour the caregiver finds unacceptable, the caregiver should acknowledge their effort. 	2
<ul style="list-style-type: none"> ▪ If the person tries to respect the caregiver's boundaries, the caregiver might find it easier to cope and be reassured that their needs are important to the person (RI). 	3

Table 15: Support after an episode of illness

Item	Survey
<p>The caregiver should be aware that after an episode of illness:</p> <ul style="list-style-type: none"> ▪ What people with bipolar disorder need after an episode can vary from person to person. 	2
<ul style="list-style-type: none"> ▪ Embarrassment (after a manic episode) can lead to the person trying to distance themselves from those who know what happened when the person was ill. 	2
<ul style="list-style-type: none"> ▪ The person might not recall what happened when they were manic. 	2
<ul style="list-style-type: none"> ▪ Some of the things the person might need when trying to get well are rest, routine, something to do, something to look forward to and love/friendship. 	2
<p>After an episode of illness, the caregiver should:</p> <ul style="list-style-type: none"> ▪ Take care of themselves if they are exhausted and burnt out after an episode. 	2
<ul style="list-style-type: none"> ▪ Try to be on hand to support the person (within personal limits), without being domineering or overindulgent. 	2
<ul style="list-style-type: none"> ▪ Adjust their expectations of the person, as it can take time to get well after an episode of illness. 	2
<ul style="list-style-type: none"> ▪ Ask how they can help if the person has ongoing symptoms or is finding it hard to cope. 	1
<ul style="list-style-type: none"> ▪ Do things with the person rather than for them, as this may help the person to rebuild their confidence. 	1
<ul style="list-style-type: none"> ▪ When possible focus on wellness and positive behaviour, rather than illness and problem behaviour. 	2
<ul style="list-style-type: none"> ▪ If the person finds it hard to do things, the caregiver should encourage them to set a manageable goal to do something small as a start. 	2
<ul style="list-style-type: none"> ▪ Encourage the person not to try to get everything done at once. 	1
<ul style="list-style-type: none"> ▪ Encourage the person to prioritize essential tasks and do low stress activities. 	1
<ul style="list-style-type: none"> ▪ Let the person recover at their own pace, but actively encourage or invite them to do things if they find it difficult to become involved in life again (e.g. to pursue leisure or work activities that are not too stressful). 	2

The caregiver should be aware that sometimes caregivers can find it hard to adjust to the person's independence, even though they are happy the person is well.	2
If the person is much better and able to do more for themselves, but the caregiver finds it difficult to reduce their active caregiving role, the caregiver should consider:	
<ul style="list-style-type: none"> ▪ The benefits of not continuing to be as actively involved in caregiving as they were before. 	2
<ul style="list-style-type: none"> ▪ Taking time to relax and focus on other aspects of their (the caregiver's) life, relationships, hobbies or work. 	2
<ul style="list-style-type: none"> ▪ Finding other ways to relate to the person that do not involve such an active caregiving role. 	2

Table 17: Ways to encourage the person's confidence

Item	Survey
<ul style="list-style-type: none"> ▪ When appropriate, acknowledge the person's strengths, abilities and the things the person does that they appreciate. 	1
<ul style="list-style-type: none"> ▪ Tell the person that they believe in the person and their ability to live well despite the illness. 	1
<ul style="list-style-type: none"> ▪ Acknowledge the efforts the person makes to manage their illness and any progress that is made. 	1
<ul style="list-style-type: none"> ▪ Make time to do things with the person that they both enjoy and that are unrelated to the illness. 	1
<ul style="list-style-type: none"> ▪ Relate to the person without being condescending or patronising. 	2

Table 18: Ways to respond if the person refuses to treat or manage their bipolar disorder or refuses the caregivers help

Item	Survey
The caregiver should be aware that:	
<ul style="list-style-type: none"> ▪ Bipolar disorder that is not treated or managed can have a very negative impact on the person and their family. * 	2
<ul style="list-style-type: none"> ▪ It can be hard for the person to accept that they have bipolar disorder, and/or need treatment. * 	2
<ul style="list-style-type: none"> ▪ Some people engage in behaviour that makes their bipolar disorder worse (e.g. abusing drugs or alcohol or staying up all night to try and become hypomanic). * 	2
If the person refuses to seek treatment the caregiver should:	
<ul style="list-style-type: none"> ▪ Listen and observe to try to understand why the person refuses treatment. 	2
<ul style="list-style-type: none"> ▪ Assess if it is urgent that the person receives treatment (e.g. If the person is very ill or at risk of harming themselves or others and they need urgent treatment). ** 	2
If the person who refuses treatment is NOT very ill, the caregiver should:	
<ul style="list-style-type: none"> ▪ Be quietly patient, supportive, and when appropriate, encourage the person to seek treatment. 	2
<ul style="list-style-type: none"> ▪ Keep an eye on them to see if they develop more symptoms or get worse. 	2
If the person who refuses treatment is well enough to reason (e.g. they are not psychotic or too manic to recognise that they are ill), depending on their	

<p>situation, the caregiver could:</p> <ul style="list-style-type: none"> ▪ Discuss reasons the person has for not accessing treatment (e.g. stigma, problems with that clinician or enjoying the highs). 2 ▪ Suggest that the person at least has an assessment with their clinician to see if they might need treatment. 2 ▪ Suggest that the person discusses their concerns about treatment with someone who knows a lot about bipolar disorder. 2 ▪ Consider mentioning how treatment might help in terms of what is important to the person (e.g. might help to make it easier for the person to achieve a goal they value or prevent negative consequences) (RI). * 3 ▪ Discuss what illness related behaviour (e.g. spending sprees) the caregiver is not prepared to tolerate, as the person may seek treatment to reduce this behaviour (once they know that the caregiver won't put up with it). 2 ▪ Let the person know what boundary the person has crossed (e.g. caused financial debt when manic) and the consequences that will arise if the person does not try to manage the illness (e.g. the caregiver will not pay off the person's credit card). 2 ▪ If the person who refuses treatment finds it hard to function and has symptoms of depression but is not suicidal, the caregiver should offer to assist them to access treatment. * 2 	
<p>If the person is TOO ILL to recognize that they need treatment, the caregiver should: (Please note: getting emergency help in an illness-related crisis has already been endorsed as important to include in the guidelines.)</p> <ul style="list-style-type: none"> ▪ Gently let the person know that they think the person needs to access treatment. 2 ▪ If the caregiver is concerned as the person who refuses treatment is very ill, they should contact the person's clinician or mental health team. 2 ▪ If the person requires medical treatment but refuses to contact their clinician, the caregiver should contact the person's clinician on their behalf (e.g. if they are manic and have lost insight into their mental state) (RI). 2 	
<p>If in time it becomes clear that the person refuses to take responsibility for managing their illness, the caregiver should be aware of their options. Depending on their circumstances, the caregiver could:</p> <ul style="list-style-type: none"> ▪ Talk to the person regarding their concerns about the way the untreated or unmanaged illness is affecting the person, caregiver and others. 2 ▪ Discuss with the person how they can both work on trying to prevent these negative consequences in the future, and mention the benefits this will have. 2 ▪ Make a positive request that the person carries out certain illness management strategies (e.g. consult a clinician, cut down on their alcohol consumption), and let them know how this could benefit them (and possibly the caregiver). 2 ▪ If possible give the person a choice when stipulating illness management strategies that the person needs to carry out (e.g. " You could see the GP about your medication or contact the community mental health team") (RI). 3 ▪ Contact their own (the caregiver's) clinician to get professional advice 3 	

(RI). ▪ Contact support people they trust (e.g. friend/caregiver advocate/ support group) (RI).	
If the person does NOT want the caregiver to help, the caregiver should: ▪ Maintain regular contact with the person in case they need or want help later. ▪ Be aware that sometimes the person might push the caregiver away, and try to isolate themselves when they are ill and need support. * ▪ If the person needs help, ask them if there is someone else who they would like to help them (e.g. clinician or another support person). ▪ Assess if the person is very ill, as people who are hypomanic, manic, depressed or suicidal sometimes see no need for help. *	2 2 2 2

STIGMA, DISCRIMINATION AND DISCLOSURE

Table 19: Suggestions for dealing with stigma, discrimination and disclosure

Item	Survey
When working out how to deal with stigma or discrimination, the caregiver should be aware that: ▪ Stigma can be external (from others or society) or/and internal (stigmatising views that have become part of the individual's own belief system). * ▪ Whether to speak out against external stigma or discrimination, or not, is a choice that might differ depending on the individual and the circumstances.	2 2
When deciding whether to speak out and take a stand against stigma or discrimination, the caregiver should consider: ▪ If the process of standing up to the stigma or discrimination is likely to be very stressful for the caregiver or the person. ▪ If there are likely to be negative consequences to speaking out (e.g. people might discriminate more against the person in the future). ▪ If there are likely to be negative consequences to NOT taking a stand against stigma or discrimination (e.g. in a group situation if stigma is not addressed it might escalate, or discrimination at work might result in the loss of a job). ▪ That educating people about mental illness can sometimes change their attitudes and behaviour, and improve conditions for people affected by mental illness.	2 2 2 2
To protect themselves from the negative impact of stigma or discrimination, depending on their situation the caregiver should consider: ▪ Reading books written by people who live well with bipolar disorder (RI). ▪ Attending a support group where they and the person's bipolar disorder are accepted (RI).	3 3
In order to put stigmatized views into perspective the caregiver should be aware that: ▪ Most stigma is based on a lack of information and understanding about the illness. ▪ Many successful people have bipolar disorder	1 1

<ul style="list-style-type: none"> ▪ Bipolar disorder is a biological illness, like diabetes, and not a personality flaw. ▪ There is more to the person than their illness. * ▪ While certain illness related behaviours are socially unacceptable, these behaviours are symptoms of a treatable illness. ▪ Someone who does not know the person's individual qualities, talents and strengths might be more likely to believe stigmatized stereotypes of mental illness. 	<p>1</p> <p>1</p> <p>1</p> <p>1</p>
<p>When dealing with stigma the caregiver should:</p> <ul style="list-style-type: none"> ▪ Consider the person's personal qualities, talents and strengths. ▪ Become well informed about bipolar disorder to recognize some of the misconceptions involved in stigma. ▪ Reject stigmatized views of mental illness. ▪ Encourage close friends and family to understand that bipolar disorder is a treatable illness. ▪ If friends or relatives avoid the caregiver due to stigma, the caregiver should develop other, more supportive relationships. ▪ Consider that it is not always necessary to divulge their personal situation when standing up to the stigmatised beliefs of others. 	<p>1</p> <p>2</p> <p>1</p> <p>1</p> <p>1</p> <p>2</p>
<p>When considering how to help the person to deal with stigma the caregiver should:</p> <ul style="list-style-type: none"> ▪ Let the person decide how they would like to respond to stigma or discrimination from others. ▪ Only encourage the person to take a stand against stigma or discrimination, if this is not too stressful for the person. ▪ Remind the person that bipolar disorder is like other recurrent biological illnesses. ▪ Be aware that the person's own stigma about mental illness can cause them to lose confidence and belief in their own abilities. ▪ Help the person to distinguish their personal qualities and abilities from stigmatised views of mental illness. ▪ Encourage the person to develop their abilities, interests, and a sense of purpose, as this might increase their resilience to stigma. ▪ If the person's internal stigma prevents them from pursuing opportunities and goals that could enrich their lives, and the caregiver has a close relationship with the person, tactfully raise this subject with them. 	<p>2</p> <p>2</p> <p>2</p> <p>2</p> <p>2</p> <p>2</p> <p>2</p> <p>2</p>
<p>In order to help the person to refute internal (their own stigma about mental illness) or external stigma (stigma from others), there might be times when the caregiver should:</p> <ul style="list-style-type: none"> ▪ Encourage the person to attend a peer support group where their bipolar disorder is accepted (RI). ▪ Point out that stereotyping people with mental illness does not do justice to the complexity of human beings (RI). ▪ Be careful NOT to pass on the caregiver's internal stigma about mental illness to the person (RI). 	<p>3</p> <p>3</p> <p>3</p>
<p>When it comes to disclosing the person's illness/ the caregiver's situation, the caregiver should:</p> <ul style="list-style-type: none"> ▪ Consider their own and the person's right to privacy and be cautious about who they tell about the person's illness or their own situation. * 	<p>2</p>

<ul style="list-style-type: none"> ▪ Be aware that keeping the person's bipolar disorder a secret from close family and friends, due to concerns about stigma, can eliminate potential sources of support and lead to isolation (RI). ▪ Be aware that if there are children in the person's family, they need appropriate explanation of the person's illness, and to be allowed to ask questions about it. * ▪ Children need to be taught what behaviour is part of the illness (when they are old enough to comprehend this). 	<p>2</p> <p>2</p> <p>2</p>
<p>When deciding who to tell and what to say about the person's illness or their caregiving situation, the caregiver should consider:</p> <ul style="list-style-type: none"> ▪ Who needs to know? ▪ Who has the ability to listen, empathize, or provide support? * ▪ Who will respect the confidentiality of this information? * ▪ How much they need to know (e.g. someone they are close to and trust might need to know more than a distant acquaintance)? ▪ How informed that particular individual already is about bipolar disorder? ▪ How to explain things in a way that will make sense to that particular person? * 	<p>2</p> <p>2</p> <p>2</p> <p>2</p> <p>2</p> <p>2</p>