Nanual for Caregivers of Bipolar Disorder & Depression







MANUAL FOR CAREGIVERS OF BIPOLAR DISORDER & DEPRESSION AFFECTED

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Introduction

The Minds Foundation, which is doing exemplary work in the area of Mental Health Awareness and intervention, especially in the much neglected rural India has joined hands with BipolarIndia. In collaboration, we intend to come up with Workshops and other initiatives which would help educate people and reduce stigma around Mental Health.

Pragya Lodha, of The Minds Foundation and I were discussing the core initiatives that we could collaborate on. Since BipolarIndia organises Peer Support Meets for Bipolar Disorder/ Depression affected and their caregivers, I have become aware of the pain points which need to be addressed urgently.

One such issue is the sheer helplessness expressed by caregivers. Caregivers could be parents, siblings or spouses or even the children of those affected. Awareness about the illnesses, treatment options and other holistic approaches is scant. So is guidance in the crucial area of caring for those who are not compliant. We felt that a Handbook that builds awareness about the conditions, educates them about warning signs to watch out for and prepares them how to cope, could be of great practical value.

I, on behalf of our ever growing community at BipolarIndia, thank Pragya, her core team at The Minds Foundation and the Mental Health Professionals who have lent their expertise, for pouring in so much effort to come up with this Manual. **Disclaimer:**

This manual has been created with caregivers in mind, with the sole aim of demystifying mental illnesses such as Bipolar Disorder and Depression and make the unenviable responsibility of looking after affected patients easier.

This is not meant to be a resource that can replace professional help. In case of emergencies, do contact the helpline numbers that we have shared in this handbook.

BIPOLAR DISORDER



What is Bipolar Disorder and what is its prevalence in India?

Bipolar Disorder or BD is a Brain Disorder involving extreme swings in moods and energy levels, with some periods of normal moods in between. It can disrupt lives with the impact it has on relationships, study years, careers and finances. It is said that though there might not be a cure for this illness, it can be managed with treatment and therapy.

There are episodes of low and high moods which an individual experiences.

The episodes may be:-

Low – feelings of intense depression and despair – referred to as depressive episodes

High – feelings of elation - referred to as hypomanic/manic episode.

Mixed – for example, low mood (of a depressive episode) with the restlessness and over activity (of a manic episode).

Bipolar disorder is not the same as the normal ups and downs that we all may generally go through. The mood swings are far more extreme than that and are accompanied by changes in sleep, energy level, and the ability to think clearly. Anyone can develop bipolar disorder. It often starts during late teenage years or early adult years. But children and older adults can have bipolar disorder too. The illness usually lasts throughout life.

What are causes of Bipolar Disorder?

Bipolar disorder is caused either due to genetic inheritance that an individual may have from his first and close family (in most cases, it can also be inherited from the first set of relatives). Sometimes, stress factors in the environment like death of a loved one, difficult relationship, divorce or financial setbacks and other factors can cause it. There are some subtypes in which the illness can manifest in an individual:-

Bipolar I:

There is at least one high, or full blown manic episode which has lasted for longer than one week. Some people with Bipolar Disorder type 1 may only experience manic episodes, though most people also experience depressive episodes. Untreated manic episodes generally last three to six months, depressive episodes rather longer - six to 12 months without treatment.

Bipolar II:

The individual experiences more than one episode of major depression, but only mild manic episodes – these episodes are called as 'hypomania'.

Rapid cycling:

When there are more than 4 mood swings (manic and depressive episodes) in a year. This affects around 1 in 10 people with Bipolar Disorder and can happen with both types I and II.

Cyclothymia:

The mood swings are not as severe as those in full bipolar disorder, but may continue for a longer period of time. This can, sometimes, develop into full bipolar disorder.

What are the different ways in which Bipolar Disorder affects an individual?

BD can have a significant impact on an individual's daily life, particularly with regards to their relationships and school/work life. Bipolar disorder, like many other mental disorders affects the way in which an individual feels, thinks and behaves. There are several signs that you, as a caregiver can take note of, in order to better manage family members, friends and relatives with BD:



Signs to look for in a depressive episode:

- Low mood and feelings of sadness
- Loss of interest in doing day to day tasks that were earlier pleasurable
- Being unable to enjoy things that were enjoyable earlier
- Feelings of restlessness and being agitated
- Low self-confidence
- Feelings of hopelessness
- Feelings of helplessness
- More than usual irritability
- Suicidal ideas or thinking.
- Finding it hard to make simple decisions about day to day activities
- Difficulty in starting and maintaining doing a task
- Difficulty in concentrating on tasks
- Increased or decreased sleeping
- Increased or decreased eating
- Fatigue and easy tiredness

- Lack of interest in maintaining sexual relationships
- Crying spells
- Lack of interest to socialise



Signs to look for in a manic episode:

- Feeling overly happy or "high" for long periods of time
- May also feel irritable, agitated or may also become very sensitive on certain issues
- Having a decreased need for sleep
- Talking in a very fast manner, often with racing thoughts where the person feels that his/her thoughts go faster than the ability to talk about them
- Moving from one idea to another while talking

- Loss of inhibition in general behaviour
- Feeling extremely restless or impulsive at sudden spurs of moments
- Easily distracted
- Behaviours may sometimes be bizarre and unexplainable
- Feeling overconfidence in their abilities
- Making grandiose and unrealistic plans
- Thinking that they can do too many things at once
- Engaging in risky behaviours such as involving in impulsive (and may be multiple) sexual encounters, gambling with money that is required for more important needs, or spending without much thought and judgment.
- There may be signs that individual is hearing, seeing and / or talking to individuals who only he/she can see. These are psychotic symptoms which are seen in schizophrenia as well.
- Person may attempt impulsive suicide in the state of mania

Between episodes:

Some people with bipolar disorder may go back to normal, while many of them continue to experience low levels of depressive symptoms and mild problems even when they appear, to other people, to be 'back to normal'.

Is Bipolar Disorder Curable?

Bipolar Disorder is generally considered to be incurable but can be managed with treatment.

How is Bipolar Disorder Treated?

Bipolar Disorder is treated with a combination of medication and Psychotherapy. Medication is fundamental to ensuring mood swings do not escalate beyond control.

Which kind of Medicines help manage BD?

Usually BD patients are prescribed a combination of medicines, the prominent among them being:

1) Mood Stabilisers: These are invariably prescribed to ensure moods stay stable and within a manageable range.

2) Anti-Psychotics: may also be prescribed depending on the symptoms exhibited by an individual

3) Antidepressants: these are to be administered with great caution to BD patients because they can precipitate mania.4) Tranquilisers

Note:

a) Caregivers need to note that patients need to be monitored by Psychiatrist on a regular basis to gauge how they are progressing and whether dosage or medication needs adjustment.

b) Many of these medicines have side effects and can affect liver/kidney/thyroid function. Therefore blood tests are needed to be done on a pre-decided basis to monitor impact of medicines.

c) No medicine should be stopped or added without consulting the Doctor first!!

d) However, if side effects of a new medicine are severe, report it to the Doctor immediately so that a substitute can be prescribed.



What else can help in the patient's recovery?

1) **Psychotherapy**: regular therapy sessions with a Psychologist can be very beneficial. In the depressive phase especially, CBT (Cognitive Behaviourial Therapy) is of particular benefit. It helps the patient identify and correct faulty thought patterns.

2) **Exercise**: Regular exercise, say even a half hour walk everyday helps in multiple ways. Exercise improves physical and mental well being.

3) There are other holistic approaches that can be adopted in consultation with the treating Doctor, such as Yoga, Art Therapy, Mindfulness meditation, picking up a hobby, etc.

4) **Peer Support Groups** are great communities for patients as well as their caregivers to engage in. They encourage adherence and are a rich pool of knowledge and shared experiences.

5) If applicable, getting them to earn a living increases their self esteem and makes them feel more responsible.

How does BD manifest in children and adults?

Individuals with BD experience different symptoms depending on the kind of episode they have. In children, it can manifest as variance in mood which is much more than normal, prolonged spells of low moods, irritability, impulsive and risky behaviour and aggression.

How do you look for early signs of BD?

Early signs for Bipolar disorder can include:

- Uncharacteristic periods of anger or aggression
- Needing little sleep to feel rested
- Grandiosity and overconfidence
- Easy tearfulness, frequent sadness
- Uncharacteristic impulsive behavior
- Moodiness
- Sadness or crying spells
- Loss of pleasure in activities you normally enjoy
- Decreased or increased energy
- Anxiety or agitation
- Anger or irritability
- Appetite changes- eating less or more than before
- Trouble with concentration or attention on day to day tasks / or at work
- Changes in thinking (e.g., racing thoughts, clouded thinking)
- Trouble with work or other daily activities
- Neglecting household duties (e.g., cooking, housekeeping, paying bills)
- Feeling overwhelmed or like you need help
- Desynchrony (feeling out of sync with your environment and other people)

Most importantly, be aware of signs that the patient is contemplating (thinking about or planning) suicide:

- Talking about death, hurting themselves or committing suicide
- Feeling hopeless and/or worthless/like a burden
- Seeking out objects that could help them commit suicide (sleeping pills, poison)
- Behaving recklessly
- Stating things such as 'I am seeing you for the last time' or 'goodbye'
- Carrying out activities such as making wills or putting other affairs in order, possibly in preparation to die

For caregivers, you may also note:

There is something called as 'signal events' in which a patient might have a particular habit developing just prior to his / her episode of mania. Eg: patient would start buying 3-4 kgs of tomatoes daily whenever he/ she would go into an episode of mania and family members can make a note of such behaviours to identify them at a later stage to become aware of relapse of episode.

Be aware that bipolar disorder can sometimes be mistaken for depression, as mild hypomanic episodes may go unnoticed. Vigilance and keeping record of affect and behavioural concerns can be helpful along with professional help sought for management of symptoms. In fact, maintaining a diary listing daily changes in mood, behaviour, sleep timings, etc. helps the treating Psychiatrist spot mood changes.

Tips for Caregivers:

How do you take care of a individual with BD?

• BD patients have varying needs depending on the episode they may have.

• The best way to look after an individual with BD is to be patient.

• Encourage them to seek professional help and educate yourself on the disorder.

• If possible and required, attend doctor's appointments with them and be there for them when they need it. Ask them if they need help with anything. This may involve you helping them with their responsibilities, such as housework and sometimes share their work.

• It is imperative to know and watch for signs of suicide as well.

• If someone close to you or in your family has BD, ensure all people close to them are psycho-educated about the illness and that they understand BD the patient's needs. This can be a huge responsibility and can strain relationships, which is why consistently assessing your and the patient's needs is crucial.

• Make a plan for crises and ensure all those who are around are aware of it as well.

Remember - BD is no one's fault and it is important to forgive yourself and look after yourself as a caregiver. Only then will you be able to take care of the patient in the best way possible.



The role of medication

• Medications are very important as they control the mood swings present in these patients.

• In episodes of mania, there are anger outbursts which can be controlled with regular dosage of medicines.

• There are sleep disturbances and patients need to get enough sleep for early recovery and medicines help in maintaining this.

• Some patients may be suicidal and/ or homicidal which needs to be managed properly and can be done medically.

• In a depressive phase, to elevate mood, to regain interest in earlier activities medicines definitely help along with therapeutic help and social support from the family.

• Also proper and timely use of mood stabilizers helps to prevent further recurrence of these episodes. More the mood episodes, more difficult it becomes to control them as severity and recurrence rates of episodes increases.

Ways to enhance home environment for better management of BD:

→ Changing your home environment to suit the needs of a BD patient is not as difficult as it may seem. Start by making simple changes to your home design such as choosing a softer, warmer color scheme for your walls and furniture. These colors are less harsh and can be calming for BD patients.

 \rightarrow Lighting also plays a key role — keep bright lights only where it is needed (example, in a study room) and keep soft and soothing lights in other areas, especially areas where one can rest (living room, bedroom).

 \rightarrow Ensure valuables and hazardous materials, particularly those that can be used for suicide or self-harm, are put away.

→ It is possible for patients to become irritable and violent during an episode of mania (or sometimes depression as well), and they may attempt to harm themselves or others with things around. Buy furniture that is too heavy to lift, or if possible, bolster it to the floor/wall. Don't have too many fragile objects around.

→ It may be helpful for you to have a designated area where the patient can go to calm down if they are very angry or anxious. This is particularly useful for children with BD. Fill this room with objects that can be calming such as puzzles and books. Ensure you keep potential hazards away from here.

→ Aside from redesigning your home, it is important to have everyone living in the home aware of BD and any crisis plans that have been put into place. Encourage everyone to be patient with and understanding, and to practice self-care. It's perfectly okay to need space and time away just for yourself.

→ If you are a working parent, have your partner or another family member who the patient is familiar with, stay at home with the patient. This can be useful even if the patient is an adult. In case the patient has children, make a plan so that the children have a safe place to go if the situation at home becomes too stressful for them. This may take time depending on the patient's episode so ensure the children are left with someone they like and trust.

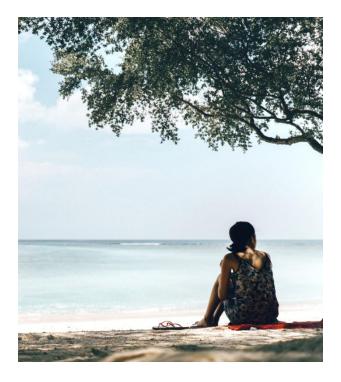
 \rightarrow Dividing the caregiving responsibilities helps better care as the burden gets shared.

Dos and Don'ts for a caregiver:

1. DO practice self-care in whatever way works best for you. Do's:

Some ideas include:

- \rightarrow Take walks or a yoga class
- ightarrow Listen to music
- \rightarrow Read books
- ightarrow Talk to friends and others
- 2. DO take regular breaks from caregiving activities.



3. DO be patient. It can take time and effort for patients to recover from their episodes.

4. DO be observant. BD is characterized by different episodes that can get out of hand if not managed.

5. DO be observant of signs of suicide, especially when the patient is undergoing a depressive episode.

6. DO create a safe space for them. Ensure that people around them are aware of how to address the patient's needs.

7. DO tell them that you are there for them. Take them to the doctor if needed and be available.

8. DO give them space. Sometimes leaving them alone can be what they need to feel better, provided they are in a safe space.

9. DO keep potentially injurious objects away. This includes medication, knives, weapons and other sharp objects that can be used to self-harm or commit suicide.

10. DO take them to a professional if their condition is worsening or not improving.

11. DO learn everything you can about this disorder. The more you know, the better equipped you will be to know what to expect.

12. DO realize that the patient can get angry and frustrated with the disorder, NOT with you.

13. DO let the patient know you are available to help.

14. DO understand that the patient may cancel plans, sometimes at the last minute.

15. DO continue to invite the patient to all the activities.

16. DO ask about the doctor or therapist appointments

17. DO send cards, notes, and other reminders of your friendship or relationship.

18. DO offer her/him lots of hugs, encouragement, and love, even when the patient may seem to withdraw.

19. DO ask for help if you need it! You are not alone. If you need professional help, seek it.

20. DO forgive yourself if things are going badly. It is no one's fault and there is always a solution.

DON'Ts:

1. DON'T tell them to "get over it" or that their symptoms are "just a phase." There is much more to their illness so be sensitive when talking to them. DON'T tell the patient to "pull yourself up by the bootstraps," "snap out of it," "what have you got to be depressed about," "you have so much to be grateful for," "there are a lot of people worse off than you," "happiness is a choice," or the like.

2. DON'T try to underplay their illness or symptoms. They feel them intensely and telling them their symptoms don't matter could make them feel worse.

3. DON'T force logical arguments on the patient. They may not understand them the way you intend them to.

4. DON'T stick to just one solution, even if it has worked before/ for everyone else. If the solution is not working for you, adapt around it to suit the patient's needs.

5. DON'T tell the patient that you look too good to be depressed.

6. DON'T tell the patient you know how they feel.

7. DON'T tell the patient not to worry, that everything will be all right or that this is just a passing phase.

8. DON'T give up on the patient

How do you take care of your own (caregiver's) mental well being?

Looking after someone with BD can be a rewarding experience but it is also mentally taxing. It is not uncommon for caregivers to experience 'caregiver burden', or stress associated with caregiving. Caregiver burden can lead to negative outcomes for the patient and you.

Take these steps to look after yourself as well:

1. Ensure you take a few moments everyday for yourself where you relax and give yourself space from the patient.

2. Make sure you eat, rest and address your other needs properly.

3. Take time to think through and/or talk about your own feelings regarding caregiving. Stay in touch with these feelings and take steps to work through them.

4. Seek professional help, or if not possible, support from friends and/or family to manage your own concerns and stress.

5. Take time to educate yourself about BD and about myths and stigma that surround the illness.

6. If you feel like you are failing or not good enough as a caregiver, remember that you are human and it is okay to make mistakes. Forgive yourself and take steps to not make the mistake again, if possible.

How do you spot changes in mood before it gets out of hand?

BD is characterized by changes in mood. Being aware of the characteristics of each type of mood is crucial to stop it from getting out of hand. Familiarize yourself with the characteristics of each type of episode (listed earlier). Additionally, be familiar with things that can trigger certain moods. For example, alcohol, drugs and high energy foods might be triggers for manic episodes. If the patient has consumed any of these, they may need immediate intervention to curb the possibility of their mood getting out of hand.

What is the importance of family therapy sessions?

Family Focused Therapy (FFT) works with existing relationship dynamics within the family and how these dynamics might affect the BD patient. This kind of therapy is beneficial because it identifies and minimize any stressors such as familial conflicts and difficulties that could contribute to worsening a patient's condition. In addition to learning how to best support the patient, members work on their interactions and communication skills so that they can create a more stable family environment overall. BD affects the family as much as the patient and it is crucial to get them involved in the healing process. It can be difficult to care for a BD patient, especially when the patient is being stubborn and/or aggressive. Sometimes, family members do not feel like supporting the patient anymore because it can be emotionally and physically overwhelming. This also happens when family members feel like nothing is working out and that the BD patient's condition is not improving. FFT can help family members manage situations like these where they might feel 'burned out'. Therapists work with each member to educate them about the disorder and how to leverage their individual relationships with the patient in a manner that best addresses everyone's needs.

Things get out of hand during mania. How do you manage the situation?

Mania is an aspect of BD that can be difficult to manage. A person experiencing mania may exhibit abnormally energetic behavior, a heightened mood, irrational decision making, and risky behaviors including substance abuse, spending sprees and risky sexual activity. Mania often lasts for a week or longer, depending on each individual. There are milder episodes of mania known as hypomania. Sometimes an individual will recognize when a manic period is about to set in, and other times this is not possible.

In order to best manage mania, it is imperative individuals work with their health care providers to identify 'triggers'. This can prevent the episode from getting out of hand. Alcohol and drugs can both contribute to manic episodes, and it is important to avoid these, especially if they have led to mania in the past. Identifying which medications are effective for you with your healthcare team is another way to manage mania. Furthermore, create a plan that you can fall back on should things get out of hand.

During an episode of mania, it is best not to agitate or argue with the individual, but rather work to keep them as safe as possible.

Remove any dangerous objects, limit access to funding by taking possession of their debit/credit cards and cheque books, and review safety plans if needed. Create a safe room or space for them where they can calm down.

Fill this room with activities that are soothing and eventually calm them down. If the situation is not resolving even after trying all possible solutions, seek professional care immediately. **In full blown mania, Hospitalisation might be necessary.** Consult the doctor for appropriate course of action.

How do you curb the individual's overspending during mania?

Overspending is often an indication of mania and can lead to hardship for entire families. It is extremely important that an individual experiencing mania, plan in advance for how to manage money. Caregivers can play a role in managing the expenditure here. Often, limiting access to money is a way to ensure that one doesn't over-spend. For example, keep enough cash to maintain your everyday lifestyle but don't keep extra cash readily available. Protect the rest in a safe with a secure password/lock. Sometimes giving control of your finances, or even just your credit cards, to a trusted friend is a helpful way to manage overspending during mania.

How do you control the individual if they get violent and abusive?

The risk of violent and abusive behaviors increases during episodes of mania. It would be ideal to watch out for warning signs that the episode is going to occur and address them before they get out of hand. It may also be advisable to help the patient stay off triggers / stressors that may increase the chances of patient feeling out of control. Educate everyone close to the patient on these warning signs and create a crisis plan with them for emergencies. Encourage them to avoid behaviors that can be triggering for the patient and keep substances such as alcohol and drugs away.

In case you may be unable to prevent the anger/violence, the first thing is to ensure potentially dangerous objects are kept away and any young children are taken away from the scene. Take the patient to a calming space and try and engage them with activities that soothe them and lessen the effects of the episode. Do not be afraid to ask for help in these steps. If the patient has been prescribed medication for these behaviors, give those as needed.

If you feel the patient has become too dangerous and no other solution is working, seek professional help immediately. In most cases, patients may need to be medically calmed to curb violent and abusive behaviors.

Always keep emergency numbers on hand.

What steps should you take if the patient becomes suicidal?

Communicating with the patient can be a key factor in preventing suicide. Ask the patient unhesitatingly if they are thinking about suicide. Be neutral and do not take a judgmental tone. This will make them feel more comfortable. Listen to them and be there for them. Keep them safe from places and objects (weapons, kitchen knives, razor blades, pills) that can assist them in suicide. If you are not with them, stay with them on the phone and try to get to them or get someone else there as soon as possible. Never feel alone with it and always ask for help. It might also help to create a safety plan early on with the patient. Inform medical providers and seek professional help immediately.

Always keep emergency hotlines and contacts on hand.

There are several organisations, crisis centers and suicide prevention helplines that are offering a great support to the emotionally distressed and those individuals who feel suicidal. Some of the helplines that may be approached in times of need are:

• The Samaritans Mumbai – 022 6464 3267, 022 6565 3267,

022 6565 3247

Email: samaritans.helpline@gmail.com Address – 402, Jasmine Apartments, Opposite Kala Kendra, Dadasaheb Phalke Road, Dadar (E) 400014 Mumbai

• MINDS Gujarat – +919033837227; info@mindsfoundation.org, Bhavnagar and Vadodara, Gujarat

- Sikkim 221152, Police Control Room, Gangtok
- iCall +91 22 2556 3291, e-mail icall@tiss.edu, Mumbai
- Thanal 0495 237 1100

E-mail – thanal.calicut@gmail.com

Address – Iqra Hospital, Malamparamba, Calicut 673009 Kerala

• Prathyasa - +91-480 - 2820091

Address – Vidya Jothi, Cathedral Junction Irinjalakuda 680 685

• Pratheeksha - +91 484 2448830

E-mail - rajiravi2000@hotmail.com

Address – Near Ambedkar Park, Peruvaram Road

North Paravur 683 513

Kerala

• Saath – 079 2630 5544, 079 2630 0222

Address – B12 Nilamber Complex, H.L. Commerce College Road Navrangpura

Ahmedabad 380 006

- Roshni 040 790 4646
- E-mail help@roshnihyd.org

Address – 1-8-303/48/21 Kalavathy Nivas, Sindhi Colony S.P. Road

Secunderabad 500003

• Lifeline Foundation – +91 33 24637401, +91 33 24637432 Address – 17/1A Alipore Road, Sarat Bose Road 700 027 Kolkata

• Sumaitri – 011-23389090

E-mail- feelingsuicidal@sumaitri.net Address – Sumaitri, Aradhana Hostel Complex

No. 1 Bhagwan Das Lane, Bhagwan Das Road New Delhi

• Maithri – 91- 484 – 2540530

E-mail – maithrihelp@gmail.com

Address – ICTA Shantigram, Changampuzha Nagar (P.O.)

Kalamassery

Kochi 682 033

• Connecting India – 9922001122, 18002094353

Website – connectingngo.org

Address – Connecting Trust

Dastur Girls School, Moledina Road

Pune 411001

• Nagpur Suicide Prevention Helpline – 8888817666

• Sneha - 91-44-2464 0050, 91-44-2464 0060

E-mail – help@snehaindia.org

Address – #11, Park View Road, R.A. Puram

Chennai 600028

• Maitreyi – +91-413-339999

Address – 255 Thyagumudali Street,

Pondicherry: 605001

BipolarIndia

Online and Offline Peer Support for Patients & Caregivers www.BipolarIndia.org, Mumbai.

Non-compliance (especially with medication) and denial is a major challenge.

What is the solution? Addressing medication adherence first requires identifying the major barriers leading to non-compliance. Some barriers include expensive medicines, difficulties getting to and from pharmacy/doctor to collect medicines, forgetting to take medicines, or even the patient not wanting to take medicines out of fear.

Once these barriers have been identified, caregivers should work with the patient and professional healthcare providers to devise appropriate solutions. Shared decision making is an evidencebased practice that can be used in relation to decisions around medications. In this practice, patients are made fully aware of their condition and the pros and cons of all the options available to them. Based on this, they can make informed decisions on their treatment, and collaboratively work with their healthcare provider to achieve their goals.

Involving the patient and doctor in a close relationship like this can ensure the provider can monitor medication adherence and understand what might be causing non-compliance. This is especially helpful if the reason for non-compliance is a mental barrier such as fear of taking medicine due to side effects. Therapists, caregivers and doctors can work with the patient to work through their mental barriers step by step.

Technology could be one method to encourage compliance with medication and treatment.

Some apps remind patients to take their medicines. One could also set a daily alarm on their phone to go off at the right time for medicine. Other methods include creating a schedule that accommodates taking medication alongside another activity the patient does regularly. For example, the patient can take the medicine at breakfast, which they eat every day. Placing the medicine near breakfast preparation materials can remind the patient to take it. Another way to encourage compliance could be to place visual aids such as notes and signs around the house that remind the patient to eat the medicine or go for their treatment.

If travelling to get more medicines or for treatment is too expensive, patients could try and find alternatives to that medicine that are near where they live or work, or ask someone else to get the medicine for them. Taking a bulk amount of medicine might be useful as it will cover your medicine supply for a few weeks, or even months, at a time. If medicines themselves are expensive, it might be helpful to look into any government programs that subsidize their costs or talk to your doctor about cutting costs.

If the patients are incapable of reminding themselves to take the medicines, trusting someone else with the responsibility could be helpful. Having this person remind them to go, or even take them, for treatment sessions can greatly improve compliance to treatment.



One helpful tip is to use medicine dispensers: a small box with separate tiny compartments for morning, afternoon and evening doses. Some have slots for an entire week. This also helps in checking whether all doses have actually been taken by the patient or not.

How can you encourage the patient to be regular in his schedule during depressive episodes?

During a depressive episode, the BD patient might find it difficult to do something as simple as changing their clothes. As a caregiver, it is important to understand these challenges from the patient's perspective and encourage them to get back to their routine as much as possible.

1. Talk to them and remind them of their positive qualities. Patients tend to have lower self-esteem during depressive episodes and need the positive reinforcement.

2. Encourage them to talk and listen to them actively. Even if they are repetitive, it can be good for them to get things off their chest.

3. Help them create a schedule for daily activities and place it around the house so they are reminded to follow it. Including something as ordinary as taking a shower in this schedule will be helpful for them to establish a routine.

4. If possible, be with them and establish specific times for each activity. Go to sleep at the same time and wake up at the same time each day. Doing this consistently will help them create a routine and because you're doing it with them, they may be more encouraged to follow it.

5. Make their home environment as simple as possible as this will make it less stressful for them and make it easier for them to stick to a routine.

6. Offer to help them with chores and if possible, take them along. This will help normalize such activities and indirectly, help them be more regular in their schedule. 7. Take them out for other activities every now and then. It will help them break the monotony and could be fun. These activities could be watching a movie, exercising or even playing sports.
8. Give them self-help books and videos to engage with. These can be motivating and can help normalize their condition to them because they are not alone. Many such videos can be found on popular online platforms such as YouTube.

9. Remember that it will take them time and effort to do these activities, so be patient. They may not readily do any of these things and will need pushing. It is okay to be persistent as long as it is within reason and will not hurt them more.

10. Don't try to force logic on them. They may not understand it in the same way that you do.



What is the importance of coordinating with the psychiatrist during potential crisis situations?

Coordinating with an expert like a psychiatrist during potential crisis situations can help you manage the situation better. The psychiatrist can suggest solutions to the crisis and make it less stressful for you as a caregiver. It can also stop things from getting out of hand and can make it easier for you to manage potentially hazardous situations. It's important to make a crisis plan that involves the psychiatrist beforehand. If the patient is seeing a Therapist also, she could play a crucial role in coordinating with the Psychiatrist, pointing out red flags.

Medication dosage and change is an important aspect in the management of patients with BD which can be taken care by the psychiatrist most effectively.

Why should a caregiver accompany the individual to psychiatrist visits?

In some cases, it can be beneficial for the caregiver to accompany the patient to psychiatrist visits. Sometimes it may be a requirement. Nevertheless, it is a way to show support for and understanding of the patient's situation, which can help them in their treatment compliance. Patients, especially young children, have to necessarily have a parent or caregiver come which also helps them feel at ease. For patients who might be unable to speak for themselves for given reasons, a caregiver can step in and explain everything to the psychiatrist. Even something as simple as helping an older patient walk to the psychiatrist's office can do a lot to improve treatment outcomes.

The presence of a caregiver also ensures that medication may be bought in the right amount. Caregivers can also help be support in case of any emergency situation that arise at the OPD. An added advantage of having the caregiver come along is to give a accurate history, follow up and progress in the patient's state of well being in case the ability is compromised in certain circumstances. However, it is important to note that not all patients may want someone around during such visits. They may perceive it as a threat to their independence or may not feel comfortable opening up in the caregiver's presence, even if they are familiar. It is crucial to talk to the patient about their preferences and then take appropriate steps.

Remember

1. Often, caregivers have to take time off work to fulfill caring obligations, or they might also not be able to work full time at all. This could lead to economic hardship and the caregiver not feeling that their professional self is fulfilled. As a caregiver, give yourself time to acknowledge this and seek help if it becomes too unbearable for you.

2. Always have a crisis plan and familiarize yourself and everyone close to the patient with it. This is crucial in case you notice the patient is contemplating suicide.

3. Remember that every patient is different. BPAD is a spectrum and does not manifest in the same way for everyone, even if trends between patients are similar. Work in the way that best suits the patient's individual needs.

4. Forgive yourself, keep going and look after yourself!



MAJOR DEPRESSIVE DISORDER (MDD) OR DEPRESSION



DEPRESSION MANAGEMENT

1. What is MDD and what is its prevalence in India?

Major Depressive Disorder (MDD) or Depression, is a mental illness in which a person experiences persistent depression. According to National Mental Health Survey of India 2015-16, MDD had a lifetime prevalence of 5.3 percent in India.

2. What are the different ways in which it affects an individual?

Individuals with Depression primarily lose their ability to take pleasure in even the smallest of things. In addition to this low mood or depression, a person with MDD may experience loss of energy and appetite. People with MDD may also experience weight loss, changes in sleep, and a decrease in mental and physical activity. They may face difficulties concentrating and have recurrent thoughts of death and/or suicide.

3. How does MDD manifest in children and adults?

Children with MDD exhibit a lack of interest in activities they used to enjoy in the past. This is usually accompanied with increased negative feelings and other symptoms such as tiredness, insomnia and lack of appetite. They might want to miss school and other activities more often. They also may not socialize as much. Like adults, children may exhibit the other regular signs of MDD that one can see in adults as well (Answer 2).

4. How do you look for early signs of MDD?

It is fairly normal to experience all the symptoms of MDD after facing loss and/or other struggles of everyday life. This does not necessarily mean you have MDD. When these symptoms overwhelm daily life, last for a long period of time and start having a physiological impact, it is possible to be diagnosed with MDD. Pay attention to how long these symptoms have persisted and how it may be affecting the person.

5. How do you take care of an patient with MDD?

Patience is key when it comes to looking after a person with MDD. Most often individuals with MDD try to hide their symptoms, which can make it difficult to respond to their needs. Be patient and educate yourself on the signs of MDD, particularly more subtle ones. Make sure to talk to the person and listen to them carefully, even if what they are saying makes no sense to you. They may not understand any logical arguments at the time and just need you to be available for them.

6. Other tips to help the patient recover from MDD

It can be very challenging for the patient to even get out of bed at times. However, encourage them to take up light exercises such as walking. This elevates mood and improves physical wellbeing also. Ensure that they have their meals on time. In consultation with the Doctor, the patient may consider taking up other activities such as Yoga, Art Therapy, Mindfulness Meditation, etc.

7. Ways to enhance home environment for better management of MDD

The best way to make the home environment welcoming for a patient with MDD is to ensure the people around are aware and sensitive to the patient's needs. Educate them on recognizing and responding to important signs and symptoms.

8. Dos and Don'ts for a caregiver

1. DO be patient. It takes time and effort for a patient with MDD to talk about their thoughts.

2. DO be observant. In most cases MDD symptoms are not easily visible and it takes awareness to notice and address them.

3. DO create a safe space for them. Ensure that people around them are aware of how to address the patient's needs.

4. DO tell them that you are there for them. Take them to the doctor if needed and be available.

5. DO give them space. Sometimes leaving them alone can be what they need to feel better, provided they are in a safe space.

6. DO keep potentially injurious objects away. This includes medication, knives, weapons and other sharp objects that can be used to self-harm.

7. DO take them to a professional if their condition is worsening or not improving.

8. DO take time out for yourself. Looking after yourself as a caregiver will ensure you can look after the patient properly as well. Whether it's taking walks or listening to music, do what makes you feel good. Take a break if you need it.

9. DON'T tell them to "get over it" or that their symptoms are "just a phase." There is much more to their illness so be sensitive when talking to them.

10. DON'T force logical arguments on the patient. They may not understand them the way you intend them to.

11. DON'T minimize their illness or symptoms. They feel them intensely and telling them their symptoms don't matter could make them feel worse.

12. DON'T stick to just one solution, even if it has worked before/for everyone else. If the solution is not working for you, adapt around it to suit the patient's needs.

13. DO ask for help if you need it! You are not alone. Seek professional help if you need it.

14. DO forgive yourself if things are going badly. It is no one's fault and there is always a solution.

9. How to take care of your (caregiver's) mental well being?

Looking after someone with MDD can be a rewarding experience but it is also mentally taxing. It is not uncommon for caregivers to experience 'caregiver burden', or stress associated with caregiving. Caregiver burden can lead to negative outcomes for the patient and you.

Take these steps to look after yourself as well:

1. Ensure you take a few moments everyday for yourself where you relax and give yourself space from the patient.

Make sure you eat, rest and address your other needs properly.
 Take time to think through and/or talk about your own feelings regarding caregiving.

Stay in touch with these feelings and take steps to work through them.

4. Seek professional help, or if not possible, support from friends and/or family to manage your own concerns and stress.

5. Take time to educate yourself about MDD and about myths and stigma that surround the illness.

6. If you feel like you are failing or not good enough as a caregiver, remember that you are human and it is okay to make mistakes. Forgive yourself and take steps to not make the mistake again, if possible.

10. Telltale signs that the patient is suicidal and what steps to take.

Telltale Signs:

- Talking about death, hurting themselves or committing suicide
- Feeling hopeless and/or worthless/like a burden
- Seeking out objects that could help them commit suicide (sleeping pills, poison)
- Behaving recklessly
- Stating things such as 'I am seeing you for the last time' or 'goodbye'

• Carrying out activities such as making wills or putting other affairs in order, possibly in preparation to die

Steps to Take:

Communicating with the patient can be a key factor in preventing suicide. Ask the patient clearly if they are thinking about suicide. Be neutral and do not take a judgmental tone. This will make

them feel more comfortable. Listen to them and be there for them. Keep them safe from places and objects (weapons, pills) that can assist them in suicide. If you are not with them, stay with them on the phone and try to get to them or get someone else there as soon as possible. Never feel alone with it and always ask for help. It might also help to create a safety plan early on with the patient. Inform medical providers and seek professional help immediately. Always keep emergency hotlines and contacts on hand. (Helpline nos. shared in previous section)

11. Some facts to remember

1. Often, caregivers have to take time off work to fulfill caring obligations, or they might also not be able to work full time at all. This could lead to economic hardship and the caregiver not feeling that their professional self is fulfilled. As a caregiver, give yourself time to acknowledge this and seek help if it becomes too unbearable for you.

2. Always have a crisis plan and familiarize yourself and everyone close to the patient with it. This is crucial in case you notice the patient is contemplating suicide.

3. Remember that every patient is different. MDD is a spectrum and does not manifest in the same way for everyone, even if trends between patients are similar. Work in the way that best suits the patient's individual needs.

4. Forgive yourself and look after yourself!

You are not alone.

Helplines that may be approached in times of need are:

• The Samaritans Mumbai –

022 6464 3267, 022 6565 3267, 022 6565 3247

Email: samaritans.helpline@gmail.com, Mumbai

• MINDS Gujarat – +919033837227; info@mindsfoundation.org, Bhavnagar and Vadodara, Gujarat

- Sikkim 221152, Police Control Room, Gangtok
- iCall +91 22 2556 3291, e-mail icall@tiss.edu, Mumbai
- Thanal 0495 237 1100
- E-mail thanal.calicut@gmail.com, Calicut, Kerala
- Prathyasa +91-480 2820091

Irinjalakuda

• Pratheeksha - +91 484 2448830

E-mail – rajiravi2000@hotmail.com, North Paravur, Kerala

• Saath - 079 2630 5544, 079 2630 0222

Ahmedabad

- Roshni 040 790 4646
- E-mail help@roshnihyd.org, Secunderabad
- Lifeline Foundation +91 33 24637401, +91 33 24637432 Kolkata
- Sumaitri 011-23389090
- E-mail- feelingsuicidal@sumaitri.net, New Delhi
- Maithri 91- 484 2540530

E-mail – maithrihelp@gmail.com, Kochi 682 033

• Connecting India – 9922001122, 18002094353

Website - connectingngo.org, Pune 411001

- Nagpur Suicide Prevention Helpline 8888817666
- Sneha 91-44-2464 0050, 91-44-2464 0060
- E-mail help@snehaindia.org, Chennai
- Maitreyi +91-413-339999

Pondicherry