

About Illness

This section will cover some basic information about schizophrenia and how to support your family member suffering from schizophrenia.

What is Schizophrenia?

Schizophrenia is a disorder that affects how a person thinks, feels, and behaves. It manifests usually in late adolescence or early adulthood.

Myths & misconceptions

Schizophrenia is one of the poorly understood illnesses in our society. There are various myths associated with it. Evidence gathered from studies and real narratives indicate that the following myths (though prevalent) are not true.

Myth 1:

Schizophrenia is a rare condition.

Fact:

Schizophrenia is not a rare condition. The lifetime risk of developing schizophrenia is widely accepted to be around 1 in 100. People living with schizophrenia prefer not to talk about it due to the stigma attached. This makes the illness seem rare or non-existent.



Myth 2:

There is no treatment for schizophrenia.

Fact:

There are many effective treatments available for Schizophrenia. Long-term treatment may be required (as required in the case of many other chronic physical illnesses such as diabetes, blood pressure), but when treated properly, many people with schizophrenia are able to enjoy fulfilling and productive lives.



Myth 3:

Patients with schizophrenia cannot lead a healthy and fruitful life.

Fact:

Treatment, if started early, can lead to decrease in symptoms and improvement in functioning of patients with schizophrenia. There are interventions that that can help the person lead a more productive life.

The above myths and misconceptions are baseless. It is important that we challenge these wrong perceptions. You should talk openly with the doctor about any query or concern you may have. This will help you get factual and scientific information.



What are the symptoms of schizophrenia?

The common symptoms of schizophrenia, as experienced by most people, can be divided into three categories:

1. Positive symptoms
2. Negative symptoms
3. Cognitive symptoms

A person may experience symptoms only from any one of these categories or some symptoms from all of these categories.

1. Positive Symptoms



Hallucination: Person perceives things that don't actually exist in reality. These may include seeing things, hearing voices, or smelling things that others around them can't see, hear or smell.

Delusions: These are false beliefs that don't change even when the person who holds them is presented with new/ contradicting ideas or facts.

People who have positive symptoms often also face other problems like confused thinking, difficulty in concentrating or the sense that their thoughts are blocked.

Tip: Both hallucinations and delusions are symptoms of the illness and continued medication helps in alleviation of these symptoms.

2. Negative Symptoms



Negative Symptoms are associated with disturbance and disruption in the normal emotions and behaviour of a person. You may observe that the patient:

- doesn't feel any interest in his/her day to day activities.
- is not reacting to any good/ bad event like other people do or as they used to before the onset of illness.
- is speaking little or not at all .
- seems to have a reduced ability to start or carry out even most basic activities (like brushing teeth, eating meals on time, getting up etc.)
- is not interacting with other people or is interacting very little sporadically.

●**Tip:**

You can help the patient in alleviation of negative symptoms by taking small and consistent steps with them, such as:

- Help the patient to prepare a schedule that involves doable and achievable activities of daily living.
- Integrate some pleasurable and social activities in their schedule.
- Appreciate their efforts (no matter how small or insignificant they might appear to you) taken in the direction of doing daily activities.

3. Cognitive Symptoms

Cognitive symptoms include trouble in focussing attention, poor ability to understand the information, difficulty in making decisions about seemingly simple issues and trouble in implementing the instructions.



Other Symptoms

- Changes in ordinary behaviour, like staying alone most of the time, getting irritated at small things etc.
- Changes in sleep pattern, such as staying awake late at night, preferring to spend most of the time in bed.
- Exhibiting peculiar behaviour, such as smiling without any reason, talking to oneself and mostly staying alone by oneself.
- Maintaining poor hygiene like not taking a bath or brushing your teeth.
- Having trouble in speaking clearly.
- Feeling anxious.

In case you are exhibiting any of these symptoms, please do not ignore the same and do speak with your doctor about it.

What are the causes of Schizophrenia?

There are numerous factors that lead to the development of schizophrenia in an individual:

1. Neurotransmitter Imbalance:

The brain is made up of nerve cells, called neurons, and chemicals, called neurotransmitters.

An imbalance of these neurotransmitters, especially, dopamine, is thought to cause the symptoms of schizophrenia.

The medications, used for the treatment of schizophrenia, try to restore the imbalance of neurotransmitters.



2. Genetics:

Scientists have known that sometimes schizophrenia runs in families. People who have a close relative with schizophrenia are more likely to develop the disorder than people who have no relatives with this illness.

Scientists believe that many different genes may increase the risk of developing schizophrenia, but no single gene causes the disorder by itself. It is not yet possible to use genetic information to predict who will or will not develop schizophrenia.

There are many people who have schizophrenia but don't have a family member with the disorder and conversely, many people with one or more family members with the disorder, do not develop it themselves.

3. Environmental Factors:

Scientists also believe that interactions between genes and certain aspects of the individual's environment are necessary for schizophrenia to develop. Such environmental factors can be: exposure to certain viruses, malnutrition before birth, problems during birth, psychosocial factors etc.

Their interaction differs from individual to individual and depends on one's unique biological make and psychosocial environment.



You may often wonder, “Why it happened to my family member?”

Numerous factors lead to the development of schizophrenia in an individual. These factors interact in multiple and complex ways, thus it is not possible to predict what exactly might have caused the illness. It is important to acknowledge that there is no one single factor to be held responsible for it.



How to tell others about the illness?

In life, you may encounter a situation where other people misunderstand the illness or have misconceptions about it. You can share the facts about the illness given here.

Don't feel ashamed of the illness, it can happen to anybody. A person with schizophrenia can lead a normal life with appropriate treatment and support.



What are the available treatments & therapies?

Good news is that we have many effective and proven treatments and therapies available for schizophrenia:

1. Pharmacological Treatment:

Antipsychotic medications are usually taken daily in pill form. Some antipsychotics are available in liquid form. Some antipsychotics are also available as injections that are administered once or twice a month. Few people have side-effects when they start taking medications, but most side-effects can be tackled with. Doctors and patients can work together to find the best medication or medication combination and the right dose.

2. Psychosocial Treatment:

This treatment involves the learning of specific psychological and social skills by the patient and his/her family members to address the everyday challenges of schizophrenia.

3. Other Treatments:

Certain biological treatments are available for patients whose symptoms do not respond to conventional treatment methods. One such treatment that has been found to be effective is electroconvulsive therapy (ECT).

The treatment plan of a patient is formulated on a case-to-case basis by a mental health professional after thorough assessment. For treatment to be successful, it is important to follow the treatment regimen diligently and go for regular follow-ups with the doctor.

How can I support my family member with schizophrenia??

Caring for and supporting a loved one with schizophrenia can be hard. It can be difficult to know how to respond to someone who may be exhibiting behaviour that appears bizarre, may be unresponsive to your requests and seems not ready to take initiative for anything.

Here are some things you can do to help your loved one:



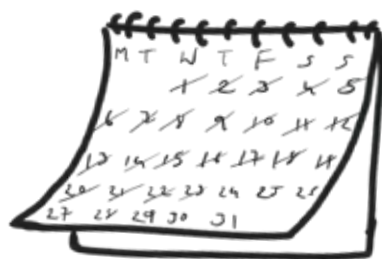
1. Ensure Treatment Adherence:

Encourage the patient to take the medication regularly. You can also assist them in taking the medicines on time by using simple reminder techniques, such as setting an alarm, maintaining a pills box etc.

If the family member experiences discomfort or side-effects with any form of treatment, it is essential to discuss about it with the treating doctor instead of stopping treatment abruptly. Abrupt stoppage of medication can lead to sudden exacerbations in symptoms, worsening the course and prognosis of the illness.

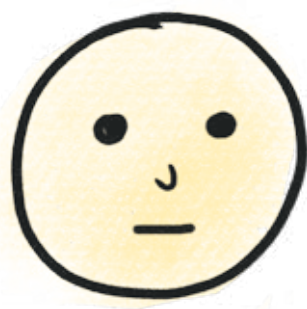
It serves many purposes. It helps in monitoring medicinal compliance and in adjusting the dose of medicines, if required. It also aids in the discussion of any issue.

Keep a written note of any important incident or an observation you might have. This will help you to remember the key issues that you want to discuss with the doctor.



2. Know the early signs of recurrence of symptoms:

Discuss the early warning signs of recurrence of symptoms with the treating psychiatrist. Develop a plan of action about what can be done as soon as you see the early signs of relapse.



3. Equip yourself with the core psychosocial skills

a. Communicating with the patient

Keep in mind the following simple principles while communicating with the patient:

- Talk in small, simple and direct sentences.
- Focus on one topic at a time.
Don't give more than one instruction at a time or talk about multiple topics at the same time.
- Remain consistent, with regards to your style of talking with the patient and your expectations from them.
- Don't use critical or intimidating language.
- Don't pressurize/ force the patient to do any activity.

- Remain supportive and appear attentive when you are with them.
- Use positive reinforcements or appreciate them, whenever possible.
- Don't shy away from expressing your disapproval of any unacceptable or dangerous behaviour, without using harsh and threatening language.

b. Problem solving skills

Situations can arise with the patient that may require your direct intervention like the patient may stop taking medicine, may not take care of hygiene or may not maintain their daily schedule etc. In such situations, problem solving technique can help.

Problem solving technique involves the following steps:

- Focus on the immediate problem behaviour.

- Describe the problem specifically and in a straightforward way.
For instance, instead of stating the problem as “You are not maintaining proper hygiene”, describe the exact problematic behaviour such as, “You are not bathing everyday” or “You haven’t brushed your teeth for 3 days”.
- Talk to the patient about the potential costs and benefits attached to changing this behaviour.
- Discuss with the patient about the possible course of action, based on the cost and benefit analysis.
- Talk about the possible ways you can assist them in following the course of action chosen by them.



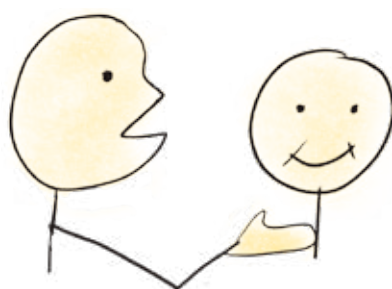
The problem solving skills are applicable in various situations. It is important that you start practicing these skills with the patient for problems that are concrete, current and in situations where the patient has the capacity/ ability to engage in an alternate behaviour or change their behaviour. Remember to use the communication techniques while problem solving with the patient.

4. Encourage self-care and independence

For people suffering from the symptoms of schizophrenia, things such as self care and personal hygiene can become difficult to maintain. Teaching or encouraging them to participate in basic household chores, such as laundry, cooking, and other ways to care of home and oneself, can help them build their self-esteem.

Tips:

- Make a list of daily activities that the patient needs to learn or perform, after consultation with him/ her.
- Together list the activities that the patient can do independently or those they might need assistance with.
- The patient can define each task as a personal goal.
- Break each task into smaller and achievable subtasks.
- Patient can learn new tasks by observing you first and then doing them with assistance from you till they feel confident of doing them independently.
- Reward and appreciate the achievements of personal goals and completion of activities.



- If the patient is unable to complete a particular task, it is important to understand the reasons for it and address the real problem (you can use the problem solving technique).
- Remain consistent in your communication, expectations and support to the patient.

5. Managing anxiety/ fear

Certain situations might invoke anxiety or fear in the patient.

In certain situations, you may find that the patient is unable to perform even simple tasks that they know very well. For instance, they may feel anxious in travelling by bus alone.

Talk to the patient about their fear and anxiety. Provide reassurance.

You can follow the following steps to help alleviate anxiety:

- Divide the task into small units of behaviour or sub - tasks. For instance, suppose the patient is feeling anxious to travel alone by metro to go see the doctor. Together with the patient, divide the task into specific steps that the patient will have to take in order to travel alone.
- Identify the least anxiety provoking task that they can do and start with it. For instance, the patient can start by going to the metro station during non-rush hours.
- Gradually, you can ask the patient to start performing the task independently or with minimal supervision. For instance, the patient may buy the ticket while you are standing a little away.
- Once the patient has mastered performing one task, then only move to another task.

- As the patient starts performing the activity independently, you can help him/ her in preparation for the activity. For instance, the patient can keep a route map or important phone numbers while travelling alone.

It is important that while you are helping your family member, you should neither be overinvolved nor totally absent from their life. Don't complete all tasks for them. You may assist them in completion of tasks. The purpose of assistance should be to help the patient become independent. While you are at it, remember that Rome wasn't built in a day!!



6. Taking care of Physical Health

Taking care of physical health is important for patients with schizophrenia and their family members. There are some steps that you can take to ensure that you and your family members are leading a healthy life.

a. Physical Health Monitoring:

- It is important that you get all the tests done after doctor's advise.
- Some of the medication for schizophrenia might lead to weight gain as a side effect. Weight gain can lead to other health problems in the future. It is important to get the weight checked periodically. If there is any rapid weight change you observe, please talk to the doctor in the next visit.
- Similarly, for all other tests, in case you observe variations in test findings, talk to the doctor in the next visit.

- In case of any health concern, talk to your doctor immediately.

b. Physical Activity

Patients with schizophrenia may not feel like doing much all day. This may be a part of the symptoms of the illness. However, this is not good for their physical well-being.

Patient should be encouraged to engage in some physical activity each day. The patient can decide what activity they would like to take up. It can be walking, running, playing a physical sport, exercising or yoga. Please refer to the module on 'Physical Activity' for more details.



7. Eating Right

Nutritious food taken at regular intervals is important for physical health and to avoid any health problems in the future. Please refer to the module on 'Eating Right' for more details.

8. Finding support for yourself

- Schizophrenia is a stigmatized illness. Not talking about it and not seeking help just increases the stigma and increases the feeling of isolation and loneliness.
- Involve the family member with schizophrenia in everyday family discussions. Don't exclude them from daily family activities.
- Ask them for their inputs in decision-making, whenever possible.
- Don't restrict yourself from social get togethers or having an active life beyond the care of your family member. Involve those you think can help.

- As a primary family member, you also have the responsibility to protect your member from critical and harsh comments of society. Challenge the misconceptions, whenever possible.
- Try to be part of social forums or support groups wherein you can meet other people like you.
- Find out support systems available to you within family or in community. Some people find talking to fellow caregivers quite helpful.

It may seem difficult to care for someone with schizophrenia. It may get easier to take care of them and yourself if you start integrating some of the above skills in everyday life.

