

Schizophrenia

Information for Patients & Caregivers

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Schizophrenia :

Patient / Family Education Material

The doctors have diagnosed you / your family member to be suffering from schizophrenia or a similar psychiatric illness. This write up will provide you with some details about schizophrenia. (If your doctor has given a different diagnosis but yet we have told you to read this, please go ahead and read further, as most of the issues will be applicable to your case too, as these are similar conditions).

Not all patients who have schizophrenia experience the same type of illness. This variation is similar to other medical problems like diabetes– the disease may be the same, but each individual patient may have a different experience: some may have very mild diabetes, which is controllable with diet and exercises; some others have to take different types of tablets and some have to take insulin injections daily. Similarly, different patients with schizophrenia or psychosis may have differences in terms of type of symptoms they have, the way they behave, their view about their own illness, their response to treatment, etc. This material is going to give you an overall idea about your / your relative's condition. Please feel free to ask us questions/doubts after you read this. Schizophrenia affects men and women almost equally. However, for the sake of simplicity, in this booklet we refer only to men. Note that most aspects are relevant for both men and women.

Symptoms of schizophrenia :

Frequently asked questions:

Does he have any illness?

What are the symptoms of the illness?

Why does he behave like this?

Schizophrenia is a medical illness. Just like how many medical illnesses affect the body, schizophrenia affects a person's brain and mind. Individuals with schizophrenia have varied symptoms. Commonly they talk / smile to themselves without obvious reason; they may not mix with others as they used to do previously; they get angry easily sometimes without obvious reason; not taking proper personal care (not taking bath, not brushing / changing clothes), talking about strange things, being suspicious, fearful without apparent reason, etc. Most often the patient will not realize that he is ill and will resist any attempt to help him.

It may be useful to understand symptoms under the following heads:

1. Positive symptoms: These include suspiciousness (others are trying to harm or talking about him etc.), talking strange things, hearing of voices which others are unable to hear, etc. These symptoms usually improve with medications.
2. Negative symptoms: These include not engaging in meaningful activities, not speaking much, not taking care of one's own routine / career etc. These symptoms improve only minimally with medicines. These symptoms will require efforts from patient, family and the treating team, such as motivating the patient to do daily activities, keeping him occupied in activities, etc.
3. Cognitive symptoms: These include not being able to concentrate, forgetting things, not getting thoughts, inability to decide, plan, etc. These symptoms can improve to some extent by extra efforts as mentioned above and may require special training to improve these symptoms.
4. Other symptoms: These are emotional problems like feeling tense, pounding heartbeat, worries about future, anxiety about doing things and interacting with others, feeling low, not enjoying things that he used to enjoy earlier, feeling worthless, under confident, etc. Some patients may express desire to die and may attempt suicide. Irregular sleep and eating habits are also common. Many patients with schizophrenia may also be addicted to tobacco, alcohol, etc. Medicines as well as counselling may be required for treating these symptoms. Your patient may have symptoms which may not be listed above. Feel free to ask your doctor about it.

Many patients with schizophrenia do not believe that they have any mental illness and may not appreciate the seriousness of their condition and the need for treatment. Because of this, they may refuse to take treatment.

Causes of schizophrenia :

Frequently asked questions:

Why did this illness Start?

Is it hereditary?

Is it caused by black magic?

Is it caused by tension? Or by studying too much?

About 4-5 in 1000 people between the ages 16 and 50 develop schizophrenia. The number of people who suffer from schizophrenia-like conditions is about the same

as those who suffer from epilepsy (fits), stroke (paralysis) or vitiligo. The cause for schizophrenia is not clearly known. In most patients it occurs because of multiple reasons, which may or may not be obvious to you.

1. Subtle changes in the brain: Schizophrenia seems to be caused by certain changes in patients' brains. These changes are subtle and involve some chemicals that nerve cells produce. These are called neurotransmitters (e.g. dopamine, serotonin, etc.). It is also believed that nerve cells are connected to one another in a different/improper manner in brains of individuals with schizophrenia. Because of these reasons, functions of different brain parts may become excessive or deficient. These changes result in changes in patients' behaviour. The changes in the brain are generally subtle - scanning or other tests may not be of any help in most cases to identify these changes.

2. Genes: Changes in the brain described above are largely due to problems in the genes of the patients. You may know that we are all born with a set of genes that we get from our parents. Each one of us is unique and different from others because we carry different combinations of genes. It is believed that some combination of genes may make a person vulnerable to develop schizophrenia (see below under "stress"). As a result, we observe that relatives of schizophrenia have more risk of developing schizophrenia. However, since many genes are involved and other factors are also important in causing schizophrenia, most individuals who have relatives with schizophrenia do not develop the illness. Similarly, many patients with schizophrenia may not have anyone else in the family with similar illness.

3. Subtle injuries to brain: Any minor injury to the brain before birth (e.g. malnutrition, infection or use of harmful medications during pregnancy), during birth or after birth may increase the risk of developing schizophrenia.

4. Stress: Different forms of stress including adverse social circumstances, personal problems (exams, relationship difficulties), family problems, financial and occupational difficulties etc., may lead to schizophrenia. You may observe that not all individuals who face stress develop schizophrenia; we also know that some patients with schizophrenia would not have faced any significant stress. It appears that whether a person develops schizophrenia due to stress depends on his set of genes: if he has certain set of genes, he may develop schizophrenia no matter how little stress he faces. On the other hand, some may face even a lot of stress without developing schizophrenia, as their genes may protect them against the adverse effects of stress. An example of a volcano may help you to understand this. The boiling lava represents stress and the plate of earth between the lava and the surface represents the genes. Some persons are born with a thin plate (risky genes) – even a

small amount of lava (stress) will result in volcanic eruption (schizophrenia). Some are born with very thick plates (protective genes) – there will be volcanic eruption (schizophrenia) only when the amount of lava (stress) is of grave nature.

5. Use of certain substances (e.g., amphetamines, cannabis, etc.) may also cause schizophrenia, again, in those who are genetically at risk of developing it.

These things don't cause Schizophrenia :

Black magic

Faulty food

Faulty parenting

Evil eye (Drishti /Nazar)

Treatment :

Frequently asked questions :

Is there any treatment which can cure this illness?

What are the types of treatment available?

How long the treatment should be given?

If he develops other medical problem what should be done about his psychiatric medicines?

There are two main forms of treatment for schizophrenia. Both are equally important:

1. Medicines and
2. Psychological, social and related interventions.

1. Medicines :

Medicines are an essential part of treatment of schizophrenia. Commonly used medications are: risperidone, olanzapine, quetiapine, haloperidol, fluphenazine, clozapine etc. As you would have read above, subtle chemical changes occur in the brains of persons with schizophrenia. Medications are given to minimize these changes. Medications will generally show their effect after a few days or weeks. Doctors generally start low doses of medications and depending on the benefit and side effects, adjust their dose. Doctors will make maximal efforts to avoid side effects, but despite this, you may expect a few side effects to occur.

Increase in sleep, tremors of hands, stiff feeling in the body, increased salivation and tiredness are common ones. Many patients experience weight gain and changes in the sugar and cholesterol levels in blood. The doctors may advise blood tests to detect these early. The side effects can be minimized after discussion with your doctor. Medicines like trihexyphenidyl, procyclidine, etc., may be given to treat some side effects. It is important to remember that side effects are generally more during the initial weeks of treatment and will gradually reduce when the dose of the medications are reduced.

Duration of treatment :

Generally treatment is continued for several months and may be years. This is because many patients experience relapse if medicines are stopped (see “What to expect in the future?”). The treatment should be continued with regular follow ups with your doctor. Commonly, patients and families stop medicines for a number of reasons including improvement in symptoms, side effects, patients’ refusal to take medicines, lack of knowledge about how long to take medications, etc. It is important to consult your doctor before stopping treatment. The doctors may decide to stop your medications depending on a number of factors, including your risk for relapse, impact that a possible relapse may have on your education/job/personal life, etc. You may discuss with your doctor regarding the option of stopping medications periodically, but it is important to note that a majority of patients with schizophrenia have risk of relapse if medications are stopped. In most cases, medications given for psychiatric illnesses may be continued even when the patient experiences other medical problems. However, you should show your doctor the medications that you are taking and check whether you should continue it and if so, whether at the same dose or not.

Many patients, who have experienced improvement with medications, report that they feel better after stopping medicines. This happens because when they stop medications, they stop experiencing side effects of the medicines like stiffness, sleepiness, tiredness, etc., and symptoms of schizophrenia do not reappear immediately after stopping medications. However, after a few weeks or months, the symptoms may restart and on some occasions, it may be difficult to treat a relapse. HENCE, CONSULT YOUR DOCTOR BEFORE STOPPING MEDICINES FOR WHATEVER REASON.

Generally, smoking, drinking alcohol and use of other drugs should be avoided by psychiatric patients, as they can affect illness and also reduce effect of medications. Even if patient takes these drugs, psychiatric medications should not be stopped.

MYTHS ABOUT MEDICATIONS: The Following are not true :
Psychiatric medicines are only sedatives. These medicines are addictive. These medicines damage kidneys/liver /eyes etc. These medicines are very powerful and will make the patient weak.

2. Psychological, social and other treatments :

Medications are essential for treating schizophrenia. However, they are not sufficient. Medications will yield optimal results only if a number of other measures are also adopted. This is similar to the case of other medical conditions like diabetes, hypertension, etc., where, other measures like regular exercise, diet and stress-free lifestyle are as important as medications. Many patients face problems like lack of motivation, difficulty in concentration, forgetfulness, etc. Moreover, the patients may have difficulties in interacting with people, controlling their emotions and may have family and social problems. These have been mentioned above as negative, cognitive and other symptoms. These may not improve with medicines alone. Patients with these challenges may benefit from regular counselling, training in improving concentration, memory, engaging in hobbies and productive occupation, etc. Individual and / or family counselling is available for dealing with these challenges. Psychologists, psychiatric social workers, psychiatric nurses and psychiatrists themselves can help patients and families in these difficulties.

The role of patients themselves, their family members, friends and relatives and of the society is as important as that of doctors/therapists in these measures. It has been observed that in developing countries like India, patients with schizophrenia have better outcome than patients in developed countries. One of the possible reasons can be the support and protection given by the families and the society to the patients. The love and care provided by the families, their role in supervising medications, their support in helping the patients in getting back to their education / work, etc., are crucial in their recovery. The table below shows some behaviours of the patients with schizophrenia and how the family should react to them.

These psychosocial measures are as important as medications for patients with schizophrenia: Patients and families should take active part in their recovery and should be prepared to provide extra time and efforts required for these interventions.

Challenging behaviours of patients with schizophrenia :

Behaviour	What do family members usually do?	Why does the patient behave like that?	Do's and Don'ts for family members
Talking to self	Getting angry and scolding the patient; ridiculing; arguing with him regarding his behaviour	Patient may be hearing voices when alone and replying to them.	Engage the patient in some activity if the patient is co-operative or ignore the behavior and report to the psychiatrist
Getting angry suddenly	Reacting angrily; arguing, beating, restraining, etc.	The patient may be reacting to some voices, or may be feeling unusually threatened	Do not react angrily or argue; do not challenge; avoid looking into his eyes as they may perceive it threatening. Ensure your and patient's safety and call for additional help if necessary
Being fearful/suspiciousness	Trying to reason out with the patient and getting angry / frustrated if he does not listen. Taking to faith-healers.	The patient may be having belief that actually someone is going to harm him or talking about him or knowing about him somehow	Don't try to argue emotionally and don't try to prove him wrong. Understand that for the patient, his belief is true. Reassure to the extent possible.
Talking strange things	Ridiculing / getting upset	The patient may be having strange experiences / beliefs	Acknowledge patient's experiences. Don't try to reason out / argue
Keeping quiet and not mingling with others	Criticizing, thinking that patient is just acting	The patient may be wary about meeting others because of fear / suspicion. He may have lost motivation or skills to socialize. He may be feeling depressed	Encourage him to socialize / talk to others but don't force. Encourage him to share their concerns and acknowledge the difficulties

Not studying / showing interest in work	Thinking that the patient is 'lazy' or 'acting'. Passing critical / sarcastic / angry remarks	The patient may have lost motivation to do things; he may have difficulty in performing tasks involving thinking / planning / concentrating	Encourage the patient to do simple, brief-lasting tasks. Try to form a time-table that is not too burdensome or boring. Appreciate even little efforts that he takes; ignore and not criticize if he does not follow your advice.
Not taking medications	Thinking that he is becoming stubborn and passing emotional or critical comments	The patient may not believe he has illness; may have side effects which he may not share with you; he may feel that taking medication makes people know that he is not well and may feel ashamed	Persuade the patient to take medications as per the doctor's advice. However, if he becomes too angry, do not pressurize or argue. Encourage him to talk to the doctor about his concerns regarding medications. If he does not want to speak to the doctor, then you talk to the doctor on your own.
Expressing wishes to die / talking about suicide	Many families take this seriously and seek doctors' help. Some may ignore such behaviours	He may be depressed or fearful or may be hearing voices that tell him to kill himself	Reassure the patient and try to instil hope. Keep a close watch. Consult doctors as early as possible

Please note : Patients do not willfully act differently, but they do so because of the disease.

Keep direct criticisms and arguments to the minimum or avoid them altogether. A warm and friendly attitude helps in all situations.

What to expect in the future?

Frequently asked questions:

Will this illness occur again?

Is it a lifelong illness?

Will he ever get alright?

Most individuals who develop schizophrenia improve substantially with treatment. Following improvement, the doctors start reducing the dose of medications very gradually. Only a few patients will be able to remain well if treatment is stopped (Figure-1). A majority of patients experience repeated relapses of the illness - most of them because they stop medications and a few even while taking medications. Though patients who experience relapse also improve after re-starting or adjusting the dosage of the medications, some of them may have incomplete improvement in between episodes (Figures-2 and 3). Each relapse may cause disruption in the patient's education / work / relationships; with each relapse the patient's confidence may go down and the family members may get frustrated. Hence, it is best to avoid relapses. The best method of avoiding relapse is to take medications as prescribed by the psychiatrists. Though schizophrenia is described by many as a severe mental disorder, it is only a small number of patients that do not recover from their first episode of illness despite treatment (Figure-4). Patients who do well with treatment have the features listed in the box (Prognosis box)

Outcome of the condition :**Patients who are likely to have good outcome:**

1. Starting of illness after 20-25 years of age
2. Early treatment
3. Less frequent relapses
4. Those with less negative/ cognitive symptoms
5. Good family and social support
6. Those who had good social relationships before becoming ill
7. Good response to treatment
8. Following regular treatment as advised by doctors
9. Having a job/work
10. Not using addictive

Figure 1:

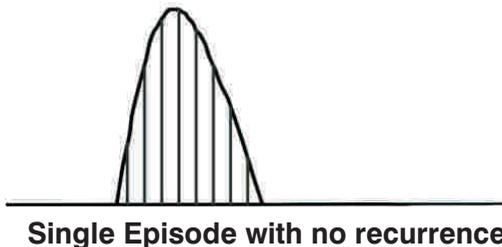
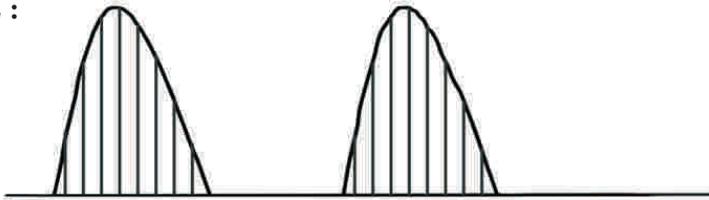
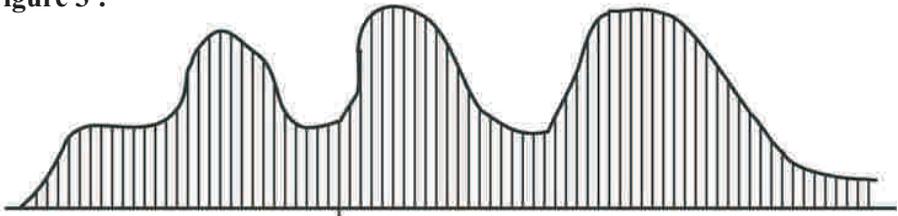


Figure 2 :



Episode course with complete improvement

Figure 3 :



Multiple episodes with incomplete recovery

Figure 4 :



Continuous illness with no recovery

Marriage and issues related to children :

Frequently asked questions :

Will the illness get cured after marriage?

Can he marry?

Can he/she have children?

Will his children have the same illness?

Marriage :

Many believe that marriage cures patient from psychiatric illness. It is not true. However, marriage of patients with schizophrenia is a complex issue and the decision regarding it should be taken after taking due consideration of the following issues:

1. The disorder as well as the medications given for its treatment may alter the sexual desire and performance in both men and women. Fortunately, in most cases, doctors will be able to address these issues. The ability to beget children is not seriously affected in these patients. However, women who are receiving medications should discuss regarding their plans for conception with their psychiatrists – as some medications will have to be avoided during early months of pregnancy, they may suggest alternative treatments. Moreover, as the doses of medications have to be adjusted through the pregnancy and delivery, they will have to be in constant consultation with their psychiatrists.

2. The patients and their families should carefully think whether the patient is in a proper condition to have a meaningful relationship with his spouse and the new family. As marriage could be stressful, especially in situations where the patient has to move to another family, there may be chances of relapse. The family should have reasonable confidence that the patient will be able to handle the stress. The other issue is the ability of the patient to lead independent life (financially).

3. A common question is whether the children of the patient will develop schizophrenia. As schizophrenia is caused partly by genetic risk, the risk for children of persons with schizophrenia is higher compared to children of those who do not have schizophrenia. The risk is estimated to be about 10% (about 10 times more). Seen from another perspective, there is about 90% chance that children of patients with schizophrenia do NOT develop schizophrenia. Unfortunately, it is difficult to predict whose child may develop schizophrenia.

All these issues are important considerations for the would-be spouse and his/her family too. It is imperative that both parties discuss about these issues before the marriage. However, commonly this does not happen and the families get patients with schizophrenia married without disclosing the illness. The consequences of such actions on the patient's illness and relationship are highly unpredictable.

Commonly, family members expect the doctors to decide whether the patient could get married. Please note that while it is important to discuss such issues with doctors, the final decision should be taken by the patient and the family members. The doctors will be willing to discuss different aspects of marriage, but will refrain from making decisions for the families

We have attempted to provide an overview of the condition that you / your relative have/has. You may have additional questions. We urge you to discuss with your doctors/therapists regarding any questions that you want to ask about your health.

Final words: Don't be hopeless about your / your relative's life just because you/he have/has this illness. A large number of patients with schizophrenia have been able to lead nearly normal lives with their own efforts, support from their families and healthcare professionals. Some of them have conquered their schizophrenia to even win the Nobel Prize!