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Schizophrenia: Information for Consumers, Families and Caregivers

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Summary: Schizophrenia is a severe, lifelong brain disorder that causes changes in your thoughts, perceptions, emotions and behaviours. It can make you hear or see things that others cannot see. It can make you have beliefs that others do not believe, such as feeling that others are out to harm you. It can be extremely stressful, because these symptoms can cause troubles with relationships, with work and school. The good news is that there is help and treatment that can help get things better again.

Introduction

Schizophrenia is a serious brain disorder that causes changes in a person's thoughts, perceptions, emotions and behaviours. It can make someone hear or see things that others cannot see. It can make someone feel unsafe, afraid, and lead to avoiding other people, and loss of function. Without proper treatment, it can cause serious problems with school, work and relationships. Fortunately, help is available for those with schizophrenia. In addition, there are many things that family and friends can do to support their loved ones with schizophrenia.

Do I Have Schizophrenia?

The following is a list of some symptoms of schizophrenia. If you (or a loved one) have these symptoms, speak with a doctor.

Do you ...

- Hear voices that others can't hear?
- See things that others can't see?
- Have extreme difficulties thinking clearly? Find that your thoughts appear jumbled?

What are the Symptoms of Schizophrenia?

There are three main types of symptoms in schizophrenia:

1. Active (or "positive symptoms"): unusual thoughts or perceptions, including hallucinations, delusions, thought disorder.

Hallucinations: Hearing voices is the most common type of hallucination in schizophrenia. Some people hear one voice, others hear many. These voices sound like a voice inside the person's head. The voice may make comments about the person, or be critical and say mean things. Or the voice may order the person around and tell them to do things. Other types of hallucinations include seeing people or objects that are not there.

Delusions: Delusions are strong personal beliefs that not commonly accepted by others. Types of delusions include:

- Delusions of reference: You feel that others are talking about you. For example, when you turn on the television, or read the newspaper, you feel that its about you.
- Delusions of persecution: You feel that others are out to harm you. Wherever you go, you may feel that people are spying on you, following you, and planning to harm you in some way.

2. Passive (or "Negative symptoms") symptoms are a loss of skills or abilities, such as having a loss or decrease in the ability to initiate plans, speak, express emotion, or find pleasure in everyday life. These symptoms are harder to recognize as part of the disorder and can be mistaken for laziness or depression. You may notice that its hard to think clearly.

3. Cognitive symptoms (or cognitive deficits) are problems with focusing, remembering, making decisions and solving problems.

How Common Is It?

Schizophrenia affects about 1% of the population.

What Causes Schizophrenia?

There is no one single cause for schizophrenia, however there are different factors which can increase a person's risk of getting schizophrenia:

- Family history: Being related to other family members with schizophrenia can increase a person's risk of getting schizophrenia.
- Drug use: Using certain types of drugs, such as marijuana, or alcohol can increase a risk of psychosis. In people at high risk (e.g. such as those with family members with schizophrenia or psychosis), it is safest to avoid stimulants (such as cocaine, amphetamines), marijuana or PCP ("angel dust").
- Stress: Having significant stress from school, work, home or relationships can increase one's risk.

How is Schizophrenia Treated?

Although there is no cure for schizophrenia, there are many treatments that can help significantly such as:

- Medications, and
- Psychosocial interventions such as counselling/therapy.

Treatment: Medications

Medications that treat psychosis (antipsychotic medications) are effective in reducing symptoms such as hallucinations and delusions.

The original antipsychotic medications include chlorpromazine (Thorazine®), haloperidol (Haldol®), perphenazine (Etrafon®, Trilafon®), and fluphenzine (Prolixin®). The older medications can cause movement side effects, such as rigidity, persistent muscle spasms, tremors, and restlessness.

In the 1990s, new drugs, called atypical antipsychotics, were developed that rarely produced these side effects. Examples include: risperidone (Risperdal®), olanzapine (Zyprexa®), quietiapine (Seroquel®), sertindole (Serdolect®), and ziprasidone (Geodon®).

Everyone responds differently to antipsychotic medication. Sometimes several different drugs must be tried before the right one is found.

When on a new medication, agitation and hallucinations usually improve within days and delusions usually improve within a few weeks. Many people see substantial improvement in both types of symptoms by the sixth week of

treatment. No one can tell beforehand exactly how a medication will affect a particular individual, and sometimes several medications must be tried before the right one is found.

If side effects occur, you can try waiting until they go away. When people first start to take atypical antipsychotics, they may become drowsy; experience dizziness when they change positions; have blurred vision; or develop a rapid heartbeat, menstrual problems, a sensitivity to the sun, or skin rashes. Many of these symptoms will go away after the first days of treatment, but people who are taking atypical antipsychotics should not drive until they adjust to their new medication.

How Long Do I Need to take medications?

Like diabetes or asthma, schizophrenia is a lifelong condition that needs constant attention. Although it cannot be cured, treatment can significantly improve the quality of your life. Most people with schizophrenia need to take some type of medication for the rest of their lives as well as receive other help, such as counselling/therapy.

Don't Stop Your Medication Without Speaking to Your Doctor

When you have schizophrenia, it is important to take your medication regularly, because by doing so, you will have less symptoms of psychosis.

Relapses (return of symptoms of psychosis) occur most often when people with schizophrenia stop taking their medication.

If you want to stop taking your medication, then speak with your doctor. Your doctor can help find other options.

Common Reasons that People Stop Taking Medications

Reasons Why You Might Feel Like Stopping Your Medication

- I'm feeling better and I don't need the medication. If you're feeling better, that's great because it means the medication is doing its job.
- Its hard to remember to take my medication. Ask the pharmacist at the drug store about ways to make it easier to take your medication. Common ways include:
    - You can get a special medication pillbox that has different days of the week
    - You can take your medications with meals
    - You can set reminders on your alarm or watch
- I don't like the way the medication makes me feel; I think I may be having side effects. The good news is that often side effects go away on their own over time. But if you are having side effects that are troubling you, its better to let your doctor (or pharmacist) know about it, rather than just stop your medication.

Treatment: Non-Medication and Psychosocial Treatments

In addition to medications, many other things are important:

- **Learning about how to manage schizophrenia.** It helps significantly when the person with schizophrenia, as well as family and close friends learn about how to support the person with schizophrenia.

  Key things include:
    - Basic facts about schizophrenia
    - Being aware of early warning signs of relapse, and knowing what to do if there are signs of relapse
    - Coping skills to deal with persistent symptoms

- **Getting help for any substance abuse**. Many people with schizophrenia end up with problems with drugs or alcohol Getting help for these problems is very important.

- **Work and vocational training**. Because schizophrenia often strikes at the critical years of 18-35, it may stop people from being able to finish their education or find a job. Special programs geared for those with schizophrenia can help with finding work.

- **Family Education.** Patients with schizophrenia are often discharged from the hospital into the care of their families, so it is important that family members know as much as possible about schizophrenia.

- **Counselling and therapy**. Mental health professionals (such as psychiatrists, psychologists, social workers, nurses or occupational therapists) can provide talk therapy.

- **Self-Help Groups.** Self-help groups for those with schizophrenia and families can provide a unique support that professionals cannot. Self-help groups are composed of people dealing with the same issues, and are a powerful way of getting mutual support from one another. It helps to know that you are not the only way dealing with an issue, and its helpful to be able to benefit from the knowledge of others going through the same thing. In addition, self-help groups in the long run can advocate and help change the system to better serve those with schizophrenia.

Self-Help for Schizophrenia

There are many things that friends, family and caregivers can do to help:

- **Emotional support**: Give emotional support to your loved one. Tell things such as "I want you to know that I'm here for you. How can I help you?" "Tell me what I can do to support you." When your loved one feels safe to turn to you, it makes it much more easier for you to make suggestions or advice for your loved one.

- **Helping your loved one get treatment.** If your loved one is not even wanting to get help, you may need to speak with doctors or others in order to learn how to find help.

- **Helping your loved one follow through with treatment.** Even if your loved one has professional help, it can still be hard to follow through with treatment. You can help by offering to accompany or take your loved one to doctor's appointments. If medications have been prescribed, then support the person in taking their medications. On the other hand, if you do not feel the medications are helpful, you can tell their doctor as well.

- **Validate feelings even if you can't validate delusions.** How should you respond when someone with schizophrenia makes statements that are strange or clearly false?

  Because these bizarre beliefs or hallucinations are real to the patient, it will not be useful to say they are wrong or imaginary. Going along with the delusions if you do not believe it will not be helpful, either. What you can do is you can validate how the delusions make your loved one feel, and support them with that. For example, if your loved one is feeling scared from feeling that they are being followed by the CIA, then you can validate how scary that must be, and offer your support. You may have to set limits as well on what you can and cannot do.

  You can calmly say that you see things differently than the patient does but that you acknowledge that everyone has the right to see things in his or her own way.

- **Don't invalidate your loved one.** Even if your loved one expresses viewpoints that you completely disagree with (e.g. delusions), don't laugh or tell the other person that s/he is 'stupid' or 'crazy', nor say 'Its all in your head', as this will make the other person less interested in confiding with you. You can validate that for them, their experience feels real, and it is upsetting.

- **Get support from people that your relative trusts.** If there is a particular person that your relative trusts (and if you trust that person as well!), enlist that person's help.

- **Reduce stress**. Psychosis is made worse if the person is under a lot of stress. Help the person identify what stresses they are under, and come up with a plan to deal with each one of them.

Ensure healthy lifestyle. Help your loved one with lifestyle interventions such as:

- Eating properly (e.g. three nutritious meals a day with healthy snacks)
- Getting enough sleep
- Get enough time outside with physical activity
- Avoiding street drugs or stimulants, or other drugs.

- **Keep things calm and avoid over stimulation.** Psychosis makes people sensitive to being overloaded. If there is too much going on (e.g. if too many people are around), help the person with psychosis to take a break by suggesting a quiet walk or having nap...

- **Have a schedule.** People with schizophrenia do best when they have structure in their lives, i.e. having a routine or schedule. Get a daily planner, scheduler or calendar. Write down in your schedule what daily activities you have, and at what times. Some people like to have a schedule made up well in advance. Other people may prefer a schedule made up a week before, or even just the day before.

- **Support systems are vital.** Especially when a person has schizophrenia, it is essential to have a good support network, which may include professionals, friends and family. Are there any other people that should be part of your loved one's support network? Contact them to get them involved.

- **Care for the caregiver.** If you are looking after someone with psychosis, make sure that you have someone to talk to who understands your experience, and that you take a break too! If you get burnt out, then who will look after your loved one?

In Case of Crisis: Tips for Families

When they are unwell, people with schizophrenia may resist treatment, believing that their delusions or hallucinations are real and psychiatric help is not required.

If it gets to the point that a crisis occurs, family and friends may need to take action to keep their loved one safe.

Although the exact laws may vary depending on where one lives, if a person is dangerous and unable to care for oneself due to mental illness, family/friends can contact a doctor (or police) to ask how to take a person to the hospital.

In the emergency room, a mental health professional will assess the patient and determine the best course of action. It may involve an admission to hospital, or other options.

A person who does not want treatment may hide strange behavior or ideas from a professional; therefore, family members and friends can ask to speak privately with the person conducting the patient's examination and explain what has been happening at home. The professional will then be able to question the patient and hear the patient's distorted thinking for themselves. Professionals must personally witness bizarre behavior and hear delusional thoughts before they can legally recommend commitment, and family and friends can give them the information they need to do so.

After the Crisis

Caregiving. Ensuring that people with schizophrenia continue to get treatment and take their medication after they leave the hospital is also important. If patients stop taking their medication or stop going for follow-up appointments, their psychotic symptoms will return. If these symptoms become severe, they may become unable to care for their own basic needs for food, clothing, and shelter; they may neglect personal hygiene; and they may end up on the street or in jail, where they rarely receive the kind of help they need.

Family and friends can also help patients set realistic goals and regain their ability to function in the world. Each step toward these goals should be small enough to be attainable, and the patient should pursue them in an atmosphere of support. People with a mental illness who are pressured and criticized usually regress and their symptoms worsen. Telling them what they are doing right is the best way to help them move forward.

Summary

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Sources

Adapted from the NIMH http://www.nimh.nih.gov/health/publications/schizophrenia/complete-publication.shtml

For More Information

The Centre for Addiction and Mental Health has information about various conditions, including Schizophrenia. Link: http://www.camh.net/About_Addiction_Mental_Health/Mental_Health_Information/Schizophrenia/index.html

About this Document

Written by the eMentalHealth Team.

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