

Skizofreni hos voksne, engelsk

### Information about SCHIZOPHRENIA IN ADULTS The disorder, its treatment and prevention



Psykiatri og Social psykinfomidt.dk

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**Approximately 30,000 people in Denmark suffer from schizophrenia.** Knowledge of schizophrenia is important if you or a relative have this disorder. The more the person knows, the better he or she will be able to cope with the disorder and avoid relapses.

**This brochure describes the disorder and the scope for its treatment.** It is mainly intended for individuals such as yourself being treated by the psychiatric service in Region Midtjylland, and for your relatives.

The psychiatric service in Region Midtjylland offers both outpatient and inpatient treatment.

We hope this brochure will help you and your relatives to learn more about your schizophrenia diagnosis.

Kind regards The psychiatric service in Region Midtjylland Tingvej 15, 8800 Viborg Tel. 7841 0000

# WHAT IS SCHIZOPHRENIA?

Schizophrenia is a serious mental disorder, known as a psychosis, characterised by changes in the way of perceiving oneself, others and the world. Typical signs of schizophrenia can be hearing voices or seeing things other people cannot see, or a changed perception of how the world works. Other signs can be having less energy, having difficulty taking the initiative, planning or carrying out everyday tasks.

Some people were sitting and talking, and then I sensed how the dog was picking up on what was being said. It understood a great deal of it. The dog was probably very clever. It was so annoying, because he read my thoughts and sent them back into my head again, but in such a laborious, distorted form, and this got mixed up with what I was trying to concentrate on, so it was really confusing. I'm sure it was just to annoy me.

> KASPER FUTTRUP, AGE 37 – HAS SCHIZOPHRENIA

In addition to signs such as these, the person may have periods of anxiety and depressive symptoms. The disorder can thus have the effect of making it difficult to maintain a normal life in terms of studying, working or family life.

Approximately 500 people in Denmark are diagnosed with schizophrenia each year. Schizophrenia occurs slightly more frequently in men than in women. This disorder affects people all over the world, in all cultures, all social strata and with basically the same frequency of incidence everywhere. The disorder often starts in early adulthood, and generally a little later for women than for men.

This disorder used to be shrouded in a lot of myths. Today, we know from research that schizophrenia is a disorder in the brain. The brain consists of billions of nerve cells that transmit signals to one another using different neurotransmitters. The nerve cells are organised into different pathways and use different neurotransmitters in order to be able to transmit an impulse from one cell to another. For example, if you burn your hand on the hob, the sensory nerves in your hand will register the pain. The sensory nerves use neurotransmitters to pass signals on to the brain to the effect that this hurts, and the signals are passed on to the part of the brain that controls the muscles in the hand so that the hand recoils from the hob by means of a reflex.

People with schizophrenia have disturbances in certain areas of the brain where the neurotransmitter dopamine is active, but there are other disturbances involved, too, which research is attempting to clarify.

#### Previously, many people believed that:

- the disorder was due to "a bad upbringing"
- schizophrenia was the parents' fault
- people with schizophrenia were either geniuses or unintelligent
- people with schizophrenia were dangerous, with criminal tendencies
- the disorder was chronic and could not be treated.

#### Today, research has shown that:

- the disorder is due to hereditary as well as environmental factors
- people with schizophrenia are just as intelligent as other people
- people with schizophrenia are no more criminal or violent than anyone else. In an acute phase of the disorder, however, they can become unsettled, aggressive and distressed, for example if they believe they are the victim of a plot and other people are trying to kill them
- schizophrenia can follow different pathways. Some people are ill for the long term, and others make a full recovery.
  - Having to explain how I feel to you would be like having to describe a painting to you. I'd be able to describe colours and shapes, but you would still never really be able to understand it.

SØREN – HAS SCHIZOPHRENIA

### WHY DO SOME PEOPLE BECOME SCHIZOPHRENIC?

There is no single explanation for why some people become schizophrenic. Schizophrenia is a disorder in the brain which can occur if someone is genetically (i.e. by heredity) predisposed to get it. Several genes are of significance in the disorder, and a person can be more susceptible or less susceptible to the disorder depending on how many of these genes he or she has. However, not everyone who has these genes gets the disorder. As a rule, it takes a certain amount of stress for the disorder to manifest itself. Today, schizophrenia is understood in terms of the stress–vulnerability model. In other words, some people are particularly susceptible to stress and can therefore develop the disorder if exposed to enough stress.

#### Heredity

There is a greater risk of developing schizophrenia if you are related to someone who suffers from this disorder. The risk is higher the more closely related you are.

#### Stress and pressures

The person is often exposed to some kind of stress before the disorder breaks out. Stress can be a lot of different things and is not just a matter of being too busy.

#### Stress and pressures can be:

- Biological
- Mental
- Social.

Biological stress could, for example, be difficulties in the foetal stage (the mother's diet is not sufficiently healthy or she gets a viral disorder, e.g. influenza), complications at birth such as oxygen deprivation during the birth or a brain infection in the early childhood years. Significant hormonal changes occur during the years of puberty, which may also be a triggering factor.

Mental stress could include having a boyfriend or girlfriend, breaking up with a boyfriend or girlfriend, a death, or other stress factors in the family.

Social stress can include both positive and negative events, such as sitting an important exam, starting a new job, becoming unemployed or leaving home.

Stress of this type is normal, and a person will only become ill if a particular vulnerability is also present.

### THE RISK OF BECOMING SCHIZOPHRENIC

In the general populace	. 1%
In a nephew/niece of a schizophrenic individual	. 3%
In a grandchild of a schizophrenic individual	4%
In siblings of a person with schizophrenia	<b>10%</b>
In children of a schizophrenic parent	13%
In a fraternal twin of an individual with schizophrenia	15%
In children of two schizophrenic parents	46%
In an identical twin of an individual with schizophrenia	50%

# WHAT ARE THE SYMPTOMS OF SCHIZOPHRENIA?

The symptoms and their development vary over time from one person to another. The disorder usually starts almost imperceptibly, but it can also be very acute initially. Some have had difficulties before, in childhood – e.q. difficulty with social skills. Before the disorder manifests itself. there is often a period of anything from months to years in which people with the disorder start to function less well at work and socially. They may isolate themselves, brood on existential questions. forget to look after themselves and lose interest in the things they usually enjoy. This period is called the **prodromal period**, and the actual disorder manifests itself after this.

# Symptoms of schizophrenia can be divided into several main categories:

- Psychotic symptoms (delusions and hallucinations)
- Negative symptoms (characteristics a person used to have, but which have been lost)
- Cognitive and linguistic disorders
- Other symptoms.

Psychotic symptoms are often called positive symptoms – not because they are good, but because they are new. In other words, the person's perception of reality does not conform to that of healthy individuals; a changed sense of reality is acquired. This may be expressed in hallucinations, delusions, linguistic and cognitive disorders, or catatonic states.

Hallucinations are when the brain incorrectly perceives a sensory impression that is not actually there.

# Hallucinations can occur in relation to all the senses:

- Hearing (e.g. hearing sounds or voices speaking to you)
- Taste (e.g. things taste rotten or of petrol)
- Sight (e.g. seeing people or things that are not really there)
- Smell (e.g. thinking you can smell poisonous gas, for instance)
- Touch (e.g. feeling as if someone or something is touching you).
- Krishna, which was a transparent light shaped like a human,
   plunged his hands into my
   carpet, and the carpet vanished
   where his hands reached down.
   There were demons swarming
   around me they were dark, and
   they had horns and tails.

KASPER FUTTRUP, AGE 37 - DESCRIBING ONE OF HIS VISUAL HALLUCINATIONS

### Perceptions regarding influence and control

Persons suffering from schizophrenia may experience that their thoughts are transmitted so that others can hear them, or that other people can transfer their thoughts to them. There can also be perceptions of having actions and thoughts imposed by other people, so the actions and thoughts are not the person's own – but those of others. These are particularly characteristic symptoms of this disorder, so they are known as first-rank symptoms.

 Catatonia. Catatonic states used to be more severe and occurred far more frequently than is the case today.
 Some people would remain frozen in distorted postures for a very long time or lie in bed motionless. Today, catatonic symptoms are more rare and more discreet. Schizophrenics may have small, eccentric movements, e.g. walking on tiptoe, patting themselves on the head in a particular way or keeping their eyebrows raised all the time.

Someone on the ward was lighting black candles everywhere. It had to be because she was doing voodoo, because candles are meant to be cosy, so you don't choose black ones. I was sure she had made a voodoo doll of me, and it was a terrible thought.

KASPER FUTTRUP, AGE 37 - DESCRIBING ONE OF HIS DELUSIONS. Delusions are ideas that make sense only to the person who experiences them. They are not shared by others, and cannot be corrected. The most common delusions are delusions about persecution, i.e. perceptions of being watched or pursued. For example, some people might feel that the CIA is pursuing them because they have some sought-after knowledge.

When I walked home in the dark in the evening, I could sense all the staring, evil looks behind all the darkened windows I passed.
I hurried as fast as I could. On the way home I alternated between a state of happiness and dread. In my happy state, I heard heavenly music quite clearly, and in the other state, I heard people arguing and cackling.

> KASPER FUTTRUP, AGE 37 – DESCRIBING ONE OF HIS AUDITORY HALLUCINATIONS

There can also be delusions of grandeur. Thus, someone is convinced that he/she is on a mission to save the world, or that the TV and radio are speaking directly to him/her with special messages. Some can also experience a delusion that their body has changed. Perhaps the person's head is about to fall off, organs are moving around the body, or the body is about to dissolve. The person might think he/she is suffering from serious ailments, and may believe he/she is a bad person who does not deserve to live. Many delusions are characterised by inverted logic, i.e. everything reinforces the delusion. Any experience which would dispel the delusion for other people will serve as evidence to the sick person that the delusion is a reality.

#### **Negative symptoms**

There are several different negative symptoms. The number of negative symptoms a schizophrenic experiences varies from person to person. It is important to remember that the negative symptoms are out of character for the person and are signs of the disorder. The person is still the same as he/she was before the disorder struck.

- Emotional blunting: A person can experience emotions becoming less "potent", e.g. it can become difficult to feel real joy, sorrow and anger.
- Loss of volition and passivity: There can be difficulties in taking the initiative and getting going with everyday tasks. Many schizophrenics find they have fewer interests and less energy; they may lose interest in their surroundings and other people, and have difficulty feeling excited.
- Impairment of contact: The person may have difficulty understanding and reading other people's intentions and aims.
- Isolation: The person may start to isolate himself/herself. Giving and receiving intimacy with other people can become difficult. For example, the

idea of giving someone a hug may be unpleasant or downright frightening.

Doubt/ambivalence: Conflicting thoughts and emotions may occur, inhibiting action. One moment, the person might want to go to the cinema - the next, the idea of going to the cinema will be appalling. Things can change so much all the time that it becomes impossible to make anything happen.

It is important to remember that these symptoms are not signs of laziness, but part of the disorder.

#### Cognitive and linguistic disorders

The way the person thinks and speaks may change, making it difficult for other people to follow the line of thought. Speech can become less expressive, with words and sentences that only mean something to the person himself/herself. For example, sentences can become long without having any specific content, and the person may begin to assign new meanings to words, or form neologisms. Speech can become so jumbled that other people simply cannot understand what is being said. The person may also take what other people say very literally. For example, if somebody says, "I'm dying of laughter!", the schizophrenic may understand that to mean that the person is actually dying. Many people who suffer from schizophrenia also find their thoughts are buzzing around in their heads and that it can be difficult to hold onto one individual thought. Others may find their thoughts suddenly come to a complete standstill.

#### Other symptoms

Basic symptoms are a number of nonspecific symptoms involving changes in perceptions of the world, other people or the self. The assurance we normally have in relation to who we are, who other people are and what the world is like may vanish. The person may be convinced that all other people are actors who are only out to deceive him/her, and that the world is false and merely a stage. He/she may also experience things changing colour or appearance, or a changed perception of time.

75–80% of people who suffer from schizophrenia have problems with:

- attention (maintaining concentration for an extended period, e.g. there could be problems with going to school. The person also becomes confused more easily)
- response time (performing everyday tasks takes longer)
- problem-solving (the person may have difficulty planning, implementing and keeping track of things like preparing food, travel and finances)

memory (e.g. the person may have problems learning new things, and may forget to keep appointments).

All these symptoms can make a lot of everyday things more difficult and can change a person's level of functioning, e.g. holding down a job or pursuing a study programme may become difficult; being around other people can be difficult, and some may have difficulty taking care of even basic needs such as food, sleep and hygiene.

Being affected by this disorder can lead some people with schizophrenia to entertain thoughts that it would be easier if they didn't exist, or even thoughts about wanting to take their own life. If thoughts of suicide emerge during the course of the disorder, it is important to seek help.

The symptoms and the course of the disorder for people affected by schizophrenia can vary greatly from person to person. Many different symptoms can occur individually or in various combinations. The symptoms can be mild, almost insignificant or severe and disabling.

# **PROGRESSION OF THE DISORDER**

The actual progression of the disorder can be divided into three phases: First, the **acute phase** which is often characterised by anxiety, chaos and psychotic symptoms. Once treatment has started, it moves on to the second phase, the **stabilisation phase**, during which the person gradually gets better and the symptoms disappear. The person starts to recover some social functions, and starts to recognise that he/she has a disorder and must learn to live with it. The third phase is the **maintenance phase**, during which the person works on maintaining the good results achieved, and perhaps improves even further.

Unfortunately, some people experience relapses of the disorder. In a relapse, the person moves back into the acute phase. Most relapses occur because the person has stopped taking his/her medication, is exposed to significant stress or starts substance abuse. It is important to keep up the treatment and thus prevent more psychoses, because if the person has a relapse (becomes psychotic again), the treatment takes longer and there is a risk of not making a full recovery.

The term "recovery" is gaining more and more ground. It means recovering as a result of understanding the facts about the disorder. Eliminating all the symptoms is not necessarily a criterion of success; instead, it is a matter of learning some strategies to tackle the symptoms so they affect a person's everyday life as little as possible.

It is important to remember that quality of life and the person's level of functioning do not necessarily go hand in hand. It is possible to lead a fulfilling life even if the level of functioning is not as high as it was when the person was well.

After the disorder has manifested itself, many will reach a stable level after about five years of its progression. The intensity of the symptoms decreases with age.

## The likelihood of a mild progression increases if:

- the person functioned well socially before becoming ill
- the person acquires the disorder late in life
- the person gets prompt treatment once the disorder manifests itself.
- the onset of the disorder is very sudden
- the person is in an environment where the level of criticism is low
- the person lives in a developing country
- the person is a woman.

Researchers do not fully understand why this is so. It probably has something to do with this: the more skills you have acquired before you become ill, the easier it is to recover. And the less stress you have in your immediate environment, the better your chances of recovery.

### FACTS

Approximately 1 person in 100 will become schizophrenic at some point, and approximately 30,000 patients in Denmark have this diagnosis. Each year, between 7 and 15 people per 100,000 head of population will be diagnosed.

Although schizophrenia is a complex, severe disorder, it is important to remember that it can be treated. The sooner treatment starts, the better the progression, and the lower the risk of relapses.

#### Intensity of the disorder and time

Major demographic surveys have shown that some people with schizophrenia never enter the treatment system. Of those who have been in contact with the treatment system, it emerges that;

- A approximately 20% have a psychotic episode with schizophrenia and, over a period of time, make a full recovery
- C 30% will have several relapses and a diminishing level of functioning
- B approximately 30% have a few psychotic episodes and end up with slightly impaired functioning compared to people who are well
- D the last 20% will continue to be psychotic with a low level of functioning and will need some support.





# SCHIZOPHRENIA AND SUBSTANCE ABUSE

Out of all those diagnosed with schizophrenia, many also have a substance abuse problem. The substance abuse usually involves alcohol or marijuana. However, many take amphetamines, cocaine or similar substances too. Stimulants counteract the medicine used to treat schizophrenia, e.g. by boosting the effect of dopamine in the brain. Stimulants aggravate the psychosis, but at the same time, the abuse can feel like a relief and a way of forgetting that you are ill. Sometimes, the substance abuse environment is the only place where the person feels accepted, whatever his or her problems. Research has shown that a great many people who have psychotic symptoms during a marijuana trip subsequently develop schizophrenia. Substance abuse involving speed, cocaine, amphetamines and designer drugs can also trigger symptoms of schizophrenia.

# **HOW IS** SCHIZOPHRENIA DIAGNOSED?

Schizophrenia cannot (as yet) be diaqnosed by means of a brain scan or blood test. Currently, the diagnosis is made by means of a consultation with a psychiatric specialist or a psychologist with specialization in psychiatry. The diagnosis is often based on the person's symptoms of the disorder and on information the psychiatrist is given about the person's behaviour from family members and those closest to the person. The diagnosis is a tool that the psychiatrist uses to identify the hest treatment for the disorder. It is important to remember that the diagnosis is not the person, but a snapshot of the disorder that is present.

Before a person can be diagnosed as schizophrenic, possible physical causes of the symptoms – such as epilepsy or substance abuse – need to be ruled out. Therefore, if there have been previous episodes of convulsions or serious head traumas, then initial investigations will include an EEG test and/or an MRI scan of the head.

In order to make a schizophrenia diagnosis, the symptoms must have persisted for at least a month, and the diagnosis must be made by a specialist in psychiatry or a psychologist specialising in psychiatry. The composition of the various symptoms is highly significant, too, in making the diagnosis.

According to the World Health Organisation (WHO) International Classification of Diseases (ICD-10), which is used in Denmark to make psychiatric diagnoses, the following symptoms must be present in order for schizophrenia to be diagnosed:

- At least one first-rank symptom or persistent bizarre delusions
- At least two of the following:
   Hallucinations accompanied by
  - delusions
  - Cognitive and linguistic disorders
  - Catatonic behaviour
  - "Negative" symptoms which are not attributable to simultaneous depression.

The symptoms must have been present and prevalent for at least a month. These symptoms must not be the result of physical disease of the brain or substance abuse.

### FIRST-RANK SYMPTOMS ACCORDING TO ICD-10

- Delusional perceptions of the thoughts
- Third-person auditory hallucinations
- Delusions of control
- Delusional perceptions of the body
- Primary sensory delusions.

# WHAT TYPES OF SCHIZOPHRENIA ARE THERE?

There are various types of schizophrenia depending on which symptom is dominant:

- Paranoid schizophrenia, notably involving persecution delusions and also often auditory hallucinations.
- Disorganised (or hebephrenic) schizophrenia, where in particular there is a change in behaviour, with unpredictable mood swings, aimless and incongruous behaviour and/or incoherent speech.
- Catatonic schizophrenia, where movement disturbances predominate.

- Undifferentiated (mixed) schizophrenia, which exhibits characteristics from one or more of the above types, but not to the extent that any one of them is diagnosed.
- Simple schizophrenia, where psychotic symptoms are absent, but there is a gradual decline in the ability to cope with the demands of society, accompanied by a reduced level of functioning. This is a very difficult and debatable diagnosis because so many other factors may be involved.

# WHAT TREATMENT IS AVAILABLE FOR SCHIZOPHRENIA?

The sooner the person starts treatment, the better the progression will be. The treatment is designed to facilitate a progression of milder, fewer and shorter episodes of the disorder and hospitalisations.

### **OPUS** treatment

Everyone first diagnosed with schizophrenia in Region Midtjylland is offered two years of intensive treatment from an OPUS mental health team or a similar offer. An OPUS team is a multi-disciplinary team that uses a broad spectrum of types of treatment. The treatment will particularly focus on:

- establishing an assured contact with a designated therapist (relational treatment). If necessary, the therapist can be proactive, i.e. the therapist can get in touch or seek out the sick person if there are any signs of him/ her dropping out of treatment
- providing anti-psychotic medication
- providing education about the disorder and about preventing relapses (psychoeducation), both for the sick person and for relatives
- involving family members, if the sick person agrees, and possibly family therapy, which can be for the individual family or in multi-family therapy groups
- providing psychological treatment, especially cognitive therapy, either individually or in a group

- providing social training, where the person practises being around other people
- providing support to help the person get active/study/find work
- providing help to make contact with/ work with the municipality
- working with a support worker in the person's own home/sheltered housing placement (if necessary).

After the two years, treatment can continue with the district or local psychiatry service. The treatment will always take as its starting point the individual's problems and, at the same time, try to keep the big picture in mind. For if there are problems with very basic living conditions (such as accommodation and finances), it may be difficult or impossible to collaborate on pharmacological treatment and therapy.

### Medication

The purpose of medication is to mitigate or eliminate especially the psychotic symptoms as well as to quell anxiety, restlessness and aggression. The type of medication used to treat schizophrenia is known as antipsychotics. Antipsychotic drugs inhibit the effect of dopamine. Antipsychotics particularly affect the psychotic symptoms, but with the help of activities and training, the person can learn to compensate for the cognitive problem areas and reduce the negative symptoms. There are different types of antipsychotics, and it varies from one person to another which drugs work best and also have the fewest side-effects. Therefore, it may sometimes be necessary to switch the medication from one drug to another in order to achieve the best possible effect while minimising side-effects. All medication can have side-effects, and the various drugs can have different ones. Fortunately, not everyone suffers adverse effects from the treatment, and when they do occur, they are of varying intensity.

#### **Possible side-effects:**

- Trembling or muscle stiffness
- Restlessness
- Weight gain
- Effect on blood lipids, e.g. raised cholesterol levels
- Effect on the white blood cells in the blood
- Effect on cardiac rhythm
- Increased saliva production, or dry mouth
- Sexual irregularities, e.g. reduced libido, difficulties getting an erection or climaxing
- Hormonal disturbances, e.g. changes in the menstrual cycle
- Allergic reactions.

#### **Check-ups for side-effects**

Side-effects must be constantly monitored, including by means of blood tests, checking weight, waist measurement, checking blood pressure and doctors' consultations to discuss the medication and side-effects. It can take weeks or months for the full effect of antipsychotic treatment to be felt. Conversely, some side-effects may be evident right from the start, but often diminish over time.

It is important to continue the medication agreed with the psychiatrist in order to avoid a relapse. Approximately 75% will have a relapse within a year if they stop medication, whereas the risk of a relapse is just 20% if they follow the treatment as agreed.

As a general rule, treatment needs to continue for one to two years after the first psychotic episode is over. If there have been multiple psychotic episodes, it is advisable to continue treatment for a minimum of five years after the psychotic symptoms have gone. Tapering off medication has to be done slowly and in consultation with the doctor.

In addition to treatment with antipsychotics, calming medication may also be needed at times if the person's condition deteriorates.

#### Education about schizophrenia

Teaching about mental disorders is also known as psychoeducation. Here, the sick person and his/her relatives are offered training in all relevant aspects to do with schizophrenia. Teaching often takes place in a group setting where the person and others who suffer from the same disorder learn the facts about symptoms, causes, treatment, social provision and early warning signs/prodromes. It is important to get the facts straight, because there are a lot of myths about schizophrenia. The teaching is designed to increase understanding of the person's own disorder and behaviour and to help create realistic expectations for the future.



#### **Psychological treatment**

Cognitive therapy is usually the basis of psychological treatment of schizophrenia. Efforts are made to identify problem areas and the thoughts and feelings associated with these. Once identified, these are worked on using new solution models and strategies.

One of the first things done in cognitive therapy is, together with the therapist, to prepare an emergency plan containing agreements on what to do if the person has a bad turn. Another aspect worked on is how to manage warning signs/ prodromes of relapses.

### EARLY WARNING SIGNS/ PRODOMES CAN INCLUDE

- Insomnia
- Irritability
- Tendency towards isolation
- Less contact with friends
- Restlessness
- Problems concentrating
- Racing thoughts
- Tension and nervousness
- Feeling of inferiority
- Lack of interest in things
- Feeling of being persecuted, that other people are talking about you, of being ridiculed, hearing voices or seeing visions
- Struggling to enjoy anything.

#### Social therapy and support options

Social therapy can include the involvement of the person's family, workplace, place of study and municipal caseworkers. It is necessary to clarify what support is needed, e.g. a support worker in the person's own home , mentoring scheme, etc. There may also be a need for help to cope with practical chores at home, help to gain an overview of finances and support for getting out and mixing with others, to the extent the person feels able.

#### Treatment for abuse

If substance abuse is involved, it is important to be informed about its effect on the disorder and also to look at the pros and cons of continuing substance abuse. Substance abuse can make treatment more difficult, and is bad for the health. Treatment for abuse will often be organised in conjunction with local authority alcohol or substance abuse treatment.

#### Hospitalisation

A patient suffering from schizophrenia is deemed to be mentally ill in the legal sense. Most schizophrenic patients have entered into a successful treatment process voluntarily, however. Enforced hospitalisation is only considered if there is a severe deterioration in the person's condition. The condition usually deteriorates because the patient stops taking necessary medication or due to substance abuse aggravating the psychosis.

The patient has certain rights when hospitalised. Further information is available in the brochure "Information about rights of adult mental health patients".

### What can be done to prevent schizophrenia?

It is important to prevent any relapse of the disorder – especially as research has shown that the more relapses a person has, the more difficult it is to recover. In many ways, prevention is about minimising stimuli and demands after a psychotic episode, reducing expectations, and meeting the person where he/she is at.

A key element in preventing relapses is to involve the family in the treatment. Armed with information and facts about the disorder, the family can help ensure tranquillity and stability in the person's life.

Involving the rest of the network is important, too. There might be other significant individuals in the sick person's circle, e.g. at the person's place of study or work. Demands on the person must be adjusted to take any relevant factors into account. For example, perhaps an application needs to be put in for a personal mentor to advise and offer guidance about professional and workrelated challenges.

# WHAT CAN YOU DO YOURSELF IF YOU ARE SUFFERING FROM SCHIZOPHRENIA?

#### Learn to recognise your disorder

It is important to learn about your symptoms and to learn about ways of dealing with them. All people who are diagnosed schizophrenics are offered education about the disorder.

#### Be aware of your warning signs

You can help prevent a relapse (another psychotic episode) yourself by being aware of the warning signs that occur. Your warning signs are personal – everybody's warning signs are different. The warning signs could be that, before the disorder worsens, you become more irritable, you isolate yourself more, you sleep less, become increasingly sad and have great difficulty concentrating. It may be overwhelming to have to think back to how you felt in the run-up to a phase of psychotic symptoms. It is therefore important for you and your therapist to work together on compiling an emergency plan. It is a good idea for you and close relatives to make a pact about who you should talk to if you become aware of warning signs. It is also important for your relatives to know what your personal warning signs are if you are in danger of having a relapse.

#### Produce an emergency plan

During the good times, if you can work with your therapist to write down the symptoms and warning signals that occur early in a period of deterioration, you will know when you need to see a doctor or get other help.

#### **Create flash cards**

Make a note of what works well for you when you are in a bad way. These cards can tell you what to do when you are in a difficult situation. For example, you could have a card that says: "When I am overwhelmed by voices, I must go for a walk or take my calming medicine." It is a good idea to carry your cards with you all the time. You might also be able to limit the voices if you are occupied by other activities, e.g. music, a bike ride or a telephone call.

#### **Comply with medication**

It is important for you to comply with medication for as long as your therapist recommends it. If you have any doubts or reservations about your medication, it is a good idea to talk to your therapist.

### Make sure you sleep well and eat healthy food

It is important that your circadian rhythm is as stable as possible, with regular sleep, and that you remember to take your meals. When you are ill, it can be difficult to get to grips with leading a healthy life, but it is important for you to receive support even for minor lifestyle changes, e.g. eating food slightly lower in fat, drinking a little less coke and going for a walk each day.

### Exercise and take part in other activities that interest you

This could help alleviate the sad thoughts and reduce the stress and unpleasantness.

#### Avoid excess alcohol

It can stop your treatment working and increase the risk of more symptoms. Consuming a lot of alcohol can cause liver damage in the long term.

### Include breaks and rest in your everyday routine.

It is a great idea to organise your routine so that there is room for breaks or for leisure activities and other positive experiences too.

### Set yourself realistic goals so the experience is a positive one

Take one step at a time and practise reducing your expectations and not taking on too much. Be aware of the small victories, e.g. that you have done the washing up. Give yourself time – be patient, even though it can be tough.

#### Practise directing your thoughts

Set yourself mental tasks at an appropriate level of difficulty. If you are unable to concentrate to read a book, perhaps you could manage to follow a film or do a Soduko puzzle.

### What could help reinforce a positive development?

- S Knowledge of the disorder
- Paying attention to prodomes/ warning signals (preparing an emergency plan)
- Complying with medication
- Sorting out basics like housing and finances
- Cognitive training and therapy
- A secure social network
- Involvement of family members and your network, who could potentially also help to look out for prodomes/ warning signals
- An appropriate level of activity (activities are necessary, because it is also possible to become stressed out by having nothing to do).

# WHAT CAN RELATIVES DO?

Being close to someone with schizophrenia can be very stressful. All the emotions come into play – anger, powerlessness and frustration with the sick person and the treatment system, which cannot always provide the help you think is needed.

It is dreadful to find that someone you really care about is utterly convinced that she is a princess, that the phones are tapped, and that the rest of us mean her harm. You feel so powerless.

> RELATIVEOF SOMEONE SUFFERING FROM SCHIZOPHRENIA

Involving relatives is an important part of the treatment so that they can help by supporting and encouraging the person affected by the disorder and perhaps also help to support the sick person in getting started with positive activities. The relatives must have realistic expectations and must help the sick person to identify achievable goals. It is important to find out about the disorder and to try to understand the changes that take place when a person becomes ill.

### What can you, as a relative, do for yourself?

- Familiarise yourself with the disorder; get the facts.
- Participate in educational programmes or seminars for relatives where you can share with other relatives of people who have the disorder known as schizophrenia.
- Avoid over-involvement. It is important to respect each another as independent individuals and to avoid encroaching on the other person's personal space.
- Accept that you do not always have the energy to provide as much help as might be needed – we all have a limit to what we can manage.
- Remember to look after yourself. Give yourself time and permission to find some places or activities where, as a relative, you can "recharge your batteries".

### What can you, as a relative, do to help the person suffering from schizophrenia?

Study what schizophrenia is. Get the facts about the disorder. The more you know, the better equipped you will be to offer the right kind of help.

- Be supportive of the treatment and the therapist. If there is anything you do not understand, ask. Perhaps attend one of the consultations with the therapist to find out what is being worked on.
- Leave some space; let go. After perhaps many years of you being the only one allowed by the sick person to help him or her, it can be difficult to summon up the courage to let go and rely on others to provide the right help. But it is important to "re-normalise" your relationship and hand over the helper's role to the therapist and other professionals. That will give both you and the sick person some space away from the disorder and its associated problems.
- Focus on the areas where you can make a difference, and accept that you cannot solve every problem. You cannot do everything. Help where you can, e.g. with some practical tasks, and accept that neither you nor anyone else can do a perfect job.
- Solve the problems step by step, with incremental changes. All major changes start with the first step. Tiny steps in the right direction are better than trying to make major changes that end up failing.
- Hold on to hope. Help the sick person to believe that he/she will get better.

- Avoid being reproachful. No one grows by being reproached for something that cannot be achieved.
- Lower your expectations. Rome was not built in a day! Change takes time, and patience is important.
- Keep a lookout for warning signs. Perhaps make a pact with the sick person that you will contact the therapist if symptoms of the disorder occur.
- Remember: Schizophrenia is nobody's fault! Self-reproach and reproaching others will not change anything. Instead, look ahead.
- Support the sick person. You must try to avoid demanding too much. Express your own attitudes and feelings instead of criticising. Remember, too, to praise and support the sick person for persisting with treatment.
- Many people with the disorder known as schizophrenia have little or no realisation that they are ill. During such periods, it is important not to try to convince the sick person of the opposite, but perhaps just to provide support in keeping in touch with the therapist.

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