

Skizofreni hos børn og unge, engelsk

*For parents and young people*

**Information about**

# SCHIZOPHRENIA IN CHILDREN AND YOUNG PEOPLE

The disorder, its treatment and prevention



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**Approximately 20,000 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 schizophrenia** and the scope for its treatment. It is mainly intended for young people being treated by the psychiatric service in Region Midtjylland and for the parents of children and young people who have been diagnosed with schizophrenia. The psychiatric service in Region Midtjylland offers both outpatient and inpatient treatment.

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

Kind regards

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# WHAT IS SCHIZOPHRENIA?

Schizophrenia is a serious mental disorder characterised by psychotic delusions; jumbled thoughts, emotions and senses; and impaired ability to take action. Psychosis is a perception or experience of reality not shared by others. Typical signs of schizophrenia can be hearing voices other people cannot hear, or seeing things other people cannot see. Other typical signs can be having less energy, having difficulty taking the initiative to meet up with friends, being unable to cope with planning and performing everyday tasks. Schizophrenia can entail passivity, anxiety and depression and can affect relationships with other people. Thus, this disorder can make it difficult for some children and young people to maintain a normal life at school, at work and in their leisure time.

“ **The voice might say: ‘You will die the next time you go home.**

**The sky will go dark, and you will be struck by lightning’.**

IDA, AGE 17

Approximately 500 people in Denmark are diagnosed with schizophrenia each year. Schizophrenia is found in young girls and boys and in adult women and men. This disorder affects people all over the world, in all cultures, all social strata and with basically the same

frequency of incidence everywhere. Schizophrenia usually occurs between the ages of 18 and 25, generally a little later in girls than in boys. However, approximately 5–6% are diagnosed with this before the age of 15. Youth psychiatry offers treatment to young people suffering from schizophrenia up to the age of 21. After that, they are referred to adult psychiatry for treatment.

## ABOUT SCHIZOPHRENIA

- It is estimated that approximately 20,000 patients in Denmark have been diagnosed with schizophrenia.
- Approximately 1 in 100 will suffer from schizophrenia at some time in their life.
- Approximately 1% of the Danish population has a schizophrenic disorder, or has had a psychotic episode.
- Equal numbers of men and women are diagnosed with schizophrenia.
- It often starts earlier in boys than in girls – approximately three years earlier.
- Schizophrenia appears to be most widespread in urban areas, perhaps because many schizophrenia sufferers seek the anonymity of the city.

The therapist can often trace symptoms of schizophrenia right back to age 2 or 3, but it is very rare for the disorder as such to start as early as that. Specialisation in hospitals in recent years (for example,

the establishment of psychosis teams such as OPUS) has improved early identification of children with this disorder.



# WHY DO SOME CHILDREN AND YOUNG PEOPLE BECOME SCHIZOPHRENIC?

There is no single explanation for why some children and young people become schizophrenic. Biological, psychological and social factors can pose a risk in terms of becoming schizophrenic. 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.

## Biological risk factors

A great deal of research is being done into exactly which gene or genes are responsible for the risk of schizophrenia.

Researchers' theories indicate that schizophrenia is linked to a large number of genes. Thus, it is possible to have a greater or lesser congenital susceptibility to the disorder. The more susceptible you are, the less it takes to trigger the disorder. A child or young person who is not genetically susceptible is at no greater risk of developing the disorder than anyone else. Researchers calculate that approximately 7% of the world's population have genes that imply increased susceptibility to schizophrenia. There is a greater risk of acquiring the disorder if someone in your immediate family has it.

## HEREDITY AND SCHIZOPHRENIA

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 .....	10%
In children of a schizophrenic parent .....	13%
In fraternal twins .....	15%
In children of two schizophrenic parents .....	46%
In identical twins .....	50%



Biological risk factors may also be determined by aspects such as whether during pregnancy the mother had any serious infections; had any physical ailments; suffered from malnutrition; was exposed to traumatic experiences; or had diabetes. The birth process may also be significant, if it was a very difficult birth.

### **Psychological factors**

A lot of things during childhood and development may pose a risk of developing schizophrenia – including crises. Crises are a natural part of the process of growing up and maturing. The effects of crises on a person depend on how the stress is handled and understood by the person and his/her relatives. Mental stress could include reaching puberty, having a boyfriend or girlfriend, breaking up with a boyfriend or girlfriend, a death, or other stress factors in the family.

### **Social factors**

A lot of different pressures can affect the well-being of children and young people. Some examples are the family moving house, and having to settle down in a new place with new friends and leisure activities. Studying can involve major expectations that are difficult to live up to. The person may be being bullied at school. Perhaps his/her parents are divorcing, and what used to be pleasant family time has been replaced by arguments and mistrust. Some people are victims of physical or psychological assaults during childhood or adolescence. Some children and young people encounter abusive environments, and in the worst-case scenario, abuse can lead to psychotic crises.

# WHAT ARE THE SYMPTOMS OF SCHIZOPHRENIA?

The symptoms and their development vary over time from one person to another. Some children and young people may find that the symptoms disappear so they can lead their lives in the same way as their peers. Others manage to lead a fulfilling life with medication; some become ill for a while on one or more occasions and have to be hospitalised, while some remain chronically ill and are affected by the disorder throughout their lives.

Symptoms of schizophrenia can be divided into several main categories:

- Positive symptoms (symptoms that were not previously present but occur).
- Negative symptoms (characteristics a person used to have, but which have been lost).
- Cognitive disruptions (changes in thinking, e.g. the extent of the ability to concentrate).
- Basic symptoms (change in the person's awareness of who he/she is, who others are and what the world is).

Positive symptoms are psychotic symptoms. In other words, the person's perception of reality does not conform to that of healthy individuals. The person acquires a changed sense of reality. This may be expressed in hallucinations, delusions, jumbled words and thoughts, or catatonic states.

A hallucination is when the brain incorrectly registers a sensory impression that is not actually there. Hallucinations can occur in relation to all the senses:

- Hearing (many young people state that the voices tell them to self-harm. The voices get louder and more insistent if they do not do what the voices tell them. Voices and sounds may be experienced through places other than the ears, and they may appear to be something that is happening outside the person).
- Taste (e.g. things taste rotten or taste of petrol).
- Sight (e.g. seeing people or things that are not really there).
- Smell (e.g. thinking you can smell poison gas, for instance).
- Touch (e.g. feeling as if someone or something is touching you).



I cannot lie down and sleep in a bed.

I feel I am falling through it – so in order to sleep, I lie on the floor.

RIKKE, AGE 15

**Delusions** are imaginings that make sense only to the person and are not shared by others, and that cannot be corrected. The most common delusions are paranoid delusions, i.e. the perception of being watched or pursued. For example, some people might feel that the CIA is pursuing them because they have some sought-after knowledge. There can be delusions of reference, where 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. Thus, it can be extremely difficult to dislodge delusions.

“ Sometimes I think I am living in a castle and being interviewed by lots of celebrities, or that I am taking part in a film. It is hard to get away from these perceptions.

ANNA, AGE 19

### **Jumbled words and thoughts**

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, he/she might start to assign new meanings to words, or create new words that do not exist. 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!", he/she may understand that to mean that the person is actually dying. Many young schizophrenics experience subjective jumbled thoughts. These jumbled thoughts affect the young person's ability to function in everyday life. Some describe having periods of completely blank thoughts, and perhaps also experience thoughts that do not feel like their own, but seem to be externally imposed, e.g. from aliens. Others describe other people being able to hear their thoughts, e.g. if they come too close, or if they look them in the eye.

“ Sometimes people can read my thoughts. So I have to think about cinnamon rolls.

MAJA, AGE 15

### **Catatonia**

Catatonic states used to be more severe and occurred 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 discreet – many may feel that their movements have slowed down, or that they have

become physically more restless. People suffering from schizophrenia may make 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.

### Negative symptoms

There are several different negative symptoms. The number of negative symptoms a person suffering from schizophrenia experiences varies from person to person. It is important to remember that the negative symptoms are out of character for the person and are a sign 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 “strong”, 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 people suffering from schizophrenia find they have fewer interests and less energy; they may lose interest in their surroundings and have difficulty getting motivated.
- **“Reading” other people:** 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 a sign of laziness, but part of the disorder.

### Cognitive disturbances

75–80% of children and young people suffering from schizophrenia have distinct disturbances in their cognitive functions. In other words, they may have problems with the following:

- **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 homework, study trips and finances).
- **Memory** (e.g. the person may have problems learning new things, and may forget to keep appointments).

Basic symptoms are a number of non-specific 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.

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 study programme or weekend job 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.

## PROGRESSION OF THE DISORDER

The onset of schizophrenia and its symptoms may be very rapid, i.e. over the course of a few months. However, the disorder can follow a longer progression, extending over many years with increasing discontentment socially, at work/school and personally, before it breaks out in earnest. This is known as the prodromal phase.

The actual progression of the disorder can be divided into three phases:

The first is the **acute phase**, which is characterised by anxiety, chaos and psychotic symptoms. Once treatment has started, it moves on to the second phase, the **stabilisation phase**, in 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**, in 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, the treatment takes longer and there is a risk of not making a full recovery.

The term "recovery" is gaining more and more ground. Recovery means healing 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 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.



# DIFFERENT DEGREES OF SCHIZOPHRENIA

The course of the disorder may be mild, or it may be severe and lifelong. The actual disorder phase starts with the first psychotic episode. Some young people may find their disorder is still developing while they are involved with youth psychiatry, and before they are involved with adult psychiatry. This makes it difficult to predict the course of the disorder.

Research shows that approximately 20% of those who have been diagnosed schizophrenic do not have any further psychoses. It may also be that minor symptoms persist to a degree that does not greatly affect everyday life. Approximately 30% have recurring psychotic symptoms, but are able to cope with everyday demands and obligations with the help of medication and treatment. A further 30% have multiple

psychotic episodes without being symptom-free in between. In the final 20%, the psychotic phase is constantly present, and the types of treatment currently available cannot improve their condition.

A person may well have a lot of psychotic symptoms and still be able to finish school or complete a youth study programme, or the converse may apply – someone with few symptoms may be unable to finish school or complete a youth study programme. It depends on factors such as the effect of the medication, and on how much the person's cognitive functions have been affected.

## Schizophrenia and substance abuse

Schizophrenia and substance abuse do not go well together. Stimulants counteract the medication used in the treatment of schizophrenia, and aggravate the psychosis. Young people often say they smoke marijuana, for example, to calm their thoughts. Many young people report that they had their first psychotic experiences in connection with substance abuse. Abuse of alcohol by children and young people is very seldom encountered in the context of youth psychiatry. Nevertheless, there is good reason to keep an eye on the consumption of alcohol, as it contributes to reducing inhibitions and augmenting emotions. Significant alcohol abuse simultaneous with taking medication may damage the liver, as the liver has to break down medicine and alcohol.

- 20% of people diagnosed schizophrenic do not have any further psychoses.
- 30% of people diagnosed schizophrenic have recurring psychotic symptoms.
- 30% have multiple psychotic episodes without being symptom-free in between.
- In 20%, the psychotic phase is constantly present.

## HOW IS SCHIZOPHRENIA DIAGNOSED?

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.

The diagnosis must be made by a doctor who is a psychiatry specialist, and the symptoms of the disorder must have been present for at least one month. The composition of the various symptoms is highly significant, too, in making the diagnosis.

The diagnosis is a tool that the therapist uses to identify the best treatment for the specific disorder. It is important to remember that the diagnosis is not the person, but a snapshot of the disorder that is present.

In Region Midtjylland, young people who are referred for diagnosis to the child and youth psychiatric section will be invited, together with their next of kin, usually parents, to appointments with two therapists either in the youth psychiatry outpatient clinic or with the specialist OPUS team. The young people will be asked about their symptoms based on a clinical-diagnostic interview guide. They will also personally describe how they experience their everyday life and the challenges it entails. The parents give their input by describing their child's development and growing up – from pregnancy through to the present.

It is not uncommon for a young person to be referred to the psychiatric service for diagnosis with the suspicion that the psychiatric disorder is something other than schizophrenia – e.g. depression, anxiety, OCD, substance abuse or an eating disorder. Looking back at the treatment initiated, it is sometimes possible to ascertain that it had limited effect because the background to the person's mental state was the emergence of schizophrenia and not symptoms of depression, for example. However, children and young people can certainly have multiple mental disorders at the same time.

“ When I go outside, I may experience that the gratings over the basement windows disappear.

Then I might have the sensation of falling down the hole. But when I blink my eyes, the gratings are in position.

NADIA, AGE 17

### What types of schizophrenia are there?

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

- **Paranoid schizophrenia**, involving notably persecution delusions, 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. This diagnosis is often used when young people are diagnosed schizophrenic. Over time, the symptoms may change and come to more closely resemble one of the other types.
- **Simple schizophrenia**, where positive 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?

Schizophrenia is a complex and serious disorder, but it is possible to get well again. The sooner treatment starts, the better the process, and the lower the risk of relapses.

Everyone first diagnosed with schizophrenia in Region Midtjylland is offered two years of intensive treatment from an OPUS mental health team. The treatment is designed to facilitate a course of milder, fewer and shorter episodes of the disorder and hospitalisations.

### Medication

Once the diagnosis has been made, the therapist often commences medication with anti-psychotic drugs. The medication is administered under the care of a doctor specialising in psychiatry. The purpose of medication is to mitigate or eliminate the positive symptoms as well as to quell anxiety, restlessness and aggression. The medication works by normalising the amounts of the neurotransmitters dopamine and serotonin in the brain. Research shows that these two neurotransmitters play a significant role in relation to schizophrenia.

The medication often helps to reduce the positive psychotic symptoms, but it is difficult to minimise the negative symptoms by means of medication. It must be emphasised that medication cannot help everyone, and for some people the medication may not have any effect on the disorder. It may be that an individual needs to try several different drugs before finding the one that produces the best results with as few side-effects as possible. This should be expected to take some time, as it often takes several months to determine whether the right medication has been selected.

All treatment involving medication can produce side-effects, but fortunately not everyone who is treated experiences side-effects. The various drugs can have different side-effects. These can intrude significantly on everyday life, e.g. if the person becomes very tired, extremely restless or agitated inside, or gains weight because the sensation of fullness has been suppressed.

### Check-ups for side-effects

Everyone being treated with anti-psychotic drugs must go for ongoing check-ups. Some side-effects are rare and are not immediately discernible, but they may become severe if not identified. Accordingly, all treatment involving medication is monitored by means of blood tests, checking weight, waist measurement, blood pressure and doctors' consultations to discuss the medication and side-effects.

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 1–2 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 5 years after the psychotic symptoms have gone. Tapering off medication has to be done slowly and in consultation with the doctor.

### Education about schizophrenia

Education about relevant matters to do with mental disorders is also known as psychoeducation. Teaching is often in a group setting where young people have an assigned therapist and 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.

### OPUS treatment provision

As previously mentioned, all young people suffering from schizophrenia in Region Midtjylland are provided with two years of treatment from OPUS. OPUS enables young people suffering from schizophrenia to meet other young people with the same diagnosis, but there will also be young people with schizotypy and schizoaffective psychosis. In OPUS, the young person is assigned a named therapist.

There is an opportunity to have a doctors' consultation when starting the OPUS process and subsequently as required.

Over the two years, the young person will be offered education about the disorder in the company of other young people. Parents and/or close relatives will be offered education in a group of other relatives. The family, the young person and the parents will be offered a 10-month course of treatment in a multi-family therapy group together with perhaps 6–8 other families.

Blood tests are taken every six months, and blood pressure, pulse, weight, height and waist measurements are recorded. The presence of psychotic symptoms will be assessed using rating scales. The young person will also undergo a psychological examination to shed light on his/her cognitive functioning level, which can be important in relation to schooling and studies.

There will often be networking meetings with the participation of social workers from the families' home municipalities, schools, school psychologists and "UU-vejledere" (youth education counsellors). The networking meetings can help ensure that the young person's needs for support are taken care of, e.g. in relation to a youth study programme. The group will also discuss the possibility of a sheltered housing placement if that offers the best support for the young person and the family.

If someone enters an acute psychotic phase, he/she may be admitted to a youth psychiatric ward. In Region Midtjylland, that would be in Herning or Risskov. For some young people this will be voluntary, but for others it may be enforced. The Danish Psychiatric Care Act (Psykiatriloven) makes provision for enforced hospitalisation if the person is deemed to be a danger to himself/herself or to others. People may also be admitted to hospital in connection with a change of medication.

### **Hospitalisation**

As mentioned, hospitalisation may be either voluntary or enforced. There are two levels of enforced admission: yellow or red. Yellow enforcement is often used by GPs when they think a young person is a danger to himself/herself. The parents then have one week to encourage the young person to seek voluntary hospitalisation. Red enforcement is often used if there has been a severe deterioration; with red enforcement, a doctor or the police make the decision to hospitalise the person.

The patient has certain rights when hospitalised. If the patient is under 15 years of age, the doctors and the parents cooperate to decide on the treatment (the Danish Act on Parental Responsibility). If the patient is over 15, the doctors can decide on the treatment (the Danish Psychiatric Care Act – Psykiatriloven). [Further information is available in the brochure "Information about rights of patients in child and youth psychiatry and their parents".](#)

## 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 young person where he/she is at. One of the key elements 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 young person's life. The family can learn about communication with the young person to avoid misunderstandings, and it will be easier to talk about difficult emotional issues. Parents may need to be helped with regard to not being so involved in the disorder, and with regard to how to deal with things their child expresses during a psychotic phase. Many parents are unsure about what to say to their child if he/she tells them about hearing voices or having visual hallucinations.

Involving the network is important, too. This applies to relatives and the school or college. Demands on the young person, e.g. from school, 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 challenges at school/college.

Many children and young people will benefit from having their day structured so that they can gradually fall in with some routines. The level of detail of structuring may vary depending on the needs of the young person. Knowledge provides reassurance, and it is reassuring to know what is supposed to be happening and when so that you can prepare. Another significant factor is to ensure there are also periods when the young person can relax and be alone. It takes a lot of energy for a young person suffering from schizophrenia to attend and be “in the zone” and on a par with others. Often, the young person resolutely resists showing the extent of his/her vulnerability – especially to family and friends.

Medication is also a preventive measure. As already mentioned, in Region Midtjylland, anti-psychotic medication is provided free of charge for the first two years. This is to ensure that the young person's finances will not be an obstacle to getting started on medication.

Living in sheltered housing for psychiatric care can also be a preventive measure. It can be a frightening thought for

many – parents and young people alike – because it raises questions about their mutual relationship. Both the young person and the parents can start to wonder if they have done something wrong. Sheltered housing can provide support for both parties when being together is too tough. The parents and the child may have a lot of ideas about blame and shame to do with the disorder, and this can be a problem if misplaced consideration comes into the equation. For

example, the young person might find living at home tough, but chooses not to say anything so as not to upset his/her parents, and vice versa. With sheltered housing, both the young person and the parents will be given advice and guidance about being together, and the young person will get help with rehabilitation of lost skills, as far as possible. Many sheltered housing solutions also offer schooling and everyday activities.

## 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 young 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, in the run-up to a psychotic episode, you become more irritable, you isolate yourself more, you sleep less, become increasingly sad and have great difficulty concentrating. It can be overwhelming to have to think back to how you felt just before a psychotic

episode occurred, but you and your therapist can fill in forms that describe symptoms. These forms may help you to realise what was happening before the psychotic episode.

It is a good idea for you and your parents and close relatives to make a pact about who you should talk to if you become aware of warning signs of a relapse. It is also important for your parents and relatives to know what your personal warning signs are if you are in danger of having a relapse. Some young people do not want their parents to be informed, and they do not wish their parents to know their symptoms. If that is the case, it is important for there to be other people you can trust.

**Make a note of what works well for you when you are in a bad way**

You can write down the things you do that work well for you when you are in a bad way. For example, that might be spending time with other people, being alone, going for a walk, playing games/computer games, knitting, or watching a film. Use flash cards, your calendar, mobile phone or perhaps your tablet/iPad so you can always carry these notes around with you.

**Comply with medication**

It is important 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 do not feel you can cope with very much, you might also find that you are more easily tempted to eat fast food, but it is important to have healthy eating habits.

**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 alongside medication will 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.

## WHAT CAN PARENTS AND OTHER RELATIVES DO?

Relatives are extremely important in the progression of treatment. There is scientific proof that the involvement of relatives is very significant in terms of the prognosis for the future, and it makes the course of the disorder easier.

It is important for relatives to take care of themselves above all. You cannot help others unless you are in a good state yourself.

There is no doubt that it is extremely challenging to be a parent of a sick child. Many emotions are involved, such as sorrow, uncertainty, frustration, anxiety and powerlessness. It may be difficult to stand on the sidelines and watch your child struggling, while some parents get the impression that they are not getting help or that help arrives very late. As a parent, you may well have other children to look after, and a job to hold down.

Parents can become so stressed that they develop depression or other stress-related symptoms. Parents and relatives can get help from their own GP, who can make a referral for psychological counselling via health insurance. They can also turn to associations of patients and relatives such as SIND and Bedre Psykiatri. These associations frequently run courses about specific disorders, and they usually offer advice.

If the young person consents, parents and relatives will often be able to obtain specific advice and guidance from the psychotherapist on how best to support the young person in everyday living. Joint counselling can be arranged to include the therapist, the young person and their relative(s).

It is important to remember that “relatives” includes brothers and sisters. There are various options available for siblings, e.g. via SIND and OPUS adult psychiatry. In youth psychiatry, brothers and sisters sometimes participate in psychoeducation, alongside their parents and perhaps grandparents, if they are old enough to receive and understand the same teaching as their parents. With the consent of the young schizophrenic, brothers and sisters may also be offered some counselling with the assigned therapist to clarify matters.

## WHAT CAN YOU, AS A PARENT, DO TO SUPPORT YOUR CHILD?

- **Study what schizophrenia is.** Get the facts about the disorder. The more you know, the better you will be able to help.
- **Support the treatment and the therapist.** If there is anything you do not understand, ask.
- **Leave some space; let go.** It can be difficult summoning up the courage to let go and rely on others being able to help your child properly. But it is important to “normalise” your relationship and hand over the helper’s role to the therapist and other professionals. That will give both you and your child 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, 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 your child to believe that he/she will get better.
- **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 your child that you will contact the therapist if symptoms of the disorder occur.
- **Remember: schizophrenia is nobody's fault!** Self-reproach and recrimination will not change anything. Instead, look ahead.
- **Support your child. Express your own attitudes and feelings instead of criticising.** Remember, too, to praise and support your child for persisting with treatment.
- Many people with the disorder known as schizophrenia have little or no realisation that they are ill. During these periods, it is important not to try to convince your child of the opposite, but to **provide support in keeping in touch with the therapist.**

## WHAT CAN YOU, AS A PARENT, 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 with the disorder known as schizophrenia.
- **Avoid over-involvement.** It is important to respect each another as independent individuals and to avoid encroaching on your child'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”.

## TEN USEFUL TIPS FOR RELATIVES

- Get the facts.
- Be mindful of your own reactions and emotions.
- Seek help.
- Learn to listen.
- Respect the young person's personal space.
- Be patient.
- Keep a grip on reality when the young person presents psychotic statements.
- Be clear.
- Be open about the disorder.
- Remember: there is more to life than the disorder.

#### About the quotations

All quotations are anonymous. The names are fictitious

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➤ [psykinfomidt.dk](https://psykinfomidt.dk)

Here you will also be able to find articles on  
psychiatric diagnoses in different languages

➤ [ungmedskizofreni.dk](https://ungmedskizofreni.dk)

➤ [psykiatrifonden.dk](https://psykiatrifonden.dk)

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