

For parents and other relatives

Information about

AUTISM IN CHILDREN AND YOUNG PEOPLE

Diagnosis, what can be done, and quality of life



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This brochure is intended mainly for parents of children or young people with autism receiving treatment in Region Midtjylland. Other relatives and professionals in the autistic person's network, e.g. social workers and educational staff, may also find this brochure a useful source of knowledge.

It covers how autism manifests itself in children and young people, treatment for autism, and what a parent can do to help the child.

We hope this brochure will help you to learn more about an autism diagnosis.

Yours faithfully
The psychiatric service in Region Midtjylland
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WHAT IS AUTISM?

Autism is a developmental disorder found in children, young people and adults. An autistic person has difficulty communicating and relating to other people in social contexts.

In addition, all autistic people have some degree or other of odd behaviour, odd movements and interests, rituals or patterns of behaviour.

Autism affects all aspects of development and is present for life. However, the way it is expressed in everyday life can be influenced and changed through development and learning.

Autism can look different depending on whether the autistic person is a young child, an older child, a young person or an adult. Autism can also look different in girls and boys.

Autism can be combined with other developmental disorders, e.g. ADHD or mental retardation.

How common is autism?

Studies show that autism occurs in approximately one per cent of the population. There are 35–55,000 autistic people in Denmark. The number of people diagnosed has risen sharply in recent years. Twenty years ago, the incidence of autism was one per mille, whereas today it is one per cent. Part of the explanation

AN AUTISTIC CHILD CAN HAVE MORE THAN ONE OF THESE TRAITS:

- difficulty having natural eye contact
- difficulty reading social signals
- difficulty with small talk
- difficulty understanding humour and irony
- odd movements, e.g. peculiar hand movements
- difficult for other people to read
- particularly sensitive to sound, taste, touch, etc.
- lacking in situational awareness
- taking things literally
- abiding by rules
- can be rigid and have difficulty being flexible
- lacking interest in playing with other children the same age
- playing their own way
- focusing on details instead of the big picture
- good at remembering details
- good at gathering knowledge about particular topics
- good at being immersed in odd interests



Passive



Aloof

THE FOUR TYPES
OF AUTISM



Odd-but-active



Stilted

for this increase is that professionals have become more adept at identifying children and young people with autism, so the diagnosis is made earlier. Another significant factor is that people with milder forms of autism are now also diagnosed.

Disability or developmental disorder?

Autism is designated in many different ways by different public systems – from a mental illness to a disability, a condition or a disorder.

This brochure describes autism as a developmental disorder, because development is disturbed compared to the normal development of a child. The developmental disorder is comprehensive, i.e. it affects all aspects of the child's development.

The degree of autism and the accompanying disorders of communication, social conduct, odd movements and interests can vary significantly from person to person. Today, researchers speak of an autism spectrum extending from normal development to autistic traits to various degrees of autism (mild – moderate – severe).

In other words, at one end of the scale there are gifted, highly-educated people with a job and a family. At the other end of the scale, there are people with mental retardation and severe autistic symptoms, in need of life-long intensive support and help.

This brochure uses the term “autism” as a general term for all types and degrees of disorder within the autism spectrum.

Four different types

English psychiatrist Lorna Wing, whose own daughter is autistic, categorises autistic people as four different types: Aloof, passive, active-but-odd and stilted.

- ❑ **The aloof type** is often illustrated as the child in a glass bell.
- ❑ **The passive type** typically remains outside social interaction and observes others without personally taking the initiative to join in, e.g. with a game.
- ❑ **The odd type** is the child who talks to everyone and asks questions, e.g. “When is your birthday?” or “What car do you drive?”.
- ❑ **The stilted type** is very rigid and inflexible. In playing with other children, the stilted child will typically be very controlling, abiding by rules and only accepting play in his/her own way.

With some children, parents or other people close to them quickly realise that the child is not developing like other children. However, other people have coped with school and only been diagnosed with autism as adolescents or adults, when social challenges become greater, e.g. starting a study programme, leaving home, getting a job or embarking on family life with children.

HOW CHILDREN AND YOUNG PEOPLE WITH AUTISM THINK AND UNDERSTAND

Children with autism exhibit three particular areas of different and impaired thinking and understanding:

❏ **The ability to understand and identify with other people's thoughts and feelings**

The child may have difficulty empathising with others. The child has difficulty putting himself/herself in the other person's shoes and imagining that other people think and feel differently from how he/she does.

❏ **The ability to understand meaning and context**

The child focuses on details rather than the big picture. For example, if the child observes a face, he/she might focus on one detail, e.g. a mouth that looks

surly, without noticing other details, e.g. a twinkle in the eyes. In this way, the child may misinterpret the overall facial expression (the big picture).

The child may also have difficulty generalising, i.e. transferring experiences from one situation to a new situation. For example, if he/she has been accustomed to shopping in one specific store, he/she may have difficulty understanding that it is possible to do the same thing (go shopping) in a different store.

❏ **The ability to gain an overview, plan, organise and be flexible**

The child often has difficulty gaining an overview of tasks and activities. The child may need a detailed plan of how to tackle a school assignment, for example.

HOW CHILDREN AND YOUNG PEOPLE WITH AUTISM LEARN

Children and young people with autism have a different way of learning compared to other children.

The normal driving force of development in children and young people includes social interests, doing what other people do, curiosity and independence. Children learn intuitively through experience and interaction with other people.

Children and young people with autism, on the other hand, do not learn intuitively and automatically in the same way as other people. Whereas other children are curious and interested in learning new things and acquiring new knowledge, children and young people with autism have a tendency to stick with particular

“ We persisted in treating her like a normal child, but we shouldn't have done that at all. She couldn't understand what we wanted of her. It was only after we got the diagnosis that we understood she is a different kind of child and needs to be treated differently. ”

HELENE AND SØREN, PARENTS OF ALBERTE, AGE 8, WHO IS AUTISTIC.

interests, patterns and ways of reacting. For that reason, they need planned, organised learning to help them through new areas of development.

Young autistic children

For example, in a young autistic child, it may be necessary to practise:

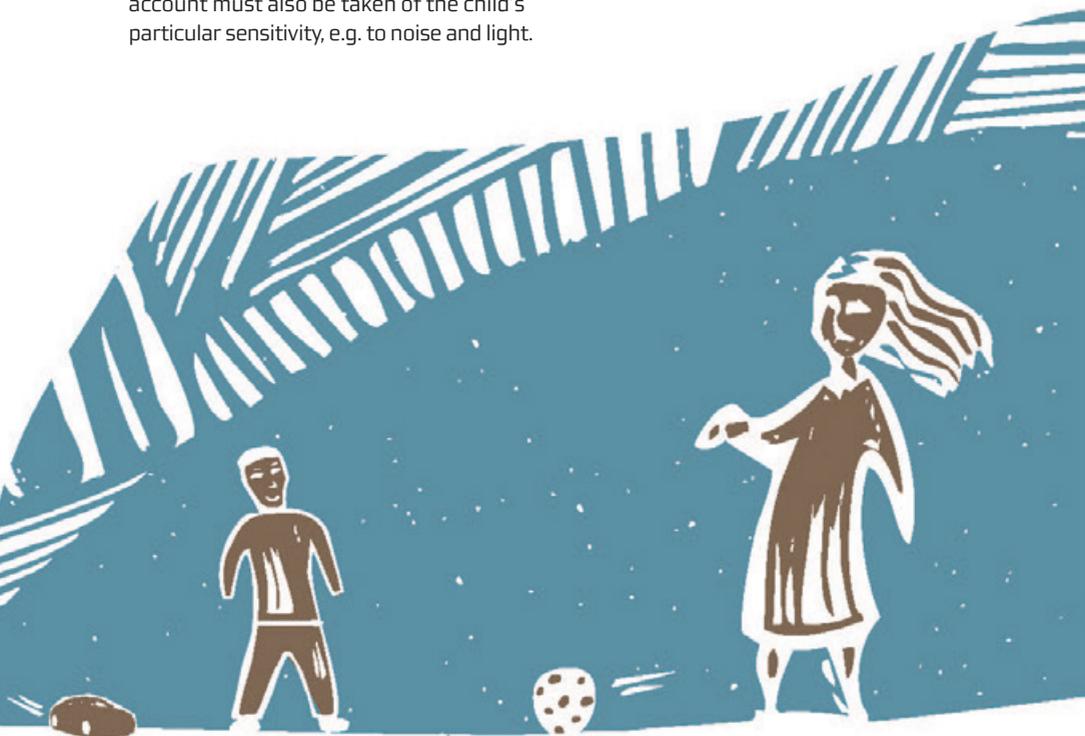
- Imitation – e.g. by copying a drawing or playing with dolls, where the child has to do the same as the adult.
- Exchanging and taking turns – e.g. taking turns to roll or kick a ball to each other, or running cars to each other.

Practising imitation, taking turns and exchanging are the starting point for enabling the child to learn from others and understand how to use language to communicate. Learning something new demands simplification, lots of repetition and peace and quiet around the child. Due account must also be taken of the child's particular sensitivity, e.g. to noise and light.

Older autistic children and young people

Older autistic children or young people still need planned, organised learning. Social education assistance is required in order to learn new things and develop in difficult new areas, e.g. romantic attachments, sexuality and personal insight. Unaided, the young person will not necessarily grasp the things that are important to understand and do in social situations with other young people.

Young children, older children and young people with autism need planned learning: tools and methods to provide personal insight, social skills and options for how to act in relation to other people. This can be accomplished through social skills training and by supporting appropriate conduct and behaviour patterns.



WHY DO SOME PEOPLE SUFFER FROM AUTISM?

Autism is a developmental disorder. This means the biological development of the brain in an autistic child is different from normal development. Today, we still do not know the precise cause of this developmental disorder. Research indicates an interaction of genetic factors and non-genetic risk factors, e.g. complications during pregnancy or childbirth.

Scientific studies of twins and families with an increased incidence of autism show that genes play a large part. A great deal of research is being conducted into genetic causes of autism. Today, a specific hereditary or genetic cause of autism can only be pinpointed in rare cases.

GENETIC TESTING

Your child will generally be referred for genetic testing if:

- ❑ a rare disease is suspected
- ❑ he/she is mentally retarded
- ❑ there is an unusually high incidence of autism in the family, e.g. if one or more siblings are autistic

As parents of an autistic child, you and your partner have an increased risk of approx. 3–10% of your next child developing autism.

HOW DO YOU TEST FOR AUTISM?

If it is suspected that your child may be autistic, he/she will be referred for child/adolescent psychiatric examination.

This is generally an outpatient examination, i.e. without hospitalisation. In special cases, however, it may be necessary to admit your son or daughter to hospital.

The examination will be done in cooperation with your child, you and your partner.

There will often also be cooperation with social educators and teachers from your child's educational institutions.

An interdisciplinary team will carry out the examination. The team consists of a child and adolescent psychiatrist, a psychologist and a social educator or nurse.

If you have a young child, a social educator or nurse will observe him/her at nursery or school. If your child is a bit older, the team

will have a chat with him/her. Part of the examination also involves a conversation with you and your partner. Your child will often also undergo a psychological examination and a medical examination by a child and adolescent psychiatrist, as well as autism-specific examinations.

If other child and adolescent psychiatric difficulties are suspected, those will also be investigated. Examinations carried out by other bodies, e.g. PPR (Pædagogisk Psykologisk Rådgivning – an educa-

tional and psychological counselling service for children up to the age of 18 and their families) or social services will also be included in the overall assessment.

Finally, the interdisciplinary team will compare all the findings and observations to ascertain whether your son/daughter is autistic and whether any other child psychiatric disorders are present. The team will also describe any help and support measures your child – and your whole family – may need.

HOW IS IT DIAGNOSED?

The International Classification of Diseases diagnostic system (ICD 10) is used in Denmark to diagnose autism. This describes autism as a pervasive developmental disorder. In order to be diagnosed as autistic, your child must exhibit permanent disorders in one or more of the three core areas. The combined symptoms must impair and restrict your child's everyday life.

His/her specific diagnosis of autism will depend on the severity of the symptoms and the age at which they manifest.

The age of a person at the time of being diagnosed with autism can vary greatly. This is because autistic difficulties have different degrees of severity and manifest at different times during childhood. Some people are only diagnosed as a young person or adult. Even if the person is only diagnosed as an adult, symptoms must have been present during childhood in order for this to be autism.

THE THREE CORE AREAS

- Impaired ability to understand and engage in social interaction
- Impaired capacity for social communication
- Odd behaviour, characterised by routines and/or repetitions which manifest in play, interests, activities and movements

“ Although it was hard when we got the diagnosis, it was a relief, too, to put words to William's difficulties. ”

LENE, MOTHER OF WILLIAM, AGE 10, WHO IS AUTISTIC.

TYPES OF AUTISM

There are different diagnoses on the autism spectrum:

Infantile autism

Infantile autism is the basic type of autism. Here, the child has more severe difficulties. For this diagnosis to be made, there must be signs of impaired development before age 3 and symptoms from all three core areas – impairment in reciprocal social interaction, communication, and odd patterns of behaviour.

Some children show symptoms as early as their first few months, when the infant's use of eye contact, social smile and "babbling" is impaired. In other words, the baby might not smile or babble back at mummy or daddy, even if there is eye contact and they are talking to the baby. In others, development appears normal up to 15–18 months, and the child only develops symptoms of autism after that.

There will often be other symptoms too. The child's sleeping and eating patterns may be disturbed, and he/she may perceive and register sensory impressions differently. The child may be anxious and unsettled, and some children lash out or self-harm. About 75 per cent of those with infantile autism are also mentally retarded to some degree.

Atypical autism

Atypical autism differs from infantile autism because the symptoms only

appear after the age of 3, and/or because the child only has symptoms from one or two of the three core areas.

The child's symptoms will often be just as obvious as with infantile autism. Children with atypical autism may also be mentally retarded.

Asperger's syndrome

Children and young people with Asperger's syndrome have difficulty with reciprocal social interaction and have odd patterns of behaviour; in some cases, this is manifested through an extreme interest in odd subjects, such as dinosaurs.

Unlike with infantile autism, linguistic and intellectual development in a child with Asperger's syndrome is normal. Everyone with Asperger's syndrome is of normal intelligence. Some have clumsy, awkward motor skills. Generally speaking, the autistic symptoms present in Asperger's syndrome are milder than is the case with infantile autism.

Pervasive developmental disorder, not otherwise specified (PDD-NOS)

This diagnosis is given to children and young people with autistic symptoms less severe than in the case of infantile autism, atypical autism and Asperger's syndrome. The child has difficulties in one or more of the three core areas of autism. Combined, the symptoms must impair the child's ability to function in everyday life.

DIFFERENCES BETWEEN BOYS AND GIRLS WITH AUTISM

There are more boys than girls with autism. The extent of this gender disparity varies depending on the autism diagnosis made, and whether the child is also mentally retarded.

GENDER BREAKDOWN

- Autism without mental retardation: 4 boys to 1 girl
- Autism with mental retardation: 2 boys to 1 girl

Not much research has been done into the reason for gender disparity. However, in recent years, there has been a stronger focus on girls and women with autism. Today, researchers attribute the difference in boys and girls to a lack of awareness about girls' and women's symptoms of autism possibly manifesting differently from boys' and men's.

Autistic girls

Autistic girls and women of normal intelligence are generally more adept than boys and men at developing strategies to manage their difficulties. That is why their symptoms of autism are initially not as obvious as boys' and men's.

Girls usually also have a more acceptable way of playing and their interests attract less attention, e.g. pets or riding. They observe and imitate social behaviour more. For example, they may imitate other people's ways of acting, points of view and personalities.

However, these girls also imitate behaviour without having a deeper understanding of the underlying mechanisms. As girls start to grow up, and there is more pressure to be able to interact with others, to be flexible and adapt to different situations, the consequences for these girls can be major. They might not be able to cope with social situations with their peers and may react with various symptoms, e.g. stress, anxiety, depression, eating disorders, etc.

AUTISM AND COMORBIDITIES

Children and young people with autism show a high incidence of other child psychiatry difficulties, developmental disorders and rare illnesses – a number of different conditions or illnesses. It is not uncommon for the child to have one or more of these conditions alongside autism.

If there are indications of there being anything else wrong with your child besides autism, it is important to establish which comorbidities are involved. This is important in order to enable the correct treatment to be given.

The comorbidities often make the child's difficulties more complex overall. For example, having ADHD can "eclipse" the symptoms of autism in some, making diagnosis more difficult.

People of normal ability with autism often experience anxiety, and their ability to function in everyday life can be greatly impaired. It is therefore important to treat the anxiety, too.

COMORBIDITIES

- 70–80% are estimated to have one comorbidity
- 25–40% are estimated to have two or more comorbidities
- **Developmental disorders:** Linguistic disorder, developmental disorder of motor skills, mental retardation
- **Mental disorders:** ADHD, anxiety, disturbed behaviour, depression, OCD, tics, psychosis, schizophrenia, eating disorder
- **Neurological and genetic disorders** e.g. epilepsy
- **Visual and aural problems**
- **Other conditions:** Problems with eating, sleeping and cleanliness. Problems in connection with sensing pain, temperature, sound, touch and taste

HOW TO TREAT AUTISM

The purpose of treatment is to promote development, well-being and quality of life for your child and your whole family. Treatment must always be based on the capabilities of the child and the family.

IMPORTANT ASPECTS OF THE THERAPY

- Treatment in the form of social education
- Psychoeducation
- Support and guidance for your whole family
- Medication to treat comorbidities

Treatment in the form of social education

As a rule, therapy for autism consists of treatment in the form of social education. The treatment is based on knowledge of autism and the special needs of children and young people with autism when it comes to support, learning and development. The treatment must be tailored to your child's capabilities and motivation to learn new things.

To develop self-perception and social skills in your son or daughter, the therapist can use a specially arranged counselling process. Here, the therapist and your

child talk together based on some specific images and stories. For example, this could be cartoon narratives or social stories – like a recipe for what will happen and how to act in a social situation. This could, for instance, be a story about going to the hairdresser's, or a story about what you can do if your little brother disrupts your play or takes your toys.

If you are the parent of an older child or young person with autism, you may find that some of this is done in group therapy. For example, there may be network groups and provision of activities and places for young people of the same age group to meet, where activities are combined with teaching in relevant subjects.

There are many different methods of treating autism. The methods that have proved effective have this in common: they deal with learning and cognitive behavioural therapy.

Psychoeducation

Education about mental disorders, developmental disorders and disabilities is also known as psychoeducation. This education is often offered to your son or daughter with autism and also to you as a parent, siblings and other relatives. It may take the form of parents' courses or parent training groups.

“ It has been lovely meeting other parents in the same situation who immediately understand how things are for you. ”

SARAH, MOTHER OF AHMED, AGE 6, WHO IS AUTISTIC.

The purpose of psychoeducation is to give everyone around your child a common understanding and shared knowledge of autism.

This is intended particularly for parents and any siblings, but is also relevant to other relatives and the family's network.

Grandparents often play a major role in family life with children. Armed with more knowledge and understanding, they will be better equipped to support the child and the family.

Psychoeducation can also help ensure quality of life and prevent psychological problems in the siblings of an autistic child.

PURPOSE OF PSYCHOEDUCATION:

Benefits to parents:

- Knowledge and understanding of autism
- Advice on how to support and help their child
- Less everyday stress
- Reduced feeling of inadequacy (many parents feel inadequate)
- Opportunity to share experiences with other parents

Benefits to the autistic child or young person:

- Personal insight and knowledge of the challenges of being autistic
- Ways of acting in everyday life
- Less everyday stress

Benefits to siblings:

- Knowledge and understanding of autism
- Opportunity to share experiences with other siblings

Benefits to grandparents:

- Knowledge and understanding of autism
- Advice on how to participate in the family and support the child in everyday life
- Opportunity to share experiences with other grandparents



AUTISM AND MEDICATION

- Autism cannot be treated with medication
- Comorbidities can often be treated with medication
- Autistic children often respond differently to medication than non-autistic children
- Autistic children and young people more often experience side-effects
- It is a good idea to increase doses slowly at first and to taper off medication gradually
- Treating a comorbidity with drugs is never a solution on its own

Support and guidance for the family

Usually provided by the municipality, e.g. a family advisor, autism consultant or social educator. In addition, your caseworker can also apply for special support, e.g. compensation for loss of earnings, relief or arranging for a nanny, etc.

It is also possible to seek guidance for problems that are particularly difficult to deal with from Denmark's national guidance pool, VISO.

Medication to treat comorbidities

Autism cannot be treated with medication. However, medication can often treat the comorbidities that many autistic children and young people have. ADHD or OCD are examples of comorbid mental health disorders. Epilepsy is an example of a comorbid physical illness. Many also take medication to treat disturbed sleep or disturbed behaviour.

Medication for other mental disorders

Comorbid mental health disorders (co-occurrence of psychiatric diagnoses) can include ADHD, OCD, anxiety, depression, Tourette's syndrome or psychosis, for example.

A specialist child and adolescent psychiatrist must initiate any medication for treating a comorbid mental health disorder. At first, the specialist will need to supervise and monitor treatment with medication. Later, your GP can maintain the treatment.

Medication to treat disturbed behaviour

Many autistic children and young people have difficulty regulating their emotions, their level of activity and their conduct in different situations. Some, however, will have particular difficulty with this. They will tend to react with aggression, restlessness and hyperactivity – some will also self-harm or exhibit rigid behaviour, repeating the same rituals.

If your child has this type of disturbed behaviour, he/she will often be offered medication. The medication may help your son/daughter to regulate his/her behaviour in cases where social education and behavioural therapy do not help enough.

ADHD AND AUTISM

Note that ADHD medication may be less effective in an autistic person who also has ADHD

Medication to treat disturbed sleep

Autistic children and young people often have a disturbed sleep rhythm. It takes longer than normal to fall asleep, and the child may wake up many times at night. This affects the child's and the parents' well-being.

Medication in the form of melatonin may help; if, good bedtime routines and trying a ball duvet or chain duvet (special duvets that "hug" your child to provide security) are not enough.

Melatonin is a naturally occurring, sleep-inducing hormone. Before melatonin treatment, your son or daughter's sleep must be recorded for at least 14 days.

Some children and young people only need to take melatonin for a brief period. Others have to take melatonin as required or more permanently. Side-effects are rare and mild.

Medication to combat physical illness

Autistic children and young people can be physically ill, too, requiring medical treatment, e.g. for epilepsy.

Other states of physical illness, such as pain, infections, etc., can manifest as sudden behavioural changes in autistic children and young people. They may react with anger, restlessness, tiredness, etc., because they may find it difficult to tell anyone about their symptoms, or because they are sensing and registering bodily signals differently from other people.

A physical illness or condition can be a particularly major challenge to severely autistic children and young people, especially if they are also mentally retarded.

Many people of normal ability with mild autism can react to physical symptoms and physical illness with anxiety and uncertainty. They will often have a particular need for a more specific, pacifying explanation.

WHAT CAN PARENTS DO?

As a parent, it is important for you to get used to the idea that your child is different and has special needs.

Autistic children need special support – including from their parents – in order to develop and become self-reliant.

It is important to ensure there is room for everyone in the family. There must be room for your autistic son or daughter and his/her special needs, but there must also be room for your other children's needs, your own needs and your partner's needs.

Being the parent of an autistic child is demanding. Accept help and support from your network. Perhaps the municipality could help meet your family's needs by providing some extra support and relief?

WHAT CAN YOU, AS PARENTS, DO?

- Find out about autism
- Participate in psychoeducation
- Ask if there is anything you do not understand
- It is important to partner with others. Accept help and relief
- Be particularly aware of the needs and reactions of siblings
- Develop social relationships with others. Several patient and relatives' associations organise groups for parents, Facebook groups, etc.



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WHERE CAN YOU FIND MORE INFORMATION ?

📄 psykinfomidt.dk

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

📄 Autismeforening.dk**📄 Socialstyrelsen.dk/viso**

A national Danish knowledge and special advisory organisation
on social affairs and special needs education

📄 dukh.dk

The independent disability consultant scheme

Scan the QR code to access more facts
about autism in children and young people,
useful links, videos, books, etc.





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