

Information about

AUTISM IN ADULTS

Diagnosis, what can be done, and quality of life



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This brochure is intended for autistic adults and their relatives who want to know and understand more about what it means to be autistic. The brochure is also intended for the person's network. In addition to relatives, the network also includes professionals such as social workers and educational staff.

The brochure includes facts about diagnosing and causes, for example, but it also provides knowledge about making sense of autism, and what relatives in particular need to be aware of as they try to support autistic adults in developing and enhancing their quality of life.

We hope this brochure will contribute knowledge and insight that may help lay the foundation for leading a fulfilling life with autism.

Kind regards

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WHAT IS AUTISM?

Autism is a disability found in both children and adults. Autism can occur in people with quite average intellect and in people who are developmentally retarded, and autistic people can have various functional skills and therefore also different needs for support in everyday life.

All types of autism have some behavioural similarities typical of autism. These similarities are known as the core areas of autism, and are outlined briefly below. The similarities apply to all autistic people – irrespective of their intellectual resources and other capabilities. In other words, the following applies to all autistic people to one degree or another:

- ❑ **mutual social interaction is a challenge.** This covers many different behaviours, but is often a matter of inappropriate/aberrant behaviour in interactions with other people.
- ❑ **mutual communication is a challenge.** This includes the use of and ability to apply and interpret all the tools we humans use to ensure that we understand one another, e.g. words, tone of voice, body language and facial expressions.

- ❑ **behavioural repertoire is limited.**

This includes having particular routines and activities, or particularly intense interests. Autistic people are concerned about the present moment, and what is directly visible, and they have difficulty imagining anything abstract or adapting to new conditions.

- ❑ **characterised by perceptual disorders.**

This includes an unusual way of perceiving sensory impressions (e.g. hearing, taste, sense of smell). This typically results in hypersensitivity or lack of sensitivity in relation to one or more of the senses.

Autistic people usually also have a number of positive common characteristics such as honesty, reliability, immersion (concentration), commitment, creative thinking and an enhanced ability to notice and remember details.

” **Eye contact is difficult to achieve successfully, because it is difficult to determine whether you are giving too much or too little eye contact for the person talking to you.**

MARC SEGAR – AUTHOR
WHO IS AUTISTIC

Autism is designated in many different ways by different public systems – from a mental illness to a disability or a condition. **This brochure describes autism as a disability** because on the one hand it represents a reduction in functional ability socially and in terms of communication and, on the other, because society and people around the autistic person generally represent barriers to the autistic person.

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

The term used in the International Classification of Diseases diagnostic system used in Europe (ICD 10) is “pervasive developmental disorders”. In this brochure, we use the term “autism” as a narrow designation for the various autism diagnoses, including pervasive developmental disorders, Asperger’s syndrome, other pervasive developmental disorder (PDD), atypical autism and infantile autism. People who have been diagnosed with Asperger’s syndrome, for example, also have a type of autism because they share the same basic difficulties of any autistic person.

” Despite having autism, you are still **first and foremost a human being**, but remote.

This means **things that are normal to other people are not normal to me.**

And things that are normal to me are not normal to other people.

In a way, I am **very poorly equipped for survival** in this world; I am **like an alien from outer space**, stranded **without an instruction manual**. But my human worth is intact. My self-awareness is undamaged. I find **great significance, value and meaning in my life** – and I have no desire to be “cured” in order to be myself. Realise that we are **just as alien to one another**; that my way of being is not simply an impaired version of your way.

Question your assumptions.

Make your **conditions clear**.

And **collaborate with me** in an attempt to **build more bridges between us**.

JIM SINCLAIR – AUTISTIC ADULT

WHAT CAUSES AUTISM?

There is no single cause of autism. Nevertheless, research indicates that the primary causal factor in autism is genetic, i.e. autistic people are born with genes that cause their brain to develop differently. The prevailing current theory is that this different development of the brain begins early in the embryonic stage and causes changes in the connections between key areas of the brain. Accordingly, some researchers believe children with autism are born without a neurobiological “starter pack” needed to develop a social sense. That means their brains do not automatically learn about their surroundings and acquire the knowledge about people that the rest of us take for granted. Initial research into

the “autism gene” shows that autism is associated with not one but several genes, and that genetics cannot explain the major variation in the degrees and types of autism that exist. For this reason, research into autism is also a matter of identifying some non-genetic risk factors that may need to be present simultaneously with a special genetic variation in order for autism to occur. Examples of non-genetic risk factors that can lead to the development of autism in a small percentage of cases include viral infections in the mother during pregnancy, complications during the pregnancy or birth, and side-effects of medication. However, in the vast majority of cases, the cause of autism in an individual is unknown.

HOW IS AUTISM DIAGNOSED?

A diagnosis of autism is given on the basis of a multi-disciplinary examination involving psychological testing/assessment, interviews, observation, autism-specific diagnostic tools and psychiatric assessment and medical examination. Although there are many screening tools and questionnaires for autism, none of these can be used in isolation to make a secure diagnosis of autism.

Autism is diagnosed when a person exhibits characteristic behaviour within three core areas which, combined, describe the basic difficulties of autism:

- Aberrant social interaction
- Aberrant social communication
- Limited, stereotypical and repetitive repertoire of interests and activities.

When these basic difficulties affect the person's level of functioning in all situations, a diagnosis of autism can be made.

Within each core area, a number of symptoms comprise the criteria for making a diagnosis. Symptoms are a description of behaviour and not a description of the whole person. The diagnostic criteria provide relatively certain and unambiguous diagnoses – especially for infantile autism and in the matter of whether or not it is autism. A diagnosis can help other people to understand the person better and can help the person's network to take action to improve the person's circumstances.

In the longer term, the diagnosis can also help the person to better self-perception.

In 80% of cases, the autism diagnosis is given in childhood. There are several reasons why the remaining 20% of cases are only diagnosed in adolescence or adulthood, e.g.:

❏ **During childhood, the environments the person operated in** were generally very predictable and accommodating. Thus, the symptoms of autism only start to become apparent when the surrounding world becomes more abstract and demanding for the person, e.g. in the form of expectations of being able to participate in social contexts and of assessing, making decisions and solving problems. For a diagnosis of autism to be given, however, it is a prerequisite for symptoms of autism to have been present in childhood too.

❏ **The most obvious difficulties** the person has had were accounted for under a different diagnosis – e.g. ADHD or disturbed behaviour in childhood, and those around the individual considered this a satisfactory explanation of the individual's typical behaviour (this phenomenon is known as diagnostic overshadowing).

❏ **By drawing on exceptional intellectual resources** and a personal network, the person was able to cope well outwardly, i.e. at school and possibly in further education or at work, and yet other people had difficulty reconciling the person's exceptional intellectual resources with, in some cases, his or her very odd characteristics, including traits such as being socially inept, taking things very literally and not having many practical skills.

Diagnosis in adulthood often results from the following:

❏ **Hospitalisation or treatment for a mental disorder**, e.g. depression, OCD or psychosis, where it becomes clear to adult psychiatry professionals that the person has some profound difficulties beyond the condition for which he or she was referred.

❏ **A referral for a psychiatric diagnosis** due to a suspected mental disorder, e.g. social phobia, when in fact it turns out to be autism.

- ❑ **The person has committed a criminal act** and undergoes a forensic psychiatric examination.
- ❑ **A failed work trial and rehabilitation process** which gives rise to psychological diagnosing and perhaps a referral for psychiatric diagnosing.
- ❑ **The person has become a parent** of a son or daughter who is diagnosed with autism.

It is important to remember that the symptom picture will change with the person's age and development, as autism is a developmental disorder. Autism also frequently occurs with other developmental issues and accompanying

conditions. For this reason, a diagnosis should always be supplemented with ongoing interdisciplinary assessment of the person's special development and needs. This ongoing assessment – not the diagnosis – should form the basis of treatment, which is an individually tailored support package.

INCIDENCE OF AUTISM

Danish and international studies indicate that approximately 1% of the population is autistic. Some studies suggest the incidence could be even higher.

DIFFERENT DEGREES OF AUTISM

The degree of autism can vary considerably. At one end of the scale, there is a very mild form of autism in which the person's disability is limited, as the individual is in fact able to enter into social situations as well as to adapt to new situations and people. This will usually require a great deal of mental energy, even for mild autism.

At the other end of the scale, some people are severely autistic and have enormous difficulties entering into social situations,

have considerable difficulties communicating, and can be very rigid in their habits. Taking a long-term view, the degree of autism is not always stable, but may manifest to different degrees and with different forms of expression in the individual.

In connection with family studies and genetic research, it emerges that some close relatives of autistic people have what is known as "the broad phenotype".

This means that these close relatives have an increased incidence of some of the traits that are characteristic of autism. The underlying difficulties that typify autism are thus also found as individual symptoms in part of the population, but these individual symptoms are common human traits and do not inherently constitute a disability.

Whatever degree of autism a person has, it is important to emphasise that autism is no barrier to learning new things and developing. Adults with autism, like any other adults, still have scope for developing themselves and acquiring new skills. The difference is that autistic people have a permanent need for support if they are to continue their development throughout their adult life.

THE BACKGROUND TO AUTISM

Autism remains a mystery, and the only certainty is that autism is very different from what it appears to be at first glance. As previously stated, the background to typical autistic behaviour is a different way of processing information in the brain.

Let us imagine that the brain basically comprises two systems: **The delivery system**, which delivers all the sensory impressions our senses pick up, and **the control system**, which governs what is to be done with these sensory impressions.

Every second, the delivery system delivers approximately 11 million sensory impressions. Not all of these impressions are of equal value. Our control system thus has to select the key impressions, and usually ends up selecting and processing 16–40 sensory impressions as a basis for our perception of a situation.

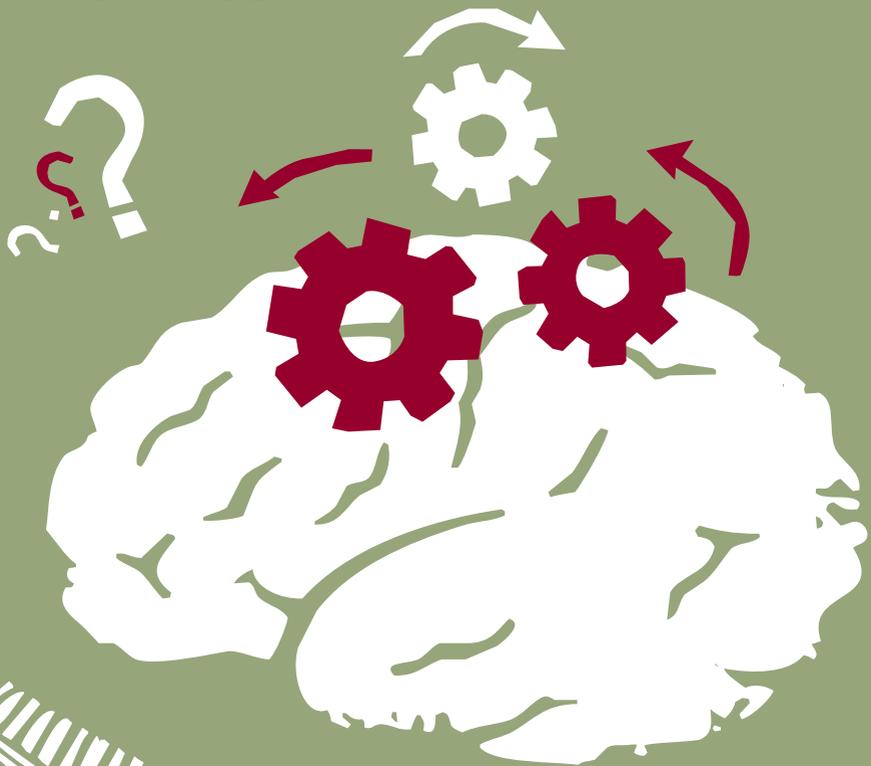
One of the ways in which the control system performs this sorting exercise is via knowledge, experience and emotions, which, combined, determine which details are important in a given situation and which details do not matter.

In an autistic brain, the delivery system works extremely well – sometimes exceptionally well. The control system, on the other hand, is much less effective. The control system in an autistic brain does not undertake enough sorting of the sensory impressions, which makes it difficult to quickly create a cohesive understanding of a situation. Instead of producing a meaningful overview (a “big picture”), the brain is busy processing both significant and insignificant sensory impressions (relative to the situation in question) – detail by detail. The positive aspect of being focused on details is

” I see thousands of details – not the big picture. When I do see a big picture, I cannot be sure it is the correct big picture. The context I come up with might be completely different from the context other people see. I am suffocating in an incomprehensibly huge number of impressions. I have to expend so much energy sorting out all this input that I become overwhelmed. As a result, I might have to shut down and close off all the sensory impressions.

That is why the means of communication **completely overshadows the substance being communicated.**

ANNIE – AUTISTIC ADULT



that the person's brain does not subconsciously dismiss a lot of sensory impressions and information about the world. Thus, autistic people will usually notice a lot more details in the physical world than people without autism would.

This different way of processing sensory impressions and the distinct tendency to focus on details also give rise to the basic difficulties that face autistic people:

❏ **It takes longer**, or may be utterly impossible, to get your bearings and gain an overview of social situations, as social situations are complex and never involve exactly the same details. Therefore, even familiar situations can be perceived as new and unpredictable.

❏ **It is more difficult to plan** tasks and be flexible.

❏ **It is difficult to develop** and understand non-verbal communication (eye contact, facial expressions, body language), which is a very important factor in relation to entering appropriately into social interactions. Most non-autistic people learn early on to see things from someone else's point of view (inferring what people are thinking, and their emotions and intentions) via non-verbal communication. An autistic person usually only learns this much later, and rarely to a sufficient degree.

❏ **It is difficult for an autistic person** to make the best use of his/her resources due to lack of social motivation.

❏ **It is difficult to respond** appropriately to different types of sensory impressions: Some react strongly to relatively minor sensory impressions (hypersensitivity), while others look for strong sensory impressions (lack of sensitivity).

Delving deeper into this different way of processing sensory impressions, numerous studies have identified atypical functions of the brain in autistic people. However, it is not a matter of any kind of brain damage; rather, some aspects in the brain are different. Research findings vary greatly. Some studies have shown abnormal structure in some cells, or abnormal stratification in some areas of the brain. Other studies using brain scans have shown that some areas of the brain are smaller or larger than normal, and others in turn show different brain activity.

One theory is that the different centres in the autistic brain are connected in a different way, with fewer or incorrect nerve connections between the parts of the brain (this is known as disconnectivity theory). This could explain why the control system is incapable of doing its job effectively, as this system is dependent on good, long nerve connections in order to fetch knowledge, experiences and emotions from other parts of the brain while sorting significant and insignificant sensory impressions. At the present time, there is insufficient knowledge of how autistic people's brains work, or of the causal factors that determine why some people are autistic,

in order to be able to change the basis on which the diagnosis is made. But existing knowledge offers a better understanding of what the world looks like to an autistic person, and thus why they exhibit the behaviour that is characteristic of the diagnosis.

As yet, there is no overall understanding of the atypical brain function and

different way of processing sensory impressions in autistic people, but a number of results from experiments are beginning to shed light on signs of autism in the brain. However, there is no doubt that the brain works in a different way, and that this is what is behind typical autistic behaviour. For this reason, autism is also regarded as a life-long disability.

ACCOMPANYING DIAGNOSES AND ACUTE CONDITIONS

In up to 80% of people diagnosed with autism, one or more other mental and/or physical disorders also require treatment (co-morbidity). In some cases, this means that, in addition to autism, the person will also be given other diagnoses. Identifying co-morbidity and planning a tailor-made combination treatment is a specialised task. The disorders most frequently found alongside autism are:

- Attention deficit
- Tics/Tourette's syndrome
- OCD
- Anxiety
- Depression
- Mental retardation
- Disturbed behaviour
- Epilepsy
- Visual and aural problems.

There can also be acute conditions such as micropsychoses at times of stress or depression, problems with eating and sleeping, mood swings, changes in the level of functioning, sudden angry outbursts, self-destructive behaviour and perceptual disorders.

It is important for autistic people to have regular health check-ups and to receive treatment for the accompanying conditions that can occur in combination with autism. The treatment is made more complicated, however, in that it can be difficult or impossible for autistic people themselves to identify and understand symptoms of any co-morbidity. Accordingly, they need their relatives and the professional network around them to help them with interpreting the physical and mental symptoms, as well as to notice and record any changes in their behaviour or loss of functions.

Autistic people also have difficulty describing symptoms to a therapist. First, the description can appear to be much too concrete and fragmented, and lacking in important subtleties. Secondly, good evidence is accumulating that autistic people have difficulty with autobiographical memory. In other words, they may have difficulty recalling their own experiences. This is why they need therapists to collect the necessary knowledge of how their symptoms have been over a period of time, and in what context they occur – by means other than simply asking them. Thus, both relatives and the person's professional network also have a responsibility to

support autistic people in documenting their own symptoms to help create a history of specific matters in their lives, and/or to assist with describing to the therapist the symptoms they have observed.

” **AUTISM IS LIFE-LONG, BUT BEHAVIOUR MANIFESTS DIFFERENTLY IN DIFFERENT PHASES OF LIFE – AND FOR THIS REASON, IT WILL ALSO BE NECESSARY TO MODIFY SUPPORTING EFFORTS THROUGHOUT THE PERSON'S LIFE.**

THEO PEETERS – WRITER AND
AUTISM SPECIALIST

WHAT TREATMENT IS AVAILABLE FOR AUTISM?

Autism cannot be treated as an illness that can be cured. Numerous different types of support measures must be put in place to enable the person to lead a fulfilled life with autism. In terms of treatment efforts involving special needs assistance, it is beneficial to regard autism as a disability. When speaking of autism as a disability, the focus is divided between:

- what it takes for the individual to acquire new types of behaviour and strategies
- society's approach, where the focus is on adapting environments so that

autistic people acquire experiences of being able to successfully enter into and keep on top of everyday life.

Currently, no medication is available to reduce the underlying difficulties of autism. Medication is only used in cases where the accompanying mental or physical disorders require treatment.

The ethical dilemma

Adults with autism, their relatives and their network frequently encounter an ethical dilemma associated with being of age and being an adult, and having the disability of autism:



- On the one hand, an autistic adult has rights, including influence and personal decision-making capacity.
- On the other hand, an autistic adult has needs in terms of support/treatment, usually involving needing help from other people.

Relatives and professionals alike should constantly pay attention to weighing up both elements in cooperating with an autistic person.

Special needs assistance as a treatment method

The purpose of special needs assistance is primarily to ensure that autistic people gain some more concrete experiences and acquire more knowledge, and thus a better basis to enable them to make good choices and achieve greater independence, quality of life and social inclusion.

Special needs assistance also includes elements with a view to supporting the person's rights. Thus, it is important on the one hand:

- that special needs assistance is always tailored and adjusted to the individual's personal profile and his/her motivations and wishes. This means special needs assistance will differ from person to person.
- support autistic people as they learn how they can live life to its full potential and participate in society with everyone else. This involves practising social and functional skills

relevant to increasing independence, instilling useful routines, finding one's place in society and, not least, building positive self-perception and good self-worth.

Any special needs assistance should include three basic elements:

- Examining the perspective and prerequisites of the individual
- Strategies to compensate for difficulties and barriers
- Motivation for learning new things.

Compensating for the difficulties that accompany autism is very much a matter of creating predictability and an overview. Predictability will give the autistic person the feeling of being in control of his/her life, reduce the level of stress, create the opportunity to find coherence in everyday things and, not least, to experience the greatest possible degree of independence.

” I need people to respect our agreements. I need to work on one thing at a time, and I need help and support when I need to start a new activity. I need someone to support me.

MARTIN AGE 31 – DIAGNOSED WITH ASPERGER'S SYNDROME

Predictability can be created when other people understand the need to be explicit about what is happening:

- Be specific about things that are not concrete in order to support the reduced capacity to visualise that challenges many autistic people.
- Be specific about the details in such a way that they are part of a big picture, i.e. offer the person concrete and visual descriptions of contexts in order to help him/her to obtain understanding and meaning.

- Be specific about sequences, progressions, routines, etc., in order to reinforce overview and flexibility.
- Be specific about the meaning of activities in progress.

Autistic adults can also benefit from assistance with understanding their own behaviour and that of other people, thus practising their social and communicative skills.

WHAT CAN YOU DO YOURSELF IF YOU ARE AUTISTIC?

” **Personally, I think the best way to deal with autism is to understand it.**

MARC SEGAR – AUTHOR
WHO IS AUTISTIC

Quality of life is important to everyone, irrespective of our individual abilities, age, gender, etc. Quality of life can be designated as a perception and feeling of wellbeing that is closely linked with our wishes and thoughts about what constitutes a meaningful life. A typical threat to quality of life is meaninglessness. This is why it is important that, in order to enhance your quality of life, you aim at

giving meaning to all the elements in your life. Moreover, all experience indicates that if you have a good perception of yourself, you will be more robust and thus will also find it easier to lead a meaningful life.

The Social Administration in your municipality of residence and/or your student counsellor can help you to gain an overview of the available options for getting help and support in relation to the following four key aspects of your life:

- **Housing:** Does your housing situation match your special needs and wishes?

❑ **Education and work:** How can some of the things you enjoy doing be used educationally or professionally? Do you have a plan for how to achieve your future educational and professional goals?

❑ **Leisure:** Where and how do you find yourself energised, and what are your interests?

❑ **Relationships and friends:** Do you have relationships and are you in contact with your peers?

AS A RELATIVE OR PART OF THE PERSON'S NETWORK, WHAT CAN YOU DO TO SUPPORT AN AUTISTIC PERSON?

It can be a major task for relatives and for the person's network to support an autistic person in leading a fulfilling life and improving quality of life. Some autistic adults with average intellect can find they are almost independent of support measures at times because they are able to maintain stability by means of useful routines and strategies. But as soon as tough events or circumstances arise that change these routines, and the person's strategies are no longer sufficient, a real need for support reasserts itself. This is why it is important for other people to realise that the autism will not go away, but that there needs to be a life-long focus on the underlying challenges an autistic person faces.

What you can do as a relative or someone in the person's network:

❑ Acquire knowledge of autism

❑ Listen carefully to the person's wishes, dreams and values

❑ Take the person's perspective seriously

❑ Introduce knowledge and a wide range of options and choices for the autistic person

❑ Help with "translating" the world for the person and, if necessary, show him/her what to do next

❑ Take the initiative and accompany the autistic person when difficult challenges are looming.

As a relative, it is also important for you to be aware of an autistic person's changing needs for assistance throughout life, taking the present context as the starting point, and based on the person's abilities, wellbeing, potential for development, wishes and needs.



Our thanks to the authors

Mette Jacobsen, educational consultant, and Rikke Steensgaard, psychologist, Autismefokus [focus on autism], Specialområde Autisme [specialist field: autism], and Meta Jørgensen, consultant, Child and Youth Psychiatric Centre, Aarhus University Hospital, Risskov.

Our thanks to technical editor

Per Hove Thomsen, professor, senior consultant, dr. med. sci., Child and Youth Psychiatric Centre, Aarhus University Hospital, Risskov.

Where can you find **MORE INFORMATION** ?

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

📄 Autisme.dk

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Edition 1.01 2014