

Information about

# AUTISM IN ADULTS

Diagnosis, interventions and quality of life



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**This booklet is intended for adults** with autism and their relatives as well as for professional networks.

**The booklet describes** various facts about autism, for example incidence, diagnosis and what we know about causes. It also provides information on how autism can be understood, and what people with autism, their relatives and other network members need to be aware of to ensure the best possible quality of life for the autistic individual.

**We hope** this booklet contributes knowledge and insights which can help pave the way for being able to live a good life with autism.

**Terminology:** The booklet uses the term 'autism' as a generic term that covers autism, autism spectrum disorders (ASD) and the diagnoses in the 10<sup>th</sup> revision of the International Statistical Classification of Diseases and Related Health Problems (ICD-10). ICD-10 is the diagnostic system which is used in Europe, and which uses the term 'pervasive developmental disorder' to cover the various autism diagnoses, including: infantile autism, atypical autism, Asperger syndrome, other pervasive developmental disorders (often abbreviated to PDD) and pervasive developmental disorder, unspecified.

Autism is understood and termed in many different ways by the various public systems – from mental illness and disability to a condition. This booklet describes autism as a disability because it entails, on the one hand, a social and communicative impairment, and because society and the surrounding environment typically constitute barriers for people with autism. To accommodate the different preferences associated with language use, the terms 'autistic individuals' and 'individuals with autism' are used.

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# WHAT IS AUTISM?

Autism is a neurobiological developmental disorder that occurs both in people with normal or high intelligence and capabilities and in people with general developmental disorders (developmental impairment). Autism involves a wide spectrum of symptoms, and autistic people can have widely differing skills, and thus also varying needs for support in daily life.

All forms of autism share a number of behavioural traits which are exclusively characteristic of autism. These traits are called the core symptoms of autism, and are briefly outlined below. The traits apply to all individuals with autism – regardless of their intellectual resources and other capabilities. This means that everyone with autism, to a lesser or greater extent:

- ❑ **finds reciprocal social interaction a challenge.** This can take the form of difficulties in interpreting social signals and contexts, as well as difficulties dealing with social relations.
- ❑ **is challenged in relation to reciprocal communication,** which covers the ability to express and understand content and intention in spoken language as well as understanding and using other communicative means such as tone of voice, mimicry and body language.
- ❑ **has a limited or repetitive behavioural repertoire,** which means

following the same routines and doing the same activities or having particularly intense interests. People with autism are often preoccupied with the present, and may find it difficult to imagine something which is due to take place in the future or which is not specific.

- ❑ **has a different sensory experience.**

This can take the form of hypersensitivity and hyposensitivity vis-à-vis sensory impressions, usually involving hearing and vision, but also the other senses such as taste, smell, touch and position.

When making a diagnosis, the focus is on the challenges which the individual or the people around him or her experience. It is worth noting that one area which can present challenges in one particular context can be a resource in another. For people with autism, it may be, for example, the skills which are needed to focus on and perceive

” **Making eye contact successfully is difficult** because it is hard to determine whether you are giving **too much or too little eye contact** to someone when they are **talking to you.**

MARC SEGAR – AUTHOR  
WITH AUTISM

details and a special ability to concentrate and persevere. Autistic people are also often described as being loyal and honest and capable of creative thinking. There is a higher prevalence of special talents among people with autism than in the general population, but this does not mean that all autistic people have a special talent.

Three to four times more boys/men are diagnosed with autism than girls/women, and on average women are diagnosed later than men. Research has shown that women need to display clearer symptoms of autism than men

before they are diagnosed as being autistic. Therefore, several researchers believe that women with autism may be underdiagnosed, and that the ratio between the genders is not in fact as large as it appears to be at the moment. One hypothesis is that girls and women are better at camouflaging their social difficulties, and that they are more successful at imitating people around them so that their behaviour is not conspicuous. This can have serious implications for the individual, as it often takes a lot of energy to conceal autistic traits from the outside world in order to fit in.

” Even if you have autism, you are **a human being first and foremost**, but you are a stranger. This means that **what is normal for other people is not normal for me**. And what is normal for me is not normal for others.

In a way, I'm terribly **ill-equipped to survive** in this world – I'm **like an alien** from outer space who's stranded **without any sort of guidance**. But my value as a human being is intact. My self-awareness is also unimpaired. I find there is **a lot of meaning to and value in my life** – and I have no desire to be cured in order to be myself. Accept that we are **equal strangers vis-à-vis one another**, and that my personality is not just a damaged version of yours.

**Question your assumptions.**

Make your **conditions clear**.

And **work with me to build more bridges between us**.

JIM SINCLAIR – AUTISTIC ADULT

## WHAT CAUSES AUTISM?

There is no single cause of autism. Research shows that genetic changes are the main causal factor, but autism may also be caused by external circumstances such as premature birth, certain infections and toxic influences in intrauterine life. In the vast majority of cases, the exact reason why a person has autism is not known. Whatever the cause, it is a congenital condition – a neurobiological developmental disorder that

causes the brain to develop differently. The prevailing theory at present is that atypical brain development begins early in the foetal stage, and results in changes in the connections that exist between key areas of the brain. So far, research has shown that autism is not linked to one gene, but to many, and that genetics alone cannot explain the wide variation in the type and severity of symptoms within the autism spectrum.

## HOW IS AUTISM DIAGNOSED IN ADULTS?

An autism diagnosis is based on a multidisciplinary examination involving interviews, observations, autism-specific diagnostic tools, a psychiatric assessment and medical examinations. Although many screening tools and questionnaires about autism exist, none of them can be used on their own to provide a reliable autism diagnosis.

An autism diagnosis is carried out when a person exhibits characteristic behaviour within three core areas, which together describe the fundamental difficulties faced by people with autism:

- ❑ Deviant social interaction
- ❑ Deviant social communication
- ❑ A limited, stereotypical and repetitive repertoire of interests and activities.

– and when these fundamental difficulties affect the way in which the person is able to function in all situations.

Under each core area, there are a number of symptoms which constitute criteria for making a diagnosis. The symptoms are a description of behaviour, and not a description of the whole person. The diagnostic criteria used provide relatively reliable and unambiguous diagnoses.

A precondition for being diagnosed with autism is that signs of autism have already been observed in childhood. Therefore, an autism diagnosis usually involves children. In some cases, the diagnosis is not carried out until the person is an adolescent or adult, and there may be several reasons for this. The main reason is that the diagnostic system was changed in 1994, when the autism diagnosis was extended to include, among other things, atypical autism, Asperger syndrome and other pervasive developmental disorders (PDD). Other possible reasons for a later diagnosis may – possibly in combination with an accommodating and predictable environment – be:

**‘Diagnostic overshadowing’.** This means that the most obvious difficulties have been explained on the basis of another diagnosis – for example attention deficit hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD), anxiety, behavioural disorders, eating disorders or personality disorders – and the surrounding environment and/or the person himself have perceived this as an adequate explanation for the difficulties or behaviour which have characterised the person.

**‘Camouflage’.** In other words, some people, because they have good cognitive/ social cognitive resources, appear to have managed to get through life reasonably well, for example at school, in their leisure time, in further education and at work. It might include the person in question trying to conceal his or her challenges socially and communicatively – for

## INCIDENCE OF AUTISM

Both international studies and studies in Denmark show that over 1% of the population has autism. Moreover, an increasing number of studies show that the incidence of autism may be even higher, perhaps closer to approx. 2%.

example by imitating other people’s behaviour. This is often described as being a very energy-intensive and exhausting process for the individual. For those in the surrounding environment, it may in some cases have been difficult to reconcile the person’s sound intellectual resources or unique strengths with traits such as social naivety, their very concrete way of thinking and the difficulties they face in carrying out practical tasks. The consequences of a ‘camouflage’ approach are currently being researched, and it looks as though camouflaging your autistic difficulties can have negative consequences, for example for your mental well-being. For some, however, the research describes positive consequences, for example in terms of being better able to form friendships and attend job interviews.

When adults are referred to establish whether or not they have autism, it may be in connection with:

- ❑ The person’s child being diagnosed with autism, and in connection with this process, the person has become aware that autism might explain some of the pervasive difficulties which he himself is experiencing and has experienced throughout his life.

- Referral for a psychiatric examination, treatment or hospital admission due to a suspected mental disorder, for example depression, social phobia, psychosis, OCD or eating disorder, where it transpires that it is due to autism alone or autism combined with another psychiatric condition.
- The person experiencing significant changes or crises in his life, and therefore becomes unable to maintain a stable existence.
- The person has not gained a foothold in the labour market, and therefore, as part of a skills identification process, is referred for a psychological assessment and possibly a psychiatric examination.
- The person has committed a criminal offence, and in this connection undergoes a forensic psychiatric examination.

Autism is a developmental disorder. The symptoms thus change depending

on the person's age and development. At the same time, autism often occurs in conjunction with developmental problems and/or in conjunction with mental and somatic conditions. Therefore, a diagnostic examination should always be accompanied by a multidisciplinary assessment of the person's development and needs. It is this continuous assessment – not the diagnosis – that should form the basis for organising specific measures to help the individual. There are currently no biomarkers (blood test, scan, electroencephalography (EEG)) which can be used to make an autism diagnosis.

A diagnosis can contribute to greater self-understanding and knowledge about and insights into the perceived challenges, and highlight the competences which are required to deal with them. A diagnosis can also give people in the surrounding environment a better understanding of the person's challenges, and better possibilities for providing the necessary support.

” It was almost as if my identity had been locked in a safe all my life, and out of the blue I was given the key. **I was able to become the person I've been all along.** I liken it to when homosexuals 'come out'. They don't change in any way to how they have always been, but **all of a sudden they stand by who they are**, are open about it and acknowledge it, and that's what I was able to do following my diagnosis – I could stand up and say **'This is me, and it's actually perfectly OK.'**

LOUISE EGELUND JENSEN, AUTHOR AND LECTURER

# DIFFERENT DEGREES OF AUTISM

Autism is a developmental disorder which manifests itself in many different ways. The combination of individual symptoms which form the basis for a diagnosis varies, as does the severity of the individual symptoms. The symptoms are also influenced by the person's cognitive level, personality and social factors, including their networks and surroundings.

Over the course of a lifetime, for an autistic individual it means that autism – and thus the opportunities open to an individual – can change in how it manifests itself over time.

Regardless of how severe a person's autism is, it is important to point out that autism is not an obstacle to learning

and personal development. Adults with autism are, like all adults, able to develop and acquire new skills. The difference lies in the fact that people with autism may need support and special arrangements in order for them to be able to develop throughout their lives.

In the context of family studies and genetic research, it has been found that a number of close relatives of people with autism have what is called 'the broad phenotype'. In other words, these close relatives have an increased incidence of some of the traits which are characteristic of autism. Some of the main difficulties faced by people with autism are also found as isolated ordinary human traits in the population – in some cases as a special skill or resource.

## MORE ABOUT AUTISM

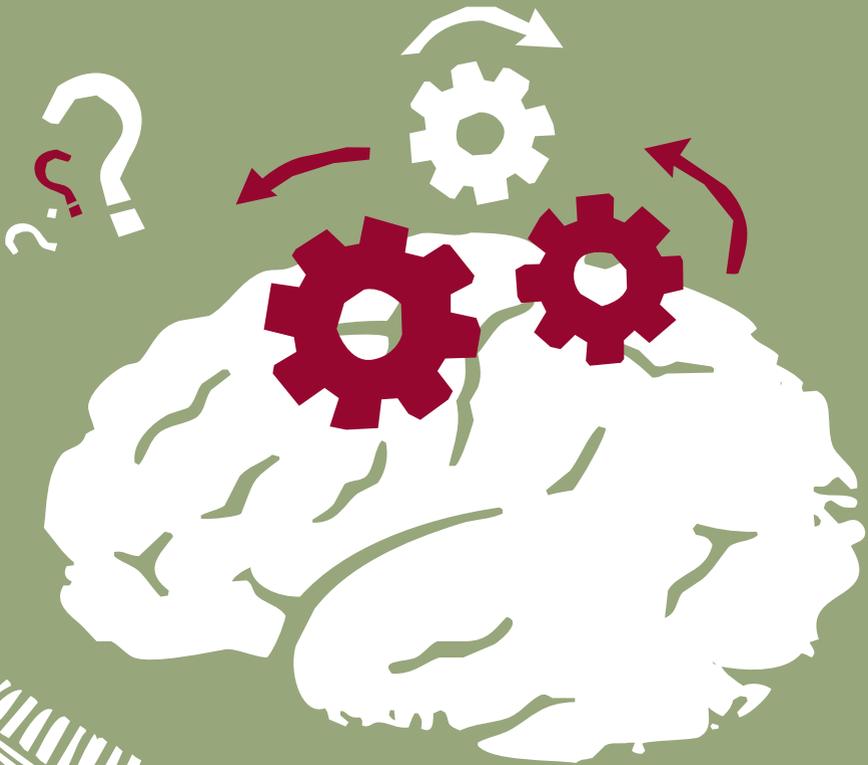
There is much more to autism than meets the eye. What exactly is behind the behaviour which is characteristic of individuals with autism is still a mystery. A riddle which is further complicated by the fact that the way in which autism manifests itself varies so much from one person to another. The following refers to the traits which are described in Chapters 1 and 3 (deviant social interaction, deviant social

communication, a limited, stereotypical and repetitive repertoire of interests and activities as well as different sensory processing) when referring to the behaviour characteristic of autism.

None of the prevailing cognitive theories about autism can explain autism in its entirety, but the following may explain some of the behaviours we consider to be characteristic of autism, and thus

**” I experience a thousand details – not a coherent whole. When I experience something in its entirety, it’s not certain that it’s the right whole. The context for me might be completely different to that for everyone else around me. I feel suffocated by the huge number of impressions. I have to devote so much energy to sorting out all this input that I am easily overwhelmed. This might result in me having to shut myself away, and remove all sensory impressions. The means of communication therefore completely overshadows what it is I want to communicate.**

ANNIE – ADULT WITH AUTISM



contribute to understanding autism, both for individuals with autism and for the people in their networks:

**The theory of reduced theory of mind:**

The theory of mind (ToM) is about understanding and predicting other people's intentions, thoughts, knowledge and feelings – having a theory about another person's mind and the ability to distinguish it from one's own. According to this theory, an impaired and/or delayed theory of mind may explain some of the difficulties faced by people with autism, for example reciprocal social interaction and communication.

**The theory of executive dysfunctions:**

The executive functions is a collective term for the brain's control tools – sometimes called the brain's director or conductor. It concerns, among other things, the ability to plan, organise, check impulses, launch/initiate, focus one's attention, be flexible and to switch strategy when problem-solving. According to this theory, people with autism can have impaired executive functions.

**The theory of detail-focused cognitive style/weak central coherence:** Central coherence is the ability to assemble several details in order to 'see the bigger picture'. According to this theory, many people with autism have a preference for detail, and find it difficult to take the details and see the bigger picture.

In addition to these cognition psychological theories, there is, thanks to the inner perspectives of autistic people, an ever-growing focus on the significance of the differences in their **sensory processing** and how this can help to explain and understand the behaviour which is characteristic of autistic individuals.

There is no doubt that neurobiological factors are responsible for the behaviour which characterises autism. Therefore, autism is also considered a lifelong disability. The prevailing hypothesis is that autism can be explained by changes which occur in the connections between the individual parts of the brain (connectivity), possibly combined with some structural changes.

These theories together with brain research provide an initial understanding of what the world looks like for individuals with autism, and thus an explanation of the behaviour which is characteristic of autism. The inner perspectives of people with autism are crucial for being able to understand both the individual and, on a larger level, autism in general. No human being can be understood on the basis of psychological theories alone, and it is vital that these do not stand in the way of adopting a curious approach to the individual person or a nuanced understanding of oneself.

# ACCOMPANYING DIAGNOSES AND ACUTE CONDITIONS

In up to 80% of those diagnosed with autism, there is also one or more mental or physical illnesses – or comorbid conditions – that require treatment. In some cases, this means that, in addition to autism, the individual is also diagnosed with other conditions. Specialist expertise is required to identify comorbidity and plan a tailor-made combination treatment. The conditions which occur most commonly with autism are:

- Attention deficit (hyperactivity) disorder (ADD/ADHD)
- Anxiety
- Depression
- General developmental disorder (mental retardation)
- Tourette syndrome/tics
- OCD
- Eating disorders
- Sleep disorders
- Stress
- Psychosis, including schizophrenia
- Other specific developmental disorders
- Behavioural disorders
- Epilepsy
- Vision and hearing problems

In addition, some people experience eating and sleeping problems (very high incidence), mood fluctuations, changing levels of functionality, self-harming behaviour, perception disorders and gastrointestinal problems. There is also an increased risk of suicidal thoughts,

suicide attempts and suicides among people with autism.

It is important that people with autism have regular health check-ups and receive treatment for the accompanying conditions that may occur in combination with autism.

Diagnosis and treatment options are complicated by the fact that it can be difficult for people with autism to detect, interpret and communicate the symptoms of any comorbid conditions themselves. It can therefore be beneficial if, as an individual with autism, you learn to keep an eye on your own well-being – both physical and mental – so that you can react to changes. This might, for example, be through knowing about how, as a person, you feel with regard to sleep, mood, socialising, food, daily chores etc. when you're feeling well, and having a plan for whom to contact if you realise that you are not thriving for a period of time. For others, private and professional networks will play a crucial role in terms of helping to decipher bodily and mental symptoms and detecting changes in behaviour as well as any possible loss of functionality, and seeking help accordingly. When seeking help, it may be beneficial to be aware of various factors:

- People with autism may find it difficult to describe symptoms to a therapist. This may be due to the communicative

difficulties associated with autism both in terms of being able to express oneself and understanding the questions which are being asked of one.

- Individuals with autism can have problems with autobiographical memory. This means that they may find it difficult to remember their own experiences.

Taken together, this means that, in addition to asking the autistic person questions, therapists may also need to obtain details about symptoms from the individual's private and professional networks – always subject to consent,

of course – or that relatives/network members participate and help the autistic individual to describe symptoms, for example.

” **AUTISM IS A LIFELONG CONDITION, BUT BEHAVIOUR CHANGES CONSIDERABLY AT DIFFERENT STAGES OF LIFE, WHICH IS WHY IT IS ALSO NECESSARY TO ADAPT INTERVENTIONS ETC. THROUGHOUT THE PERSON'S LIFE.**

THEO PEETERS – AUTHOR AND  
AUTISM SPECIALIST

## INTERVENTIONS AND SUPPORT FOR AUTISTIC ADULTS

Autism cannot be treated like a curable disease. Interventions will often involve special pedagogical support (SPS), which makes it possible to create a good life for the autistic person. By understanding autism as a disability, a shared focus emerges which is beneficial for intervention and treatment:

- the individual's opportunities for learning and development
- society, where barriers to autistic participation are broken down and environments adapted to enable people with autism to participate in society and live life with a high level of well-being

The purpose of special pedagogical support is usually to help the autistic person enjoy an improved quality of life, independence and inclusion in society. An important aspect of the special pedagogical support is therefore to help the individual find a meaningful place in society, to help them acquire a nuanced understanding of themselves and to build up positive self-esteem. It is crucial that the special pedagogical support is always adapted to the individual's particular circumstances and their motivation, desires and dreams. The special pedagogical support will therefore differ from person to person.



Any special pedagogical support should be organised to the greatest possible extent in cooperation with the autistic individual, and should be based on three basic elements:

- A study of the person's own perspectives and individual assumptions
- A development plan based on the person's motivation
- A plan for which strategies can compensate for difficulties and barriers

Trusting, authentic and safe relationships with the professionals with whom an autistic adult collaborates are a crucial aspect of the special pedagogical support.

When compensating for the difficulties which can accompany autism, predictability and overview are usually the most significant. Predictability can give the autistic person a vital sense of being in control of their life, it can reduce stress levels and make it possible to experience a sense of coherence in their daily life and, not least, the highest possible degree of independence. It is essential that this predictability is created in collaboration with the individual, and that it is always based on what is known about how the individual wants to lead his daily life. The following can help create greater predictability in an unpredictable world:

- Render visible what is not concrete, for example order, sequences, routines etc., and in this way strengthen the individual's sense of overview and flexibility.

- Render details visible, so they appear as part of a whole, for example by offering the person concrete and visual descriptions of contexts and connections, and in this way help them to understand and derive meaning.
- Explain what lies behind ongoing activities.

For many adults with autism, it can also be beneficial to help them understand their own and other people's behaviour, thoughts and feelings. This might involve helping them to translate neurotypical (non-autistic) communication into communication which is more autism-friendly.

There are currently no medical treatment options available to reduce the fundamental difficulties faced by individuals with autism. Medical treatment is only used in cases where the accompanying mental or physical conditions require treatment.

### **The ethical dilemma**

For some autistic adults, the person himself, his relatives and others in his network may face an ethical dilemma associated with the person in question being an adult and of age but at the same time in need of support or treatment. In such cases, everyone involved should be aware of the importance of the autonomy and self-determination of the autistic person, while providing them with the support they need. In these ethical dilemmas, it is necessary to constantly balance the person's right to self-determination with the person's right to care, and the easiest way of maintaining this balance is if there is close and trusting cooperation between all the parties.

# WHAT CAN YOU DO IF YOU HAVE AUTISM?

**” Personally, I think the best way of dealing with autism is to try and understand it.**

MARC SEGAR – AUTHOR  
WITH AUTISM

Quality of life is important for everyone, and it depends to a large extent on our thoughts about what constitutes a meaningful life. For us as humans, it is therefore essential that we focus on where and how we experience meaningfulness and well-being, and that we are aware that it is possible to change things that we are unhappy about.

Sometimes, it is a good idea to consider the following six areas of your life:

- **Mental well-being:** Are you usually in a good mood and do you generally thrive in your daily life?
- **Physical well-being:** Are you in good physical state without any symptoms of physical illness?
- **Relationships and friends:** Are you happy with your network? Do you have friendships and networks that make you feel happy? It’s never too late to make new friends. Many people find new friendships in connection with pursuing a hobby or interest.
- **Leisure:** Where and how do you recharge your batteries, and where do your interests lie?
- **Housing situation:** Does your housing situation match your needs and wishes?
- **Education and employment:** Do you have a plan for how to realise your future education and employment goals? May anything you enjoy doing at the moment be useful in connection with your education or future employment?

The social services in the municipality where you live and/or your educational advisor can help you get an overview of the assistance and support that may be available.

In addition, as an adult with autism, it may be beneficial to:

- Find out about autism and use this knowledge to learn more about yourself
- Be aware of which elements in your life provide and drain you of energy. This will enable you to balance your energy levels and avoid having either too many or too few plans. Also, you can find out how to recharge your batteries after engaging in an activity that has drained you of energy.
- Have a plan for whom you can contact if you need help
- Pay attention to your sensory needs and how to meet them
- Meet up with other adults with autism, for example in various associations or online

- ❑ Strike a good balance between compensatory and protective strategies and those which are more development-oriented
- ❑ Be aware of how big changes and significant events in your life affect you, and seek support when necessary
- ❑ Know that it's OK to do things differently

## AS A RELATIVE/NETWORK MEMBER, WHAT CAN YOU DO TO SUPPORT SOMEONE WITH AUTISM?

Some people with autism rely on close support for much of the day, while others may be able to function without any support at all for extended periods of time. However, when faced with difficult events or major changes, they may well again need help. As a relative or network member, it can therefore be helpful to know that autism does not disappear, but is a lifelong disability.

### **For relatives and network members, it can be useful to:**

- ❑ Find out about autism
- ❑ Listen carefully to the person's wishes, dreams and values
- ❑ Take the person's outlook on life seriously
- ❑ Show genuine interest and curiosity so that misunderstandings can be avoided in so far as possible
- ❑ Introduce the autistic individual to knowledge and a wide range of options and possibilities
- ❑ Help 'translate' the world for the person and, if necessary, show the way forward
- ❑ Take the initiative, and accompany the person out into the world
- ❑ Respect that the person might do things differently, or want some things to be different to what you would normally expect
- ❑ Listen carefully to the person's wishes, dreams and values, especially when difficult challenges await
- ❑ Know that some people with autism have a so-called uneven cognitive profile, where they might have very good intellectual resources yet face considerable difficulties with adaptive skills, for example completing ordinary everyday tasks. At first glance, this can resemble laziness, but is in fact expressing a real need for support.
- ❑ Find out about autistic communication and culture

As a relative, you need to know that the support being provided to a person with autism needs to be adapted throughout his or her life based on their current

situation and on the person's assumptions, well-being, development potential, desires and needs.

## GENERAL ADVICE ON COMMUNICATING WITH AUTISTIC INDIVIDUALS

People with autism have a special way of understanding and communicating with the outside world. Although all autistic people are different, there is some general advice to consider when communicating with an autistic individual:

- Be clear and specific in your communication. Abstract language assumes that the person you are talking to can appreciate that what you are saying might mean something different to what has been said. This can be difficult for someone with autism. It means that you should preferably avoid the use of metaphors, idioms, imagery etc. unless you know that the autistic individual is familiar with and understands them.
- If at all possible, support your communication visually. This can take the form of both images and text. Use the visual support that makes most sense for the individual. Visual support helps to make communication concrete and easier to retain. It means that the person can read the information again

if necessary, for example when you are not there to provide support.

- Ask one question at a time, and wait for answers before asking a new question. Many autistic people can find it difficult to understand what is being asked if several questions are asked at once.
- Provide one piece of information at a time, and wait until the person has registered the message. Give the person enough space and time to ask questions about the information. Listen to the autistic person, and consider/ask how the information has been understood. Make sure that you discover and resolve any misunderstandings.
- If you are unsure about whether the way in which you are communicating is understandable, ask the person directly and with interest. Likewise, ask the person directly and interestedly if you are unsure about whether you have understood what they are saying.

- Enquire directly about what the person needs in the way of support, and listen actively without assuming that you know the answer in advance.
- Non-verbal communication is also communication. The behaviour we observe can be an expression/sign of communication. Therefore, be aware of any changes in behaviour. Be curious and enquiring as regards what the changed behaviour is expressing; if possible, ask about it if you can. Wait, listen and acknowledge.
- If the person has difficulty communicating or expressing their thoughts, allow plenty of time and space. Give the person time to think. If this doesn't work, make suggestions or guess at what it is you think the person is thinking. You can do this based on what you know about the person, or make a guess according to what you might feel in a similar situation.
- It is important that you are unassuming, and do not think that you have the answer, but make it clear that you would like to guess the answer, and perhaps in this way assist the communication. It might also be that you need to draw or write instead of talking.
- Conclude your dialogue by summarising what you have talked about, and recap any agreements, ideally noting them down in writing or visually.

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