

Autism in toddlers

Information for parents



Nederlandse
Vereniging voor
Autisme

In the photo:

The photos in this booklet were created for the 'Give Autism a Face' Project. Frédérique is 5 and has autism and a developmental delay. She was very impressed with the 'studio', but quickly relaxed under the hot lights and our photographer's winning manner. Maurice is 10 and has McDD. He is posing here with his little sister Janna, who he would walk over hot coals for. Many thanks to these wonderful children and their proud parents for donating their time.

Credits

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Dutch Autism Association (NVA)

Since 1978, the Dutch Autism Association (NVA) has been representing the interests of people with autism, their family members, partners and other people connected to them. The NVA has more than 15,000 members. The key words in the objectives of the NVA are: representation of interests, support, information, contact between fellow people with autism, increasing expertise, promoting research and monitoring the quality of care.

For more information: www.autisme.nl

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St. Fam. Ommering

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Dear parent*,

The news that your child has a form of autism can cause mixed feelings in you. Perhaps you are relieved that you finally know why you have had such difficulty establishing contact with your child. That people acknowledge the fact that the development of your child is really proceeding differently, and that this is not because of 'something' you are not doing properly. And that you can now start looking for targeted help in this. But it can also make you feel sad, angry or frustrated, because you had not expected that your child would get this label, and have to live with it. Perhaps you are wondering what the future holds for your child and your family.

The purpose of this booklet is to give you more insight into what it means to have autism/Asperger's syndrome/PDD-NOS, and how you as parents can deal with it.

You will find suggestions of books to read, and websites and organisations that can give you more help. So that your child gets the opportunity to use his or her talents to the best possible extent, and learns to live with the limitations of the autism.

*When we say parents, we also mean foster parents or other carers



"This is our beautiful, exceptional Frédérique"

What is autism?

If you have autism, this means that your brain works differently. And you notice this in the contact with your child. For example, because your child makes little eye contact and does not enjoy cuddling, did not start talking until a very late stage (or perhaps has not started yet), shows little interest in other people and appears to have little need to do things together or share things with you.

If a large number of things happen at once, your son or daughter can become confused because he or she does not understand properly how all those different things and events are connected. This can make your child anxious or angry, and this is why he or she sometimes behaves differently from other children. It may also be the case that your son or daughter is bothered by certain stimuli, such as light, sound or pain, much more easily. In such cases, young children may bang their heads against a wall or sofa, for example, rock backwards and forwards, run in circles, wave their hands or make other repetitive movements.

Or it may be the case that your child does not respond enough to sounds and other stimuli.

You can't see autism on the outside, but you can sometimes notice it in a person.

Perhaps you recognise a couple of these common characteristics in your child:

- difficulty dealing with changes;
- shows little interest in other people;
- prefers always to occupy him or herself with a single toy;
- anxious in unknown situations and groups;
- no eye contact, our eye contact only in a strange way.

Apart from autism being problematic, there may be things your child is good at as a result of the autism, such as:

- a good eye for detail;
- honesty;
- sticking to (clear) rules.

More than 1% of Dutch people – approx. 190,000 people – have a form of autism.

Perhaps you know more children or adults in your vicinity who also have autism?

The diagnosis

Only a healthcare psychologist or psychiatrist can determine whether your child has autism. In young children, this takes place on the basis of conversations with the parents regarding the development of the child and the upbringing, in combination with close observation and analysis of the play behaviour of the child, and how he or she plays with the parents. The psychologist or psychiatrist also looks at the day-to-day skills of the child (whether or not he or she eats or drinks on his own, is potty trained, and how he or she sleeps).

When we refer to autism, we mean the entire spectrum of autistic disorders, of which the diagnoses of classic autism, Asperger's and PDD-NOS are the most common. These diagnoses are also often referred to as autism spectrum disorders (abbreviated to ASDs). It is not possible to make a specific diagnosis for children who are younger than four years of age, so usually the diagnosis of ASD is made. This is because it is not yet possible to recognise certain specific characteristics at such a young age. The diagnosis is often amended when the child gets older.

Your child is only given a diagnosis if he or she meets specific characteristics which are in the DSM (*Diagnostic and Statistical Manual of Mental Disorders*), a manual for psychiatrists used around the world. The criteria differ for each diagnosis:

Classic autism or core autism

A child receives this diagnosis if he or she has a large number of characteristics of autism, and the characteristics were already visible before the child turned three. Classic autism

is often accompanied by a low intelligence, but this is not necessarily the case.

Asperger's syndrome or disorder

Characteristic of this diagnosis is that your child can speak and learn well, but has difficulty understanding what other people are thinking and feeling. Perhaps your child also has a specific toy on which he or she particularly focuses, or a subject about which he or she knows a great deal. Or there is an activity which your son or daughter prefers to do all day long.

PDD-NOS

PDD-NOS is an abbreviation for: Pervasive Developmental Disorder Not Otherwise Specified. In het Nederlands: Pervasive Ontwikkelingsstoornis niet anders omschreven. Your child may be given this diagnosis if he or she does not have all the characteristics of autism, but does have some of them. Or if there is no information available about his or her first years of life.

McDD

Your child may be given a diagnosis of McDD (Multiple complex Developmental Disorder) if he or she has characteristics of autism, and in addition gets angry extremely quickly or is very anxious. This diagnosis formally falls under PDD-NOS.

Other diagnoses

Autism can sometimes be accompanied by a rare inherited syndrome, such as Klinefelter's Syndrome or Tuberous Sclerosis. It may also be the case that your child has been given a diagnosis of ADHD, epilepsy or a mental handicap.

For more information on autism:
www.autisme.nl

A diagnosis is more than a label!

A good diagnosis involves the healthcare psychologist or psychiatrist making it clear to you and your child which characteristics of autism your child has, what he / she primarily has difficulty with, but also what he / she is good at. And that you receive targeted, specific advice about how to deal with the autism of *your* child: at home, at school and during his or her free time.

An early diagnosis

Autism cannot be detected straight away in a child, and particularly with young children, the people around you will have a tendency to say that you shouldn't worry, particularly if your child is happy. These people do not see how your child is when he or she is overstimulated, and screams and cries and keeps you awake, for example. If your child does not have a diagnosis, it is more difficult to explain that your child really is different. With a diagnosis, you can not only learn to better understand your child's behaviour yourself, but you can also explain it better to other people. This can result in you feeling less powerless. By having more knowledge about autism, you can also better learn to deal with it. Your entire

family is involved in this. In their day-to-day lives, young children spend most of their time playing at home, and the day-to-day role of parents is greater than when a child is going to school. A child with autism needs a great deal of attention, which is sometimes at the expense of attention for brothers and sisters, and attention for one another. Family guidance provided by a remedial educationalist or psychologist can help achieve a good balance in this, and create a peaceful atmosphere in the family. So that you can continue to do fun things together, and brothers and sisters can also receive attention.

If your child receives a diagnosis of autism, you will probably wonder where it came from. Autism is genetically determined to a large extent, influences from the child's environment only play a limited role. Do you perhaps recognise yourself, your partner or another family member in your child's behaviour? There might be other family members who have a diagnosis, but this doesn't have to be the case. Sometimes a child in a family can have a 'spontaneous' genetic divergence, which can result in autistic symptoms. It can also be the case that there are more people in the family with autism, but that they have not all received a diagnosis. As there used to be much less knowledge



"We are very proud of how Maurice gets along with his sister"

about autism than there is now, this diagnosis was occasionally missed. If you suspect that an adult member of your family may have autism, have a look at www.cass18plus.nl for more information about diagnosis of autism in adults.

Playing together and in therapy

If your child has autism, playing together is certainly not easy, but it is important to encourage your child to do this. A central objective of various therapies for young children with autism is to ensure that the parents and child learn comfortably to interact with one another, play together and communicate. With the help of behavioural therapy, playing together, and sometimes also video recordings in the home situation, parent and child are trained by a therapist. The ultimate goal, of course, is to apply the things learned in therapy in day-to-day situations.

As your child already has a diagnosis at a young age, treatment can start earlier. The earlier you start treatment, the more possibilities there are to steer the development of your child. It should be noted, however, that the effectiveness of a treatment differs for each child.

What it is ultimately about is finding a balance between stimulating the development of your child, while building self-confidence in your child at the same time, allowing him to be himself. But this is easier said than done: you want your child to develop as well as possible, but if you burden your child too much with therapy, this could result in more and worse stereotypical behaviour being displayed, such as rocking backwards and forwards or hand waving. At the end of the day, the most effective approach is different for each child.

Commonly used methods include:

TEACCH

TEACCH is an abbreviation of Treatment and Education of Autistic and related Communicative handicapped Children. This method is geared towards offering structure in the environment of the child and in the day-to-day interaction with the child. A great deal of use is made in this context of visualisation, using pictograms, for example. TEACCH is used a great deal in schools for special education, medical day care centres and day centres, in particular in special autism groups. For more information: www.teacch.com

Floortime:

Floortime is a play therapy geared towards stimulating social development. For more information: www.floortime.nl

Applied Behavioral Analysis (ABA)

This behavioural therapy is currently viewed in the US as the number one therapy for treating children with autism. Opinions are divided on this in the Netherlands, primarily because the training is often extremely intensive. PRT (Pivotal Response Treatment) is a promising behavioural therapy which is based on ABA and which focuses on teaching social and communication skills. For more information on ABA: www.abainternational.org, and for more information on PRT: www.centrumautisme.nl

Together with the person who has diagnosed your child, look for the therapy which offers the best help for your child. And don't forget: as a parent, you know your child better than anyone, and this knowledge is extremely valuable for school, therapy, etc.! Another important tip for you as parents: take good care of yourselves! Make sure you have moments to recharge your batteries, go out without children now and again, get a relaxing hobby, etc. This is the only way you will have enough energy to continue caring properly for your special child, and for the rest of your family.



"It's not always easy having a son with autism, but he has already taught the people around him a lot, thanks to his way of thinking and looking at things."

Going to the crèche or playgroup

Some toddlers who have autism go to ordinary creches or playgroups. As a parent, you can already give the leaders a lot of information about how you deal with your child's sometimes difficult behaviour at home. A remedial educationalist or play therapist can also give the leaders tips on how to handle these children. For example, so that the leaders learn to see when certain behaviour of a toddler requires extra attention, and when it doesn't: when is hand waving an expression of joy, and when is it expressing stress or anxiety?

For many young children with autism, it is difficult to attend a regular playgroup or school, because they need more intensive attention and supervision. In such cases, it can be helpful to follow a specific day treatment for a period of time. There are various types of day treatment:

1. Medical Daycare Centres (MKDs): for children with development and other problems, and normal intelligence.
2. Daycare Centres for Children with a Mental Handicap (KDCs): for children with a mental handicap.
3. Specific treatment groups for children with autism and language and speech disorders.

4. Specific residential groups or part-time treatment for young children with autism in mental health care.

Depending on the development of your child, there will be a type of day treatment which better suits him or her.

Going to school

If your child is already almost 4, you will be thinking about which school will be the most suitable for your child. Most children with autism need supervision and a clear structure at school. Ordinary schools can offer sufficient supervision for some of these

children, but other children with autism do better at special schools. This means that you will have to look for the school which will be most suitable for *your child*. There are various reasons for choosing a school: because it is close to home, because it can offer a special education for children with autism, or because brothers or sisters already go to the school. Whichever school you choose, it is always important to meet with the school in advance. Ask the school how it can work with you to ensure that your child gets suitable education, and can develop in the best possible manner. In this context, try to look, together, at what your child has difficulty with: can he or she function in a larger group or is more individual attention needed?

Structure is a keyword in the supervision of children with autism at school. This applies both to 'ordinary' education and to special education. One tool which is often used to provide structure is a clear day schedule, displayed using pictograms, for example. A clearly structured space also helps: set locations for materials, a set place to work and a set timeout place where a pupil can withdraw if there have been too many stimuli. There is a great deal of information available on supervising children with autism in education, but unfortunately not every primary school (by a long way) knows how to find this information. For more information and tips on education and autism: www.landelijknetwerkautisme.nl.

And remember, as parents there's nothing wrong with being critical! Don't be satisfied with whatever a school offers you if you feel that this is not the best for your child!

Do you want to know more about autism in children?



DVD suggestion:

DVD: a surprising start. Part 1: Children with autism. In this information film, the parents of Thimo and Ewout talk about the autism of their sons in an open-hearted manner. Thimo is a boy aged almost 4 who has received a diagnosis of classic autism. Ewout has been given a diagnosis of Asperger's, and is nine years old. The two boys and their parents are followed in their day-to-day life. Subjects addressed in the film include: what does the diagnosis mean for these families? What good sides and difficult sides the parents experience in their special children? Which guidance to parents and child get, and how do they ensure that there is enough relaxation in their lives? Prof. Dr. Rutger-Jan van der Gaag provides expert background information about autism in the film.

'A surprising start' is in the first part in a six part series of information films called 'Autism: a life long', made by WonderlandFilm, commissioned by the Dutch Autism Association.

These films can be ordered at www.autismeboek.nl

"I find it difficult to estimate what Thimo's future will be like. What does he still need to learn? But in the Netherlands, there are so many options to receive help, I'm sure it will work out fine!"

(from: NVA information film 'A surprising start').

Books to read aloud:

- Mick (Colette de Bruin)
- Zeno Alone (Inne van den Bossche)

Suggested reading for parents:

- Children with Autism (Peter Vermeulen)
- 10 Things You Should Know about Children with Autism (Ellen Notbohm)
- Autism Help Manual (Chris Williams and Barry Wright)
- Life with Your Autistic Child. A Guide for Parents and Professionals (Lorna Wing)
- Explosive Behaviour in Autism. What Do You Do About It? (Linda Woodcock and Andrea Page)

More book suggestions:

www.autismeboek.nl

Websites of organisations that can help you further:

www.autisme.nl

The Dutch Autism Association (NVA) provides information and advice, contact between fellow people with autism, and represents the interests of people with autism and the people close to them.



www.autipas.nl

A useful resource for helping other people understand autism.

www.mee.nl

MEE offers information and advice about assistance for people with autism and their families in your local area. You can find address details for regional MEE organisations at www.mee.nl.

www.cce.nl

The Centre for Consultation and Expertise (CCE) is available for clients and their families, for mediating in deadlocked care provision situations.

www.landelijknetwerkautisme.nl

Information and advice on autism in education.

www.onderwijsconsulenten.nl

Education consultants can be brought in if a child is at risk of falling too far behind at school, or is already at home.

Information and Advice by and for parents

If you have any questions about dealing with autism in children, you can contact the Information and Advice Line (I&A Line) of the Dutch Autism Association. You will get through to a trained volunteer, who knows from experience what it means to have autism. Some of the volunteers have a child or partner with autism, while others have been diagnosed themselves. The volunteers help you find information, give advice and offer a listening ear on the basis of their own experience-based expertise.

For more information on the opening hours: www.autisme.nl.

**0900-AUTISME / 0900-2884763,
€ 0.05 per minute
i&a@autisme.nl**

This is a publication of the Dutch Autism Association

This booklet is intended for parents of children aged between 2 and 4 who have received a diagnosis of autism spectrum disorder, classic autism, Asperger's, PDD-NOS or McDD.

Dutch Autism Association (NVA)

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