

Children with autism

Information for parents



Nederlandse
Vereniging voor
Autisme

In the photo:

The photos in this brochure were created for the 'Give Autism a Face' Project. Maurice is 10 and has McDD. He is posing here with his little sister Janna, who he would walk over hot coals for. Sincere is also 10 and has classic autism. He and his mother form a stunning, close-knit team. Jim (11) also has classic autism, and is posing here together with his younger brother Gary, with whom he clearly had lots of fun. 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 keywords in the objective of the NVA are: representation of interests, support, information, contact between fellow people with autism, increasing expertise, promoting research and quality monitoring of care. Further information: www.autisme.nl.

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St. Fam. Ommering

St. Lakeland Foundation



Hi! Dear parent*,

You are probably reading this booklet because you have just found out that you yourself have a form of autism, or because someone at school or your parents think that you might have a form of autism. What can you do with such a diagnosis?

In this booklet, you can read what it actually means to have autism/Asperger's/PPD-NOS.

The booklet is primarily intended for your parents, but page 11 is specially for you. There you can find book suggestions, with stories of other children with autism, and how they deal with their autism.

Perhaps you're feeling a bit sorry for yourself.

There's nothing wrong with that, for a little while, but don't forget: you are much more than just the diagnosis of autism. And you also have your strong areas, maybe even thanks to the autism!

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 your son or daughter can be so unmanageable, or has so many problems with changes. And that this is not a result of how you are bringing him or her up.

But it can also make you feel sad, angry or frustrated, because you had not expected that your child would get this label. Because you are wondering why nobody ever told you before what was wrong with your child.

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, and learns to live with the limitations of the autism.

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



"Sincere's biggest talent is his huge, explosive smile!"

What is autism?

If you have autism, this means that your brain works differently. You probably primarily see this in how your child interacts with others: your son or daughter has difficulty understanding other people, and they often also don't understand how your child thinks and acts. For example, if things turn out differently than expected, your child has a great deal more difficulty with this than other children do. And if a large number of things happen at once, your child 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 experiences certain stimuli, such as light, sound or pain, differently. That soft sounds, such as a clicking pen, for example, sound very loud to them, and distract them in the classroom.

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 son or daughter:

- difficulty dealing with changes;
- difficulty making contact;
- little sense of what other people expect of him or her in a given situation;
- preference for working on a single subject or hobby;
- anxious in unknown situations and groups;
- little understanding for the emotions of others;

- likes to always do things in the same way (sticking to routines);
- no insight into non-verbal communication, such as gesticulations.

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

- a good eye for detail;
- honesty;
- an (extremely) large amount of knowledge on a given subject;
- 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

When we refer to autism, we mean the entire spectrum of autistic disorders, in 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).

Only a healthcare psychologist or psychiatrist can determine whether your child has autism, on the basis of extensive tests and discussions with you as parents and with your child. 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 extremely 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!

Whether your child has core autism, Asperger's or PDD-NOS, this does not say much about the type of guidance he or she will need. 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.

When your child receives a diagnosis

A diagnosis of autism offers an explanation for the problems which you may have been experiencing for some time with your child. This diagnosis should also provide you with a handhold while learning to deal with this.

The whole family is involved in this process. 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 or parent 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, have the occasional day out. For example, a day at the zoo or an amusement park, perhaps just going shopping together or to the library.

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

"You can never simply shout out 'guys, it's sunny, so we're going to the woods!' You have to prepare carefully for this. And sometimes this takes so long that the sun has gone by the time you're finished!"

(From the NVA information film: 'A surprising start')

'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 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.

Help

Unfortunately, there are no medicines or treatments which can cure autism. But with the right guidance, a lot of people with autism can go to school or work and maintain relationships with other people. 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, to 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 flailing. 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, see: www.teacch.com

Floortime:

Floortime is a play therapy which focuses on 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.



"My children might have their problems, but they are also lovely, kind children."

"I really love seeing my daughter enjoying herself so much at the Auti Actie Dagen"



Going to school

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. Ask the school to work with you to ensure that your child gets suitable education at a school where he or she 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? Can he or she keep up in reading and arithmetic, does he or she struggle with specific learning problems, such as dyslexia or dyscalculia, for example, or is it primarily the work rate which is a problem, due to a slower processing of information?

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!

Contact with classmates is a separate area for attention. Bullying and teasing can be a problem, particularly in the last years of primary school and at secondary school. It is important that the school is alert to this. One thing that can help is to explain to the class what autism is and what it means. For

example, with the help of a class presentation package from the NVA (see also page 11).

Sport and leisure time

Sport and activity are important in children's development. For many children with autism, this demands extra attention, because their motor development often proceeds less flexibly than in other children. Luckily, there are increasing numbers of opportunities for children with autism to enjoy sport; primarily small-scale initiatives, or just at the local sport club. In every case, sport with autism requires extra attention from the sport trainer. He or she must be able to anticipate and respond to what a child with autism needs, and have a good eye for individual differences in this. One pitfall is that trainers think they know how to interact with a child with autism, because they once had a child in the team and a specific approach worked with that child. A different child with autism can need a totally different approach!

In order to assess whether a specific situation will suit your child, you can pay attention to various aspects, including:

- is there regular contact with the parents?
- to what extent do the coaches look at the needs of each child?
- does the training have a set structure?
- does the sport focus on enjoyment, participation rather than just on winning?
- to what extent does the space allow a good overview? (indoors often enables a better overview than outdoors)
- are changes and transitions clearly announced in advance?

Many providers of leisure activities for children with autism offer guidance as well as relaxation. So that your child also learns to develop socially. For more information

on leisure activities for children with autism in your neighbourhood, please contact the Information and Advice Line of the NVA (see box) and the leisure consultants of the regional MEE organisations (address is: www.mee.nl).

Perhaps your child would enjoy meeting other children with autism. The NVA is organising Auti-Actie-Dagen in increasing numbers of provinces. To be themselves and do fun things, one Saturday a month, at a set location, with well-trained supervisors. Such as treasure hunts, making pizzas, playing music or playing a sport, or a day at the zoo or museum. And not forgetting that you as parents also have a day off! For more information: www.autisme.nl

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

Do you want to know more about autism in children?



DVD suggestion:

DVD: *a surprising start. Part 1: Children with autism.* This DVD shows how Ewout and Thimo deal with their autism and what this means for their parents. This film is part 1 in the series 'Autism a life long', a six part series of information films showing the consequences of autism in the various phases of life. The series 'Autism a life long' was made by the NVA in cooperation with Wonderland Films.

These films can be ordered at www.autismeboek.nl

Suggested reading:

- I am Special (Peter Vermeulen)
- Children with Autism (Peter Vermeulen)
- Autism Help Manual (Chris Williams and Barry Wright)
- Life with Your Autistic Child. A Guide for Parents and Professionals (Lorna Wing)

More suggested reading:

www.autismeboek.nl

Useful websites

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 for children

Class presentation package

You can order a class presentation package from the NVA. This includes a poster to



hang up and friendship books to hand out in the classroom. The package can also be used by the teacher. The friendship books contain stories of children who have autism, and others who don't, to make it clear in a playful and accessible manner what autism actually is. This package can be ordered from www.autismeboek.nl.

Books for children (to be read by or to them):

- Zeno Alone? (Inne Van den Bossche) – 4 years and older
- Bibi and Autism (Suzan Mulders) – 4 years and older
- Mick (Colette de Bruin) – 4 years and older
- The World of Luuk (Martine Delfos) – 6-10 years
- Ordinarily Extraordinary (Ellen Verspeeten) – 7 years and older
- What is the matter with Kobus? (Inge Barth-Wagenaar en David Barth) – 8 years and older
- Elephants in my Head (Robin Raven) – 10 years and older

Getting Insight into Autism, Together

- Me and Autism (Nathalie van Kordelaar and others) – 4-12 years
- The Autism Survival Guide (Luc Descamps) – 8-12 years
- My Scrapbook This Is Me, This Is What I like Around Me! (Ellen Luteijn and others) – 8 years and older



This is a publication of the **Dutch Autism Association**

This booklet is intended for parents of children aged between 4 and 12 who have received a diagnosis of classic autism, Asperger's, PDD-NOS or McDD.

Dutch Autism Association (NVA)

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