

Autism in Teenagers

Information for teenagers and their parents



In the photo:

The photos in this brochure were created for the 'Give Autism a Face' Project. Bonno (13) has PDD-NOS, possibly with McDD. Elise is 20, and with the help of a job coach and buddy, is able to manage her autism well. Many thanks to both of them 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

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 means to have autism/Asperger's/PDD-NOS, and how you can deal with this. Naturally, this booklet on its own is not enough. Turn to page 9 for a list of recommended books and websites with more information and stories by other teenagers with autism, about 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 teenage son or daughter can be so unmanageable, or has so many problems with changes. And that this is not a result of how you brought 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. This booklet is primarily intended for your teenage son or daughter. To give them more insight into what it means to have autism/Asperger's/PDD-NOS, and how you can deal with this. On pages 10 and 11, you will find information and suggested reading for parents, including websites of organisations which can help your teenager and your family further. So that your teenager 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

"My autism is part of me.
And I will only talk about it
if I want to."



What is autism?

If you have autism, this means that your brain works differently. You probably primarily see this in your communication with others: you have difficulty understanding other people, and they often also don't understand how you think and act.

For example, if things go differently than you had expected, then you may have more difficulty with this than your parents and your classmates. And if a great number of things happen at once, you can become confused because you do not understand properly how all those different things and events are connected. This can make you anxious or angry, and this is why you sometimes behave differently.

It may also be the case that you experience certain stimuli, such as light, sound or pain, differently. That soft sounds, such as a clicking pen, for example, sound very loud to you, and distract you 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:

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

- little understanding for the emotions of others;
- you always like to 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 you are good at as a result of your 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 people in your vicinity who also have autism?

The diagnosis

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).

Only a healthcare psychologist or psychiatrist can determine whether you have autism, on the basis of extensive tests and discussions with you and with your parents. You are only given a diagnosis if you meet 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

You receive this diagnosis if you have a large number of characteristics of autism, and the

characteristics were already visible before you turned three years of age. 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 you can speak and learn well, but have difficulty understanding what other people are thinking and feeling. You might also have a specific subject about you which you know a great deal, or an activity which you prefer 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. You may be given this diagnosis if you do not have all the characteristics of autism, but do have some of them. Or if there is no information available about the first years of your life.

McDD

You may be given a diagnosis of McDD (Multiple complex Developmental Disorder) if you have characteristics of autism, and in addition get angry extremely quickly or are 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. You may also have been given a diagnosis of ADHD, epilepsy or a mental handicap, alongside autism.

For more information on autism:
www.autisme.nl

A diagnosis is more than a label!

Whether you have core autism, Asperger's or PDD-NOS: this does not say much about who you are, or the type of guidance you need. A good diagnosis involves the healthcare psychologist or psychiatrist making it clear to you and your parents exactly which characteristics of autism you have, what you primarily have difficulty with, but also what you are good at. And that you receive targeted, specific advice about how to deal with *your* autism: at home, at school or during your free time.

A diagnosis of autism during puberty

During puberty, your body changes, school keeps setting increasingly high requirements of you, and your classmates are busy with themselves and are very sensitive about what others think about them. Perhaps you don't understand anything about all the changes you are faced with, and you don't know how to deal with them. Because you have autism, you develop differently to others your age. You can't see this on the outside: your body changes just like the bodies of other teenagers do. But in others, this maturing of the body is usually accompanied by a need to act in an increasingly adult manner. In your case, that need may only come a lot later. Many teenagers with autism feel younger than people of the same age, and prefer activities that younger children enjoy, in particular. And this can cause some problems in friendships.

Maybe you sometimes don't know what to do with yourself and your autism, and you feel miserable, anxious, angry or depressed. Don't keep these negative feelings to

yourself, but ask your parents or someone else to help you.

Friendships and leisure

For many teenagers, it is important to 'belong', to be part of a group, to feel that your classmates like you. There is a big chance that it takes a great deal of extra effort on your part to belong in the classroom or in a group, because you find it difficult to sense what the others in the group like or don't like. Or simply because you like totally different things to them. You might be trying to work out how you would like to behave in such a group, but that can give an unnatural impression, and sometimes result in bullying or teasing.

It may also be the case that you do not consider friendships to be that important, because you prefer to be alone. Or you do consider friends to be important, but you don't know how to go about getting them. One teenager with autism will make friends more easily than the next. It may also be the case that you prefer to be friendly with younger children, or even with adults, if they have the same interests as you.

Here are a couple of tips which might help you:

- Look for leisure activities which put the accent on 'doing' rather than talking, such as playing a musical instrument, dancing, drawing and painting, things involving animals, computer games. Maybe you excel at your hobby.
- Now that you know you have a form of autism, you might like to meet other teenagers with autism and do fun things together with them. There are special clubs and cafés at a number of locations in the Netherlands where you can do this.

"A buddy is more than a friend."

For more information on leisure activities for young people with autism in your area, please contact the Information and Advice Line of the NVA (see box on p. 11) and the leisure consultants of the regional MEE organisations (www.mee.nl).

- Of course, you can look for fellow people with autism on the Internet, on Hyves or Facebook, for example.

Sexual development

Just like other teenagers, sooner or later you will have to deal with your first sexual feelings. These often start with physical changes related to the biological maturation of the sexual organs, such as menstruation and growing breasts in girls, and the first seminal discharge in boys. If you have autism, you are generally not a great fan of changes, and it can be extremely frightening that your body suddenly feels so different.

Things like falling in love and sexuality can be additionally complicated for you, because you do not sense very well how to deal with them, what is the right thing to do in a specific situation, and what is absolutely the wrong thing to do.

Maybe, like many other teenagers with autism, you are tempted to go looking for 'rules' on how to deal with this, for example by watching how these things happen in television series or on websites, perhaps including porn websites. But these things usually happen very differently in 'real' life. And your autism could give you a tendency to apply rules which you have learnt very strictly, without any sense of what is suitable in a given situation. And it is not easy!

If you are having problems dealing with sexual feelings and all these changes in your body, you can look for help with this, together with your parents. You can find more information on this on page 10, the page for your parents.



"At the supermarket where I now work, they are very good at taking me into account."

Ready for the future

If you have autism, you will often need extra guidance and a clear structure at school in order to be able to pass your exams. This is possible at an ordinary school, but it may be the case that a special school is more suitable for you. Ask your parents and school to work with you to ensure that you get really suitable, exam-oriented education. This is worth fighting for! Because passing your exams is important and useful, in order to be able to work somewhere later on where you

can use your talents. But even without good exam results, there are options.

During puberty, important choices are made for the future: where would you like to live and work when you are an adult? Perhaps you are not yet thinking much about your future, but it is sensible to start talking with your parents about this.

For example, so that you can make the right choice of course after secondary school, one that suits you.

Do you want to know more about autism?

Suggested reading:

Various teenagers with autism have written down how they have experienced having autism. You can also find stories of teenagers with autism on the internet. Some suggested books and websites by and for teenagers with autism:

- Alone in My World (Vessel Broekhuis)
- Jackasses and Asperger's Syndrome. A manual for puberty. (Luke Jackson)
- Coping. A Survival Guide for People with Asperger's Syndrome (Marc Segar)

Specially for girls:

- Aspergirls (Rudy Simone)

Manual:

- Guide for Teenagers with Autism (Caroline van der Velde)

Web tips:

www.autisme.nl: Dutch Autism Association. Visit our Facebook page and follow us on Twitter (@autismeNVA).

www.autismeplein.nl: About autism and new media.

www.sociaalopstap.nl: Apps for your smartphone to help you in difficult social situations at school and elsewhere.

www.betergamen.nl: Toolkit for if you are gaming so much that you don't have enough time to do the other things you have to do.

www.brainwiki.nl: By and for young people with psychological problems, including autism.



DVD suggestion:

DVD: *A Sensually Stimulating Life*. Part 2: *Teenagers with Autism*. This DVD shows how Marieke and Darryl deal with their autism, and what this means for their parents and friends. This film is part 2 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 was made by the NVA, in cooperation with WonderlandFilm. 'A Sensually Stimulating Life' won a Golden Heron in 2008 for best documentary.

These films can be ordered at www.autismeboek.nl

Information for parents

As a parent of a teenager with autism, you will occasionally encounter a lack of understanding: people expect you to give your teenager more and more freedom, while in reality your child needs extra guidance and supervision. As a result, other parents - and your own child - may think you are being too protective. If you have good information about what it means to have autism, you may be able to create more understanding in the people around you (see also the reading suggestions on page 9). Autism cannot be cured, unfortunately, but with the right guidance, people with autism can often go to school, work and build meaningful relationships with other people. Below are a number of tips and suggestions to get your teenager with autism through this difficult life phase:

Dealing with autism in your family

With all the tension and stimuli at school, children with autism often offload at home, and can sometimes be disagreeable. You can't prevent this, but make sure you set apart the area your child uses for this. So that it is not at the expense of the rest of your family. Support from a family coach or parent guidance counsellor can help achieve a good balance in this. And to make sure that you are all able to keep going: ensure that there is plenty of relaxation for all the members of the family.

Guidance in sex education

Methodologies developed specifically for this target group:

- Asberger's Syndrome and Sexuality in Adolescence and Adulthood (Isabelle Hénault)
- seks@autisme.kom. A program for helping young people and adults with autism to learn about relationships and sex (Hans Hellemans, Peter Vermeulen and others)

- relaties@autisme.kom. Part 2. (edited by Peter Vermeulen and Sylvie Carette)

New media and gaming

Teenagers with autism sometimes appear to have no limits to their gaming behaviour and internet use. This book contains tips to help you find a balance in this:

- Gaming and autism (Herm Kisjes and Erno Mijland)

Preparing together for the future

The following websites can help you in this area:

- Information and advice on guiding pupils with autism in secondary education, and on the transition to further education: www.landelijknetwerkautisme.nl
- Information and advice on the transition to living independently (with supervision, as appropriate): www.woonpuntautisme.nl

What if your teenager with autism doesn't want any help?

In some cases, teenagers with autism refuse every form of help. This can give you as a parent a sense of powerlessness. It is scant comfort to know that these refusals of help are usually temporary. And maybe your child is open to other approaches, such as:

- digital resources, such as e-coaching and smartphone apps;
 - someone of the same age to act as a 'buddy' for practical help and to do fun things with.
- There are projects in various regions in which volunteers or students are used for this.

Suggested reading:

- Being unintentionally difficult during puberty and adolescence. Insight into frequently occurring developmental and other disorders. (Monique Baard, Désirée van der Elst and Mieke van Leijenhorst)

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, their families and other people around 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.

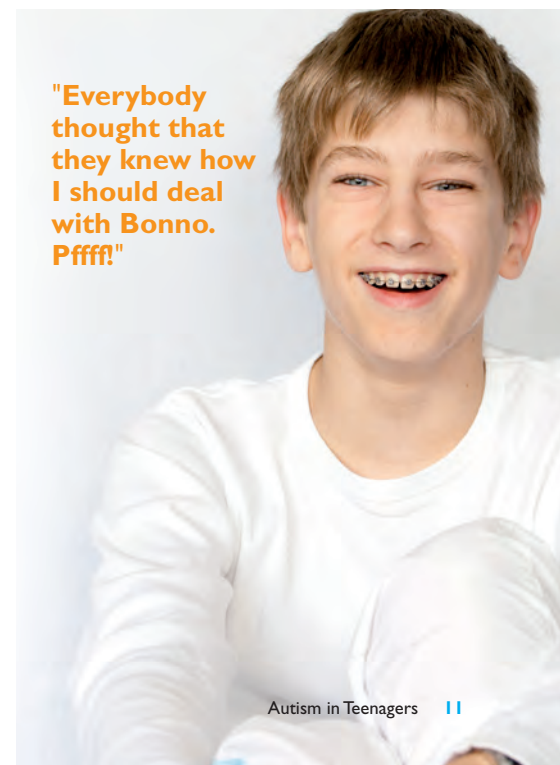
www.handicap-studie.nl

Information about studying with a limitation or handicap, including information about autism.

Information and Advice by and for parents

If you have any questions about dealing with autism during puberty, 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

"Everybody thought that they knew how I should deal with Bonno. Pffff!"



This is a publication of the Dutch Autism Association

This booklet is intended for teenagers who have received a diagnosis of classic autism, Asperger's, PDD-NOS or McDD, and their parents.

Dutch Autism Association (NVA)

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