

Section 1: Introduction and Initial Support

Information for adults following diagnosis of Autism Spectrum Disorder (ASD)

This pack has been put together from information available from specialist autism services, autistic people, and professionals working with autistic people.

Funding for this resource pack was kindly provided by the Edinburgh and Lothians Health Foundation, an operating name of the Lothian Health Board Endowment Fund, Scottish Charity Number SC007342

This leaflet may be made available in a larger print, Braille or your community language.

Resource Pack created by NHS Lothian Adult ADHD and ASD Resource Team

Foreward

This document has been produced following feedback from people diagnosed with autism and their families who requested written information about autism and autism resources in Lothian. The Lothian Adult ADHD & ASD Resource Team (previously referred to as LAAT), which includes health professionals from Psychiatry, Psychology, Occupational Therapy and Speech and Language Therapy, have contributed information gathered from their professional experience and current practice.

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The document has been reviewed by stake-holder groups of autistic people, workers in the autism field and health professionals with experience of autism diagnosis and clinical intervention with autistic people. We thank them for their ideas and input.

For the purposes of this document we will use the term Autism Spectrum Disorder to describe all diagnostic profiles, including Autism and Asperger Syndrome. We will also refer to autistic people, as a recent NAS (National Autistic Service) survey identified that more service users preferred this term.

We have written this booklet for the person recently diagnosed with Autism Spectrum Disorder but you may find it helpful to share some of the information with another person such as a partner, family member or employer.

We have checked the references and links to resources, websites and other sources of information for accuracy at the time of writing but cannot be held liable for changes that occur to the services and resources referenced. Reference is made to a range of services within Health and Social Care, Education, the voluntary sector and others. Reference to a service does not guarantee access to the service for all individuals.

Introduction to autism

What is autism?

Autism is a lifelong developmental condition that affects how people perceive the world and interact with others.

Autism is a spectrum condition. All autistic people share certain difficulties, but being autistic will affect them in different ways. Some autistic people say the world feels overwhelming and this can cause them considerable anxiety. In particular, understanding and relating to other people, and taking part in everyday family, school, work and social life, can be harder.

Autism is much more common than most people think. About one in a hundred people are living with autism in the UK. People from all nationalities and cultural, religious and social backgrounds can be autistic. Autism affects both men and women.

The appearance of autism can vary from person to person. One person with autism may be very verbal, bright and engaged, while another may be non-verbal and introverted or any state in between. Autistic people usually have some difficulties in the areas of:

- **Communication**

Autistic people may take longer than others to understand what somebody is saying. They may become confused when lots of information is given to them all at once and they may take things that people say very literally.



- **Thinking and imagination**

Autistic people may think in a rigid way. This means that they may find it difficult to consider alternatives or to accept when things are not as they expected. It can be difficult for them to think ahead and to guess what will happen next, which means that they may become anxious or confused in some situations. The patterns of thinking mean that autistic people often like routine and are good at setting up and following routines. They may have fixed interests and be adept at focusing on detail.

- **Social interaction**

Autistic people may find it difficult to work out what other people are thinking or feeling. It may be difficult for them to learn the 'social rules' about what to do with other people. They may feel anxious or fearful in unfamiliar places or with unfamiliar people because they find it difficult to make sense of what they see and hear.



- **Sensory processing**

Autistic people may experience sensory information differently. One or several senses may be affected, e.g. light, sound, touch, taste, movement, temperature. A person may be extremely sensitive or not notice differences in sensation at all. Sensory difficulties can vary from day to day and from place to place.

What do I do next?

Do I need to tell anyone I have autism?

It is up to you who you tell about your diagnosis of Autism Spectrum Disorder (ASD).

Some people find it helpful to discuss their diagnosis with their family or close friends as it can help them understand the person more easily and support them more effectively. Others prefer to keep the diagnosis to themselves. If you are not sure whether to discuss your diagnosis with your family or friends, then it may be helpful to find out a bit more about autism first of all, possibly through contacting one of the support services listed below. It is generally not a good idea to tell lots of people who you do not know well.

Some people report experiencing a range of emotions after they receive a diagnosis of Autism Spectrum Disorder. This can include a sense of vulnerability and a need to reflect on their core identity. Some people report that making connections with other autistic people and becoming part of an autistic community can offer a very positive support but this is generally a very individual experience.

If you are currently employed then you may find it helpful to tell your employer, but it is not a legal requirement. Employers are not allowed to discriminate against autistic people; indeed they are required by law to make 'reasonable adjustments' to help you in your work (see *Section 6: Finances, Employment and Education* for more information). If you are having difficulties in work it can be helpful to let your employer know so they can work with you to adjust your working conditions to make them easier for you to cope with.

If you are currently on benefits then it is a good idea to tell the benefits agency, although you do not have to.

You do not have to tell the Driving Vehicle Licensing Agency (DVLA) unless your autism affects your ability to drive.

Recommended websites and further reading- introduction to autism

What do I do next?

- **The National Autistic Society**

The National Autistic Society (NAS) has a comprehensive website with good information on matters relating to autism. The website also has links to other services, information and resources.

www.autism.org.uk

- **Scottish Autism website**

This provides general autism information as well as details of autism-specific training and education. Their online learning resource is called RightClick.

www.scottishautism.org

- **Scottish Intercollegiate Guidelines Network (SIGN) website**

This provides information about evidence based clinical practice guidelines for the National Health Service (NHS) in Scotland. There is a downloadable booklet for adults, partners, friends, family members and carers of autistic people.

<https://www.sign.ac.uk/patient-and-public-involvement/patient-publications/autism/>

- **Jessica Kingsley Publishers**

This publishing group has a wide range of books on autism.

www.jkp.com

- **Principles of Good Transitions 3 and Autism supplement**

A guide which has been developed as a result of Scotland-wide consultation in relation to transitions for young people into adulthood

<https://scottishtransitions.org.uk/7-principles-of-good-transitions/>

Where can I get support?

- **The One Stop Shop (Number 6)**

This service is free to access.



A major source of support in Edinburgh and the Lothians is offered by The One Stop Shop for Adults with High-Functioning Autism and Asperger syndrome (also called Number 6). Number 6 is managed by a UK wide voluntary sector organisation called Autism Initiatives and it receives funding from NHS Lothian and local councils. It provides a wide variety of support services at their base in the centre of Edinburgh, including:

- A post diagnosis group to help people learn about autism and how it affects them
- The 'Living Life to the Full' group which gives help with managing anxiety and depression
- Activity groups
- A 'drop in' service
- One to one sessions with a support worker
- Advice around employment and benefits
- Access to their large library of information about the autism spectrum.

You can access the support of Number 6 by phoning or emailing them using the contact details at the end of this section. Tell them that you have just been given a diagnosis of ASD and that you were advised to contact them. They will reply within two weeks and arrange to meet you to tell you more about the support they can offer.

- **Pasda – supporting families of adults with autism**

This service is free to access.

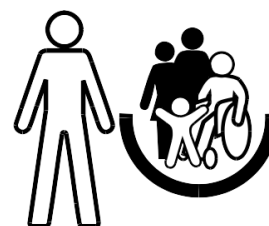


Pasda is a voluntary organisation which offers support to families in the Lothians with an adult with autism. More information about Pasda is available in *Section 5: Relationships*.

- **Social Work Department**

You can access other support services from the Social Work Department, including assessment of your support needs.

For example, you may be entitled to a support worker who can visit you in your home or somewhere else you feel comfortable. This type of support can be good for people who are unable to go to Number 6 or who need significant help with day to day living.



There are many support organisations that provide a service, some of which are specific to autistic people and others which provide more general support. Examples of autism-specific providers in the Lothians are the Autism Initiatives Outreach Service, Scottish Autism and the National Autistic Society. Contact details for all these organisations are given in the Recommended Websites and Further Reading section on the next page.

The first step in getting funding for individual support is to contact a social worker for an assessment of needs. You can do this by referring yourself, or asking someone you know well to refer you, through the Social Care system. You should tell them you have just been given a diagnosis of autism and ask to be contacted by a social worker. The operator will ask you some questions about yourself to see if social work support is likely to be right for you.

- If you live in **Edinburgh**, the telephone number is 0131 200 2324
- If you live in **Midlothian**, the telephone number is 0131 271 3900
- If you live in **East Lothian**, the telephone number is 01875 824 309
- If you live in **West Lothian**, the telephone number is 01506 282 252

Following the phone call, the operator will tell you if you will be placed on a waiting list for a social work assessment. It is important to remember that it can take weeks or even months before you are allocated a social worker. When you are allocated a social worker they will contact you and arrange to meet you to carry out an Assessment of Needs. This is a process by which the social worker will discuss with you what type of support you need, which organisation is best placed to provide it and how much funding you will be allocated for this support.

What NHS support is available for adults with autism in Lothian?

Most people who receive a diagnosis of autism spectrum disorder in Lothian are diagnosed through NHS services. In adulthood this is usually through mental health services. For many autistic people, this is the only contact they will have with mental health services, as most support after diagnosis is provided through social services and the voluntary sector.

Some autistic people may need further assessment or support by mental health services. This may be appropriate for you if you have:

- Mental health difficulties, such as anxiety and depression
- Significant attention or concentration difficulties
- Marked sensory difficulties
- Severe difficulties with aspects of daily living.

If you are already being seen by mental health services then you can discuss these with the healthcare professional. They may be able to help you themselves or they may refer you on to a colleague for further assessment.

If you are not currently seeing a health professional in mental health services, the first step is to see your GP. In some cases, your GP can treat mental health problems without referring you elsewhere. In other cases, your GP may refer you to your local mental health team for further assessment and support. If you have difficulty with sensory processing or aspects of daily living, you may be referred to a specialist mental health occupational therapist.

Recommended websites and further reading- where can I get support?

- **Scottish Independent Advocacy Alliance**

To find out about advocacy services in your area

Phone: 0131 524 1975

Website: www.siaa.org.uk

- **Number 6, The One Stop Shop**

Autism Initiatives Service - For adults aged 16 and over with autism (without a learning disability) who live in the Lothians and Borders

Phone: 0131 220 1075

Website: www.number6.org.uk

- **Pasda**

For parents and carers of autistic people

Email: info@pasda.org.uk

Website: www.pasda.org.uk

- **#actuallyautistic resources**

Peer-led resources can be a useful source of support and information for some people.

The hashtag **#ActuallyAutistic** was developed for the **autistic** community as an online community discussion space