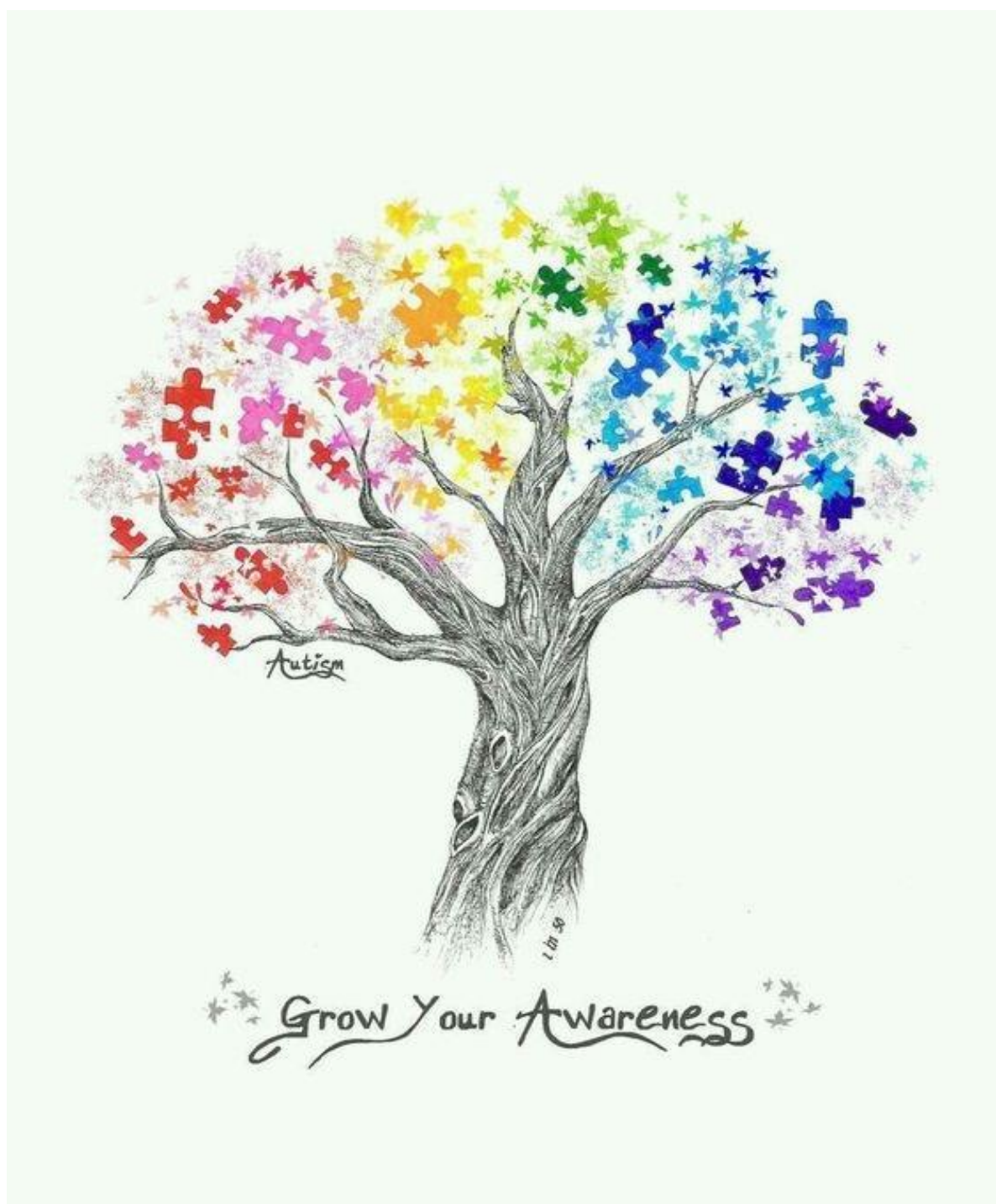


Autism Post Diagnostic Pack



Introduction

Acknowledgments

This document has been produced following feedback from people diagnosed with autism and their families who requested written information about autism and autism resources. We would like to acknowledge the Lothian Adult ADHD & ASD Resource Team (previously referred to as LAAT) for allowing us access to the document and allowing us to amend it to meet the needs of those within Forth Valley.

Terms Used

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 survey identified that more service users preferred this term.

Who is this resource for?

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.



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.

Flexibility 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.



Introduction to Autism



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.

Notes



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.

Some people find it helpful to discuss the 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 the 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 the chapter on Employment 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.



Mental Health

Many people experience times of low mood, anxiety or stress at one time or another and these are just part of typical human experience. However, sometimes these feelings become severe and start to take over a person's thinking and behaviour, to the extent that they struggle to manage their day to day life. This can be a sign that someone is suffering from a mental illness. Mental illnesses are common and are known to affect around one in four people in the population as a whole.

Although many autistic people are mentally well, people on the autism spectrum are at greater risk of developing mental health problems than the general population. It is important to remember that treatments do exist for mental illnesses, so you should seek help from your GP if you think you need it.

Some mild mental health problems can be managed with changes to lifestyle and stress management techniques. You may need help to organise these.

If you are ...	You could try this....
Stressed and anxious	<ul style="list-style-type: none"> • Try and establish a regular routine for everyday activities. • Reduce unexpected changes to your routine as much as possible
Low in mood	<ul style="list-style-type: none"> • Plan regular activities that you enjoy to help you feel better • Exercise regularly which has been proven to benefit mood and anxiety levels
Feeling worse in the morning	<ul style="list-style-type: none"> • Have a plan for each morning with specific activities to get up for
Frustrated that you are not sleeping well	<ul style="list-style-type: none"> • Try and follow a regular bedtime routine • Don't use Smartphones or tablets in bed • Avoid exercising or eating a big meal before bed time • Cut down on tea, coffee and caffeinated drinks, especially after 6pm



Mental Health

If these things do not work, or you are not able to manage them, then you may need specific treatment. Usually, the first step is to arrange an appointment with your GP. GPs can often treat mental health problems, usually by recommending some form of talking therapy or self-help and / or by prescribing medication. Sometimes they will refer you to specialist mental health services if they think that you need it.

Anxiety and depression are the most common mental health problems people experience. Some specific information about anxiety and depression is given below.

Anxiety disorders

What is an anxiety disorder?

Anxiety is a normal feeling and a common reaction to certain situations; indeed a moderate amount of anxiety can be helpful such as making a sportsperson feel more alert before a big event. In anxiety disorders this feeling becomes too severe to be helpful and can occur in the wrong context.

How do I know if I am becoming anxious?

Sometimes autistic people can find it hard to recognise when they are becoming anxious, instead just noticing that they 'don't feel quite right'. The symptoms of anxiety can be both mental and physical. The early mental symptoms of anxiety include feelings of tension, fear, negative thoughts or worry and feeling constantly tired. People can sometimes develop a strange feeling that either they or the world around them looks and feels 'unreal'.



Mental Health

Some physical signs of Anxiety

You could try this

<p>Dry mouth, churning stomach</p> <p>Eyesight becomes disturbed</p> <p>Feeling faint, feeling panicky</p> <p>Getting hot and sweaty, trembling</p> <p>Heart beat feels fast and strong</p> <p>Breathing feels fast and shallow</p> <p>Feel like you need the toilet</p>	<ul style="list-style-type: none"> • Sit down and sip a glass of water • Try to concentrate on your breathing and count each breath slowly in and out • Try to remember that this feeling will fade away shortly • Concentrate on a helpful word or phrase and say it slowly to yourself e.g. 'harmony' or 'wide blue ocean'
--	--

Other strategies that may help	You could try ...
Relaxation techniques	<ul style="list-style-type: none"> • http://www.moodjuice.scot.nhs.uk/asppodcast.asp. • Breathing exercises http://my.clevelandclinic.org/health/articles/diaphragmatic-breathing • Progressive muscle relaxation • Practicing regularly and when you are not anxious can help a lot when you need to use the technique
See your GP if your anxiety is severe or persistent	<ul style="list-style-type: none"> • Some medication may be helpful • You may be referred to a specialist

Depression

Everyone feels down or unhappy sometimes and this is a normal experience. The illness depression is when a person feels unhappy almost all the time for more than two weeks.

How do I know if I am depressed?

As well as persistent low mood or feeling unhappy for more than 2 weeks, people with depression often feel that they have no energy and don't enjoy things that they used to find fun. Sometimes people feel very negative about the future and think about hurting themselves or even ending their life. Physical symptoms of depression can include trouble sleeping and a loss of appetite.



Mental Health

You might be feeling...	You could try ...
Not enjoying things anymore Low energy levels	<ul style="list-style-type: none">• Try to have a regular structured daily routine• Take regular exercise• Get a good night's sleep• Make sure you are eating regularly and have a healthy diet
Feel like hurting myself or ending my life	<ul style="list-style-type: none">• Visit your GP who may give you medication or refer you to a specialist for talking therapy

You may require support from another person to put these things in place.



NHS Supports

CAMHS:

CAMHS (Child and Adolescent Mental Health Service) is provided by NHS Forth Valley. We work with you to understand your/your child's difficulties and where appropriate offer therapeutic interventions to help you make the changes you want to make.

The team is made up of a range of different professionals and we work together using the skills and knowledge of all the different professionals and disciplines, known as multi disciplinary working.

The strength of multidisciplinary CAMHS team-working is that distinct therapeutic approaches can be offered by utilising the different skills of each profession.

North CAMHS: Out Patient Department 3 (OPD3), Stirling Health & Care Village, Livilands, Stirling Tel : 01786 454546

South CAMHS: The Manor, Brown Street, Falkirk

Opening Hours: 9am-5pm Monday-Friday

Psychiatry:

Adult Mental Health Services are currently hosted within the Forth Valley Community Health Partnership.

The Organisation provides Adult Mental Health Services across the whole spectrum from Acute Hospital care to Community Services, Acute Admission and Assessment Services, Rehabilitation Services, Long-stay Facilities, Day Hospitals and Community Services.

Adult Mental Health Psychological Therapy Service:

The service is based at the Falkirk Community Hospital with sub-bases at Stirling Community Hospital and Clackmannanshire Community Healthcare Centre and Number 2 The Bungalows, Larbert. Clinics are also provided at a number of health centres and other locations throughout Forth Valley.

The Adult Mental Health Psychological Therapies Service offers assessment for adults experiencing psychological difficulties that are having a significant negative psychological impact on their mental health. We provide, where appropriate, expert psychological therapy. Therapy involves the person engaging in structured, time-limited; evidence based psychological interventions and can involve working through emotional distress.



NHS Supports

Speech and Language Therapy:

Speech and Language Therapists (SLTs) work with people with a range of speech, language, communication, and /or eating and drinking difficulties.

The NHS Forth Valley SLT team aim to:

- Provide an equitable, person-centred approach to people with speech, language and communication needs and to those with eating and drinking difficulties.
- Support people and their families to self-manage these needs.
- Develop the skills of other individuals involved with the person to use appropriate support strategies.
- Provide training and advice to other services when required.

The NHS Forth Valley SLT team support adults from across the whole Forth Valley area; working in a range of settings, including hospitals, care homes, clinics and in people's homes where appropriate.

Having a diagnosis of autism does not mean automatic access to these services. Should you wish to discuss a request for assistance for these services please contact your GP or NHS service directly.

NB For NHS services, if you wish to be included on this page please contact Alison Hall Autism Project Lead.



Where to get support

Carers Centres:



Falkirk Carers Centre - The *Carers Centre* provides information and support to carers of all ages living in *Falkirk* district and Clackmannanshire.

The Centre is managed by a Board elected from the membership of Central Carers Association, a voluntary organisation comprising carers and those with an interest in carers' issues.

Falkirk - Tel: 01324 611510

Clackmannanshire: 01259 226839

Email: centre@centralcarers.co.uk



Stirling Carers Centre –

If your life has become restricted by taking responsibility for the care of another who, due to illness, disability or age, cannot manage on their own, then you are a *carer*.

We aim to give you all the help you need to enable you to make informed decisions about your situation, and to support you in your caring role. Tel: 01786 447003

We provide:

- Advice & information
- Carer Support Plans
- Benefit checks
- Help with forms
- 1:1 Support
- Basic advocacy
- Respite events
- Hospital Support
- Peer support groups
- ...and more.

All our services are **free**, **confidential** and **impartial**.



General Links:



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.

<http://www.sign.ac.uk/guidelines/fulltext/145/index.html>



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

www.arcuk.org.uk/scotland



Autism Forth Valley Web Page

<http://www.autismforthvalley.co.uk/>



Website and Online Links

Autism Community



Asperger United

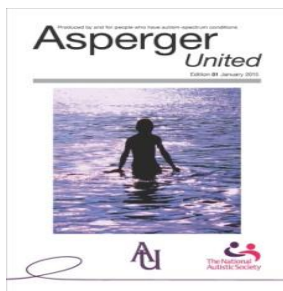
A free quarterly magazine written by and for people on the autism spectrum. <http://www.autism.org.uk/about/adult-life/resources/asperger-united.aspx>



Your Autism Magazine: our members' magazine

Keeps you up to date with the latest research, approaches and developments in autism.

<http://www.autism.org.uk/get-involved/membership/magazine.aspx>



Sam Radio

Internet community based radio station - not for profit organisation for Autistic adults.

<http://samradio.org/schedule/>



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

[#actuallyautistic resources](#)



Michael McCreary – stand up comedian

<https://www.aspiecomic.com>



Autistic Women



Scottish Women's Autism Network (SWAN)

SWAN was established in August 2012 in partnership with Autism Network Scotland.

"We meet for peer support and networking. We help each other by sharing our experiences and knowledge, having open discussions, women having the opportunity to meet like-minded women. SWAN is a network of women each with a unique perspective, shaped by individual experiences and circumstances; we represent a range of views on all sorts of issues from diagnosis to gender, from ASC as a difference rather than a disorder, to life in general."

<http://www.autismnetworkscotland.org.uk/swan/>



Scottish Autism Right Click Women and Girls Online Support

"Our women and girls programme is for autistic females of all ages, as well as parents, carers and professionals."

"The programme provides valuable information addressing key health and wellbeing challenges, as well as providing practical advice on a range of issues"

"The topics covered include: diagnosis, education, employment, positive living and parenting"

<https://www.scottishautism.org/services-support/support-families/women-and-girls-online-support>



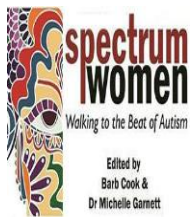
Autistic Women



The Girl with the Curly Hair Project

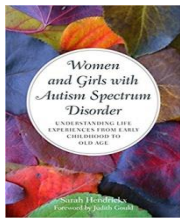
Training and advice for women and girls by young woman with ASD

Website: www.thegirlwiththecurlyhair.co.uk



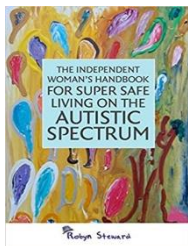
Walking to the Beat of Autism

Well-known writers provide advice, support and empowerment to fellow autistic women



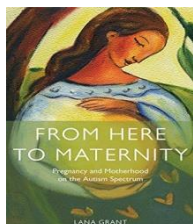
Women and Girls with Autism Spectrum Disorder

Book by Sarah Hendrickx about understanding life experiences from early childhood to old age



An Independent Woman's Handbook for Super Safe Living on the Autistic Spectrum

Book by Robyn Steward about recognizing potential risks to personal safety Topics include sex, relationships, drugs, money and mobile devices



From Here to Maternity – Pregnancy and Motherhood on the Autism Spectrum

Book by Lana Grant



Higher Education – University and College

Applying to university or college

The National Autism Society (NAS) has information on their website for autistic people who are considering applying to a university or further education college.

[UCAS](#) is the organisation responsible for managing applications to higher education courses that are offered at universities and colleges in the UK.

Disability Rights UK has further [information on applying to higher education](#).

Sharing information about a diagnosis of ASD

Many people worry that disclosing their disability when applying to university may lead to discrimination against them. Universities and colleges have a legal requirement to make 'reasonable adjustments' so that students with disabilities are not put at a substantial disadvantage. An example of a 'reasonable adjustment' could be to provide copies of the lecture notes for a student who finds note-taking during lectures difficult.

What supports are available?

You will need to contact the disability support staff at the university or college to find out about support services they offer and for a chance to talk about the support that you feel you may need whilst studying. It is useful to make contact with the support services before starting university or college so that the support is in place from the beginning of the course.



Disabled Students' Allowance

You may be eligible for a Disabled Students' Allowance (DSA), awarded through SAAS (Student Awards Agency Scotland). These grants are available to help with costs that students may incur as a direct result of their disability. Unlike a loan, these do not have to be paid back.

SAAS gives information about what you can claim under DSA, how to apply and contact details.

Student Awards Agency Scotland

Scottish Government agency giving financial support to eligible students

www.saas.gov.uk



Higher Education – University and College



The National Autistic Society

Information and support for students

www.autism.org.uk/services/scotland/further-education.aspx



Disability Rights UK Student helpline

Tues and Thurs 11am-1pm

Phone: 0800 328505

Email: students@disabilityrightsuk.org;

“We recommend that disabled students who are studying in or wish to study in Scotland contact Lead Scotland (0800 999 2568) for more specialised information and advice about education and training in Scotland. The Lead helpline is open 2pm-4pm on Mondays, Wednesdays and Thursdays and 10am-12pm on Tuesdays and Fridays.”



UCAS

This organization is responsible for managing applications to higher education.

Phone: 0871 4680468

www.ucas.com



Disabled Student Allowance Quality Assurance Group

www.dsa-qag.org.uk

<http://www.dsa-qag.org.uk/students/find-your-disability-officer>



Higher Education – University and College

Individual universities and colleges provide further information on their websites about the support they can offer students with disabilities and support needs including Autism Spectrum Disorder. Some local institutions are referenced below.



- **Stirling University Support Services**

<https://www.stir.ac.uk/student-life/support-wellbeing/student-support-services/accessibility-and-inclusion/>



- **Forth Valley College**

<https://www.forthvalley.ac.uk/student-info/support-advice/learning-support/>



Assistive Software



For some people processing (listening to and understanding) verbal or written language can be difficult. There are a variety of resources available to support your processing and retention of information. Some of these resources are free and some incur a fee. There may be funding available for these supports if you are in College or University.

Note taking

Audio Notetaker (Windows and Mac)

This program enables you to record teaching sessions directly into your computer. The audio appears visually on the screen so you can colour code important information as it is being recorded, enabling you to identify relevant points and tasks later; without having to listen to the whole lecture / meeting again. PowerPoint slides and PDF documents can also be imported into an Audio Notetaker project before the session.



Mind mapping

This type of software enables you to create mind maps, timelines, plans and Gantt charts; organizing thoughts and ideas in a structured way. You can also add references and include useful information from web pages for use in your mind map.



ClaroRead Plus (Windows and Mac)

This program can read documents and web pages aloud in a human-sounding voice. It contains a comprehensive dictionary, spellchecker, and converts text to audio for listening on an MP3 player. This software is ideal for checking your work for sense and structure.

Claro Software – there are demo presentations on YouTube channel.

This list is for illustrative purposes only and not exhaustive. There are other software programmes available.



LGBTQI Community



LGBT Health and Wellbeing

This is a community led group that provides a safe social space, campaigns on relevant issues and raises awareness within mainstream Autistic organisations and LGBT organisations. Reduce social isolation, increase confidence, self-esteem and to empower individuals to become more active within their communities. This is for people aged 16+.

Helpline : Open every Tuesday and Wednesday from 12- 9pm
0300 123 2523

<https://www.lgbthealth.org.uk/>

<https://www.lgbtyouth.org.uk/groups-and-support/>



National Autistic Society – Gender and Autism:

<http://www.autism.org.uk/gender>



Autism and the Justice System

- <http://www.autism.org.uk/about/adult-life/the-law.aspx>



Employment

A 2006 survey estimated that there were over 46,000 autistic people in Scotland, which has a total population of around 5.2 million. Many adults can and want to work; yet recent research by The National Autistic Society found that only 15% of autistic adults were in full-time employment.

Autistic people can experience a range of difficulties that make it difficult for them to find and keep a job. With the right support and training for both them and their employer and colleagues, Autistic people have much to offer in the work place. A combination of the right support and appropriate opportunities can make a real difference to many autistic people.

Why employ an autistic person?

Autistic people can make effective and highly valued employees. As is the case with all employees, it is important to match a person's particular skills to the requirements of the post. Autistic people can be very focused and have considerable skills in specific areas, which can include attention to detail, a methodical approach, strong research skills, good long term memory and excellent record-keeping.



What can your employers do to support you?

Your employer can make a number of **reasonable adjustments** to working practices to support you if you have a diagnosis of autism.

Some examples of supports and adjustments your employer can make include:

- Appointing a colleague to act as a mentor for you, to help with any issues that arise and if need be represent your views;
- Arranging general and specific autism awareness training for staff who work with the employee(s) with autism
- Bringing in help from external support organisations that offer job mentoring, coaching and general or specific job assistance to autistic people
- Using a job coach to help both employer and employee to establish a successful working partnership.



Employment

The National Autistic Society has further information on reasonable adjustments in the workplace for both employers and for autistic employees, including fact sheets for employers:

<http://www.autism.org.uk/professionals/employers/information-for-employers.aspx>

The main goal is to help promote the values and skills autistic individuals can bring to a business or organisation, which may not have been initially obvious.

Access to employment

<http://autismforthvalley.co.uk/adult-austim/employment-support/how-get-help-access-employment/>

Employability (Forth Valley)

We support people with long-term health conditions and disabilities to access paid employment. Clients work with Case Managers to assess their health, skills, experience, training and employment goals. The team provides access to a range of health supports and intervention through specialist in-house provision in partnership with NHS Forth Valley. This can include health checks, stress management, counselling, functional and cognitive assessments and advice about managing long-term health conditions.

<https://my.stirling.gov.uk/services/community-life-and-leisure/adult-education-and-community-learning/employability>

Working Health Services Scotland (WHSS) provides free and confidential advice and health support to the self-employed and individuals employed by companies with less than 250 employees.

If you have a health condition which you feel is impacting on your work, you could benefit from Working Health Services Scotland. The service aims to help you manage your condition, preventing you from having an episode of sickness absence or assist you in returning to work after a period of sickness absence.

<http://www.salus.co.uk/return-to-work-services/case-management/Working-Health-Services/Pages/default.aspx>



Daily and Social Activities



Quiet Hours

Some shopping centres and supermarkets have introduced Quiet Hours where they will often dim lights, turn music off, avoid using the tannoy and turn check-out beeps down.



Autism Friendly Cinema Showings

Including Odeon, The Vue, Cineworld, please see the cinema website to check details.



LGBT Health and Wellbeing Social Groups

<https://www.lgbthealth.org.uk/event/lgbt-autism-group-2/2018-06-09/>



SWAN Social Groups

SWAN hold regular meet ups for autistic women

https://www.facebook.com/pg/swans.scotland/events/?ref=page_internal



National Museum of Scotland

<https://www.nms.ac.uk/national-museum-of-scotland/plan-your-visit/events-and-resources-for-autistic-people/>



Autism Network Scotland have an events calendar that holds information about events being held near you.

<http://www.autismnetworkscotland.org.uk/>



The pack is a working document and will be updated and altered as required. All information is correct at time of print and may be subject to change without notice.

