

Post-diagnosis support

For parents/carers

For parents/carers, the person you care for receiving a diagnosis can be both a positive, and overwhelming experience for most people. The type of support the person you care for will want to access, and you will as a carer will want to access, will be completely dependent on your own unique needs. Here are some suggestions of potential support networks and resources you might be interested in post-diagnosis.

Autism advice line

The autism advice line is a small team of autism advisors, who are experienced in working with autistic people and their families, who are available to provide information, advice, and emotional support through telephone, e-mail, or livechat. You can also fill out a contact form, leaving your number, and we can arrange to phone you at a time that suits you.

We understand you may feel uncomfortable about reaching out to a team of people who you do not know. Therefore, you can access our "<u>Meet the Advisors</u>" page to see the names and photographs of those within the advice team.

As part of our Advice Line Plus programme, we are offering extended support. Our phone, e-mail, and live chat are open 7 days a week, 8am – 8pm. We are also offering a Chat to Us service, where an advisor can phone you regularly for a chat.

- Contact us by phoning: 01259222022
- Or e-mailing: Advice@Scottishautism.org
- Or filling out a contact form.
- Reaching out to us through our Facebook "Ask an Advisor" group.
- Or accessing our website and starting a Live Chat from the bottom right hand corner of your screen.

Right Click for parents and carers

Right Click is for parents or carers of autistic individuals who are in particular need of information and support. Our experience tells us that this is often when a child is newly or

recently diagnosed or when they are coming up to a major personal or environmental transition and so we have developed our programmes accordingly. The online programme builds over four weeks with new content being released each week and then a fifth week is available to review any of the materials which were of particular interest. The content is largely made up of videos with some supporting documents. Parents are also assigned their own autism advisor who can be contacted to answer questions or give more specific advice for your family.

Find out more.

Right Click for women and girls

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. We have engaged with women and girls from the autism community and we have drawn on the expertise of a network of professionals to develop a range of videos and other support materials.

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

Find out more.

Carers centre

Each area will have a carers centre, designed to provide support to unpaid carers. A carers centre will design an Adult Carer Support Plan for you, which explores how your caring role impacts on you and what support you might need. They can provide information and advice on benefits, respite and short breaks and support services. Some centres even offer peer support groups and can help to access counselling.

To find your local carer centre, visit <a>Care Info Scotland.

Peer-support groups and befriending

Peer-support groups involve connecting with others who are also autistic to gain a better understanding of your new diagnosis, and make meaningful connections with others. There are various peer support groups throughout the country, and an autism advisor can try to find you ones which are close to you. Here are some common ones:

- Scottish Autism Parents and Carers Group
 Scottish Autism has recently opened a <u>Facebook group</u> as a safe space for autistic people to connect and network. An autism advisor will be available during opening hours to answer questions you may have.
- Scottish Autism Facebook Affinity Group (adults)
 Scottish Autism has recently opened a <u>Facebook group</u> as a safe space for autistic people to connect and network.
- Scottish Women's Autism Network (aged 17+)
 SWAN is a female only peer network, which is mostly online. They do also have face-to-face meet ups in some areas. It is for women who have a formalised diagnosis of autism and those who self-identify as autistic with no

formalised diagnosis. Much of the support provided through this online network is about hearing others experiences and sharing advice and guidance.

NAS Social Groups

National Autistic Society Scotland operate <u>social groups</u> which are currently running online.

Please contact our autism advice line if you need support finding what may be more suitable/closer to you.

Befriending

NAS Person to Person (aged 26+)

<u>Person to Person</u> is available to autistic adults (aged 26 and over) who live in: Glasgow, East Dunbartonshire, East Renfrewshire, Inverclyde, Renfrewshire, West Dunbartonshire, North Lanarkshire and South Lanarkshire:

• Scottish Autism's Chat to Us Service

At Scottish Autism we understand that this is a challenging time for autistic people, their friends, family and carers. We understand that many people maybe feeling isolated from love ones or due to social distancing aren't able to connect with people like they would usually. Our Chat calls are designed to offer a support, conversation and signposting to anyone who needs a listening ear.

You can register for this service here.

• Other befriending networks

You can search for other befriending networks in your area

School and education

After a diagnosis, you may wish to contact your child's school to discuss how this diagnosis will affect their current assessment of your child's needs, or to access this assessment if one has not been carried out so far. You can also discuss what support is currently in place, and what support you feel should be in place.

For further support with ensuring that your child's needs are met within school, we would recommend contacting <u>Enquire</u>. Enquire is Scotland's national charity for supporting parents to understand their child's rights within school, and providing advice on how these needs can be met.

Employment, finances, and study

You may be looking to help the person you care for access supported employment programmes if they have struggled to access support into employment without a diagnosis. We can help you identify if any suitable programmes are running in your area.

You may also wish to apply for DLA or Personal Independence Payments to help financially support you. To do this, contact your local carers centre or Citizens Advice Bureau.

If they are at college or university, your institution will have a department which provides support for disabled students. Contact them to see to see what support they can offer. Many universities will have a disability advisor or similar. If you are studying in Higher Education (HNC, HND, or Degree), you can apply for <u>Disabled Students Allowance</u> to help with equipment or to fund a direct support service

There may be additional grants you are available to access. The <u>disability grants website</u> can help you identify suitable grants.

Social care services

A social care service means having a support worker, care assistant or personal assistant to support your child through day-to-day life, or being able to access a day centre or vocational opportunity. You can access these services by contacting your social work department in the first instance, you do not already have Self Directed Support. Our autism advice team are happy to explain the process for you.

Autism Alert Card

This card enables those who carry it to identify themselves as being autistic. The card highlights how the bearer may have differences in communication and interaction. It can also include a named contact who can offer their support to help police, ambulance, hospital and other key public service professionals better understand the person's needs. Where you can to access your card will depend on where you live. Some alert cards are only available for those aged 16+.

- Central Scotland
- Strathclyde
- Highlands & Islands

E-mail: autism.alertcard@nas.org.uk

Lothian & Borders

E-mail: matthew.day@aiscoltand.org.uk

• <u>Aberdeen</u>

You can also download an "I am autistic card" from the National Autistic Society Website.

Communicating your support needs in the community

The person you care for can use other resources to help people identify that they may need assistance in the community.

Sunflower Lanyard

Some autistic individuals choose wear a Sunflower Layard in some environments where they may need extra support or assistance (such as, a supermarket or airport). This can help others identify that they have a <u>hidden disability</u>, and to identify that they may need support.

CEA Card (for those over 8 years old).

A <u>CEA card</u> can be used to allow you to access the Cinema more easily. It can entitle you to one free ticket for a carer or supporting person, and can identify that you may need additional support or adjustments in the cinema. You must be in receipt of DLA, PIP, Attendance Allowance or PIP to access this.

COVID card

The coronavirus pandemic has resulted in temporary changes in social rules and laws. Our <u>COVID alert card</u> can be used to identify to police or other professionals that you are autistic if you are challenged in public, and may find these conversations difficult.

Hospital passport

A <u>Hospital Passport</u>, or health passport, can be created and kept with you should you ever need to access a hospital, but cannot communicate your needs. You can contact your local health board to see if they have their own, or download another version, such as this one from the National Autistic Society.

Keep Safe Card

Keep Safe is a project between Police Scotland and Local business, to allow people to access a Keep Safe place if they become lost, confused, or frightened when out in the community. Keep Safe participating business can be identified by a logo on their window. You can download a card detailing your information, and download an app to identify local Keep Safe place.

Advocacy or collective advocacy

An independent advocate can help you ensure that your voice is heard, and can help you communicate with others. Collective advocacy is where a group of people who share similar experiences come together to ensure that their, and the voice of their group, is heard.

You can find a local advocate or advocacy service here.

Groups, clubs, and other voluntary agencies

There may be charities and groups running in your local area which you can contact for support. You can contact the advice line if you would like us to search for you. Alternatively, you may be able to find these through the <u>National Autistic Society autism directory</u>.

For clubs for autistic children, you may find these by contacting your local community centre.

We may also be able to help you find peer support groups for other parents/carers.