

Supporting the Family

What GPs and Primary Care Practitioners need to know

- You, or the family, suspects your patient has an ASD
- Enlisting the support of the family/carer in preparing for the appointment
- Enlisting the support of the family/carer during the appointment
- The family has difficulty coping

Supporting the family

What can you do to help?

You, or the family, suspects the person has an ASD

History: Early diagnosis may improve outcomes so find out the nature and timing of first concerns; professionals that have been seen; views of the wider family; feelings about advice they have had to date.

Assessment: It will help if you conduct an assessment of need both for the individual and significant family members/carers. Focus on social and communication skills and behaviour; information processing; behaviour or concerns in more than one setting and speech and language development.

Remember that difficulties can be subtle, adults may not have been diagnosed at an earlier age for a number of reasons and females may present differently.

Referral: Refer to the relevant team for multidisciplinary assessment in your area. The NAPC (National Autism Plan for Children) set out procedures for multidisciplinary assessment and is helpful along with more recent guidelines (SIGN, 2007) and NICE (2011;2012)

Linking: Families and carers can find it difficult to maintain contact with a range of professionals. It is helpful if they can come back to the GP as a link person. If the person has been referred for multidisciplinary assessment, it is useful if the GP stays fully informed about progress with the assessment, through links with a key-worker.

Listen: Parents/carers are often told to 'wait and see' if they are concerned. If a parent expresses concern, there is likely to be a strong basis for this concern.

Support literature: Give access to support literature. Useful resources are listed at the end of this resource. Many areas now have a "One Stop Shop" which helps individuals and families/carers access local information, support and resources.

Enlisting the support of the family/carer in preparing for the appointment

Before the visit: Conduct an initial assessment over the phone, finding out about strengths, limitations and previous experiences of appointments. Seek guidance on types of communication that will work best for the patient with an ASD.

Be clear about what will happen: Provide information for the family/carers about who will be present and what will happen so they can then prepare the person with an ASD. Ask about what works best, what to avoid and find out about sensory sensitivities. Find out about the person's level of understanding, how the person prefers to be touched, whether there are specific fears and concerns.

Plan: Decide where the family/carer and patient can wait, minimise waiting time, plan the procedures, find out about behaviour strategies to use.

Enlisting the support of the family/carer during the appointment

The appointment: The person may need extra time for the appointment.

Model: Show the patient and the family member/carer what you are going to do

Structure it might be helpful to suggest to a parent or carers that a preferred activity or routine could follow the appointment and that the individual with ASD knows that this will happen

Observe: Use the family/carer's approach as a guide when interacting.

Calm the patient: Have de-stress toys available (eg squeeze balls). Ask the individual and parent / carer about calming techniques.

Enable understanding: Help the carer understand the condition; the parent/carer can help the child with independence skills such as dressing, by using visual strategies.

Advice: Resources that give advice on toileting, relaxation techniques; food and diet, sleep and dealing with anxiety are available in the web resource.

Intervention: If possible, conduct interventions in another room from discussion, to avoid negative associations.

Afterwards: Provide a written summary after the appointment for individual and/or the family/carer.

The family has difficulty coping: Research shows that families of people with ASD experience high levels of stress.

Accessing support: Social services can help with home support and short term care; self directed supports; and advice regarding benefits, housing, employment and accommodation.

Referral: Refer to local and national parent organisations and agencies that provide short term care and other support.

Resources

Autism Network Scotland connects and communicates with individuals on the autistic spectrum, their families, carers, and practitioners working in the field of autism. It is a hub of reliable and impartial information, signposting people to supports, resources and useful information. ANS offers a platform for knowledge exchange and sharing of good practice and promotes a solution focused approach. ANS supports regional networks across Scotland by providing a neutral space for discussion and communication. www.autismnetworkscotland.org.uk
The National Autistic Society is a leading UK charity providing support, help and information for those with ASD, their families, carers and links to resources including information for GPs.

<http://www.autism.org.uk/working-with/health/info-for-gps.aspx>

National Institute for Health and Care Excellence (NICE) provides clinical guidelines for different conditions. Guidelines on diagnosis and management for Autism Spectrum disorder are available for both children and adults

<http://www.nice.org.uk/guidance/cg128/>

<http://www.nice.org.uk/guidance/cg142>

One Stop Shops offer advice and support before, during and following diagnosis.

<http://www.autismnetworkscotland.org.uk/one-stop-shops/>

Scottish Intercollegiate Guidelines Network (2007) SIGN 98: Assessment, Diagnosis and Clinical Interventions for children and young people with autism spectrum disorders

The Scottish Strategy for Autism: Menu of Interventions (2013) was developed by a multi-agency group (including parents and carers). It provides a guide to intervention aimed at providing support to individuals on the autism spectrum across the age range and across the whole of the spectrum.

<http://www.gov.scot/Resource/0043/00438221.pdf>

Want to know more? This leaflet forms part of the NHS Education for Scotland web resource on Autism which can be accessed at:

<http://www.knowledge.scot.nhs.uk/home/learning-and-cpd/learning-spaces/autism-spectrum-disorder.aspx>