

What happens after the assessment?

A written report is sent to the patient and the professional who made the referral. With the patient's consent a copy is sent to the parent/s / other key informant/s and to any other professional involved who may be able to support and help the patient in the future. Normally no routine medical follow-up is necessary unless there is also another condition needing treatment such as clinical depression. Where follow-up is necessary this is often planned in conjunction with the local Social Services and sometimes in conjunction with the local Community Mental Health Team. Normally the patient and family or other carers are invited to take part in planning discussions. After discharge, the specialist staff from the assessment clinic will not usually be directly involved in this. The Care Plan will contain the details of support needed by the patient, based on the needs and as far as possible their wishes and preferences.

Information on other local sources of support is provided for patients from Leicester, Leicestershire and Rutland. This will typically include information on the Asperger Syndrome Monday Club, support through social services, local colleges and universities and with housing, welfare benefits, legal advice, and employment.

What happens if I am unhappy with result of the assessment?

Sometimes people tell us that they are unhappy with being told that they will not get a diagnosis of asperger syndrome (or autism) from the clinic. Autism is a complex spectrum condition and we are still learning more and more about it. Diagnosis is not a simple yes/no decision but we recognise that that decision may affect access to further help. All patients have a right to a second independent opinion. If your GP agrees to support you in obtaining a second opinion we will do our best to make this possible.

Useful Telephone Numbers

Professor Brugh's Secretary, Hadley House,
Leicester General Hospital
Tel: 0116 295 4553
AdultAspergersLPT@leicspart.nhs.uk

Useful Web Page and address

National Autistic Society
392 City Road, London EC1V 1NG
Tel. 020 7833 9666
Website: www.nas.org.uk

LEAT
Asperger Support Services
178 London Road
Leicester
LE2 1ND
Tel: 0116 254 1664
Email: info@leatleicester.org.uk
Website: www.leatleicester.org.uk

The Monday Club
Leicestershire Centre for Integrated Living
West End Neighbourhood Centre
Andrewes Street
Leicester
LE3 5PA
Tel: 07873 311610
Email: TheMondayClub@hotmail.co.uk

TRANSLATE
Website: www.translate-asc.org.uk
Tel: 01509 554 797
Email: translate_as1@ntlworld.com

For support on leaving school (from age 14 to 25 years) contact your Local Education Authority (LEA)
Leicester City LEA – Tel: 0116 254 9922
Leicestershire County LEA – Tel: 0116 232 3232

For support at FE College or University please contact the Student Support Services at the relevant institution.

Leicestershire Partnership 
NHS Trust

The Asperger Syndrome Assessment Process for adults

What is Asperger Syndrome?

Asperger Syndrome (or Autism Spectrum Disorder) is a developmental disorder that can be recognised in the second or third year of life. If you think that you or someone in your family might have Asperger Syndrome it can be diagnosed in adulthood too. People with Asperger Syndrome have to learn to manage life long difficulties in *their* understanding of other people and in communicating with them. So much *in* life depends on social communication, so extra help may be needed in school or with learning to live independently. Employment can be stressful because supervisors and other staff often do not understand the difficulties that people with Asperger Syndrome face. Asperger's Syndrome (or autism) is a relatively newly discovered disorder and some doctors do not have formal training in its assessment. The Trust has established an assessment process to help. Specially trained NHS staff run this *process*, in partnership with your local Social Services Department.

Why getting a Diagnosis is important

Some people who are wondering if they have Asperger Syndrome may have a different condition such as ADHD. So it is very important that a correct diagnosis is made early on, so that the right specialised help and advice can be found.

This may involve a visit to an NHS clinic to see staff trained to assess Asperger Syndrome, or related problems on the Autistic Spectrum, and other conditions.

The assessment process should also involve parents, another older relative, a longstanding partner or confidante. This is because only they can describe the early childhood and lifelong experiences in communication, problem solving and development on which the diagnosis is based.

Consent and Initial Assessment

In order for us to begin the assessment process, we need to obtain the consent of the prospective patient to involving their parent(s), or another older relative, or someone who knows them well for many years. Autism (or Asperger Syndrome) assessments are mainly based on a developmental history of the individual. This is obtained from such an informant who has had regular or day-to-day contact with the patient for as much as possible of their life. It can also be helpful for us to see other childhood health and educational records if difficulties arose early on (child health, psychology, speech and language therapy, mental health). Their information will help us to decide if the patient (you or your relative) will benefit from a full and detailed assessment for a possible diagnosis of Asperger Syndrome.

First the patient is invited to attend with a parent or informant for a half hour meeting. This is to help us decide if a more detailed assessment will be needed. People coming to this first meeting usually fit into one of three groups. A few are very obviously autistic. The doctor can often make the diagnosis and make recommendations without further delay. Some are clearly not autistic but may have a few traits of autism (which is why it was suggested they come to the clinic). We may point them to another service if they need it. The third group includes people who it may be difficult to tell what the problem is and who may need a more detailed assessment. We also advise their GP in writing.

Questionnaire on development

At the initial assessment, once we have received signed consent from the patient, we arrange for a Development Screening Questionnaire to be completed (by parent/s, informant/s). We need consent to keep this information on the medical

file about the patient because the person giving us the information is not the patient.

This is quite a long questionnaire and may take a week or two to fill out. Parents often find that looking at old photographs and school reports helps them to remember what life was like during their child's early years. If the patient joins with his/her parents in completing the questionnaire it is the parents' (or other informants replies) that we require.

Full Assessment

If we feel that a full assessment is needed we will invite the patient and parent/s (and or informant/s) to attend for a full half-day assessment. In order to complete the diagnosis we allow half a day for this to give plenty of time to talk. Due to demand there may be a long delay before this can be arranged; we can give an estimate of how long this may take.

The half day begins with a meeting with the family members present and or anyone else who has been invited, with the agreement of the patient. *Next* the parents / informant/s will spend a period of time (between 1 and 1½ hours) discussing the developmental questionnaire with the professional carrying out the assessment. After this the professional will see the patient alone for up to an hour.

We also encourage people to obtain written information on Asperger's Syndrome through the National Autistic Society, before the assessment (their address and website are overleaf).