



Your child's autism spectrum disorder (ASD) appointment

Information for parents from the Community Child Health team

Our team have discussed your child at our monthly social communication meeting. The team have added your child to the waiting list for assessment. We will send you an appointment as soon as your child is near the top of the list. In the meantime, below is information about your appointment.

Why has this appointment been arranged for my child?

This appointment has been offered as concerns have been raised about your child's development. These concerns are mainly about their social communication skills. You may have raised these concerns yourself or others might have raised them with you. The doctor who referred you for this appointment will have explained the reasons for your referral. They will have put these in writing for you after your child's appointment.

What will happen during our appointment?

Members of our team will see you and your child. This team may include a:

- consultant community paediatrician
- specialist nurse
- speech and language therapist (SLT)
- clinical psychologist.

East Kent Hospitals is a teaching hospital. This could mean that this team also includes supervised students, trainees or visiting staff. This will give these individuals valuable training and experience. It will not affect the quality of your appointment in any way. We will always check with you first, so please tell us if you would rather they were not present during your appointment. We will always respect your wishes.

Will I be with my child during their assessment?

We may assess your child on their own, without you in the room. This would be normal if your child is of school age. In order for this to go smoothly, please prepare your child for this before their appointment.

During this time, another member of the team may speak to you on your own. If not, we will ask you to wait in the waiting area for your child to finish their assessment.

What will my child's assessment involve?

Your child's assessment will focus on assessing their skills in:

- play
- communication
- social interaction.

The assessments are designed to be fun and we find that most children enjoy them. If your child dislikes the assessment or becomes upset, we will stop the assessment and make another appointment.

Your child's assessment may be video recorded. This is to help the team discuss the assessment and write their report. We will ask for your written consent for this recording. Please ask any questions you may have. Once the team has watched and discussed the recording, they will save it to your child's electronic health record.

What will I do while my child is being assessed?

While your child has their assessment, another member of the team might speak with you in a separate room. This could take up to an hour and a half.

They will ask you about your child's:

- developmental milestones, such as when your child first began to walk
- communication and social interaction skills
- their play and imagination skills.

There will also be a chance to talk about any difficulties with your child's emotions or behaviour. This may include how they cope in crowded places, and how they share toys.

If we already have this information from a previous appointment, we may ask you to wait in the waiting room for your child.

We try to reduce the time you have to wait for the assessment to be completed, so your child's assessment and talking to you may happen on different days. We will let you know if this is the case.

A paediatrician may also carry out a brief physical examination during this appointment. This will be in the main clinic room, and you will remain with your child at all times during this examination.

How long will the appointment be?

Your appointment could take up to an hour and a half (90 minutes). This includes your child's assessment and discussion of the findings afterwards.

Can I bring other children / family members / friends to our appointment?

Due to the nature of this appointment, we advise you not to bring other children with you, if possible. We understand it can be hard to get child care, but this is may be quite a long appointment. We will need you to be able to focus fully on the child we are assessing. It is also hard for other children to see toys and not be able to join in. Also, it can be strange for the child we are assessing not to have their sibling join in as normal.

You can bring other family members, friends or other professionals as support or as a source of information.

Do I need to do anything before our appointment?

Your appointment will focus on observing symptoms of Autism Spectrum Disorder (ASD) in your child.

We will ask you in detail about signs you may have seen in your child, signs that they may be developing a little differently to other children. Please think about some of these things ahead of your appointment. We may already have this information, but write it down anyway and bring it to your appointment. Please bring updated information or share how you see your child developing.

What should I bring to our appointment?

Bring any reports of assessments completed by other health or education professionals. These will help us learn more about your child.

What happens after our appointment?

- At the end of your clinic appointment, the team will discuss your child's results. Often, we are able to give you detailed verbal feedback about your child's assessment straight after our discussion. If not, we will call you at home later in the day to give you the feedback. Please ask any questions.
- Some parents and caregivers are happy for their child to be in the room during this feedback. If you prefer them not to be, we can sometimes make arrangements for this on the day.
- Our feedback might include confirming a diagnosis of Autism Spectrum Disorder for your child.
- If we are not able to finish our assessment and confirm a diagnosis, we may plan to collect further information. This could include observing your child at school.
- We will produce a detailed written report of our findings and any diagnosis made. Depending on your child's diagnosis, we will also give you:
 - written information about services you can use
 - general advice about how to manage any difficulties we have noted during your child's assessment.

We will be happy to answer any questions you may have. If there is anything in the report that is not clear and you wish to discuss it, please contact us immediately.

- We will send you a copy of our report within a few weeks of your appointment. We suggest that you give a copy of the report to your child's school. We also suggest that you make an appointment with the school to discuss the findings and recommendations.
- We will send a copy of the report to your GP.
- If your child receives an ASD diagnosis, our nurse specialists will offer you a follow-up appointment. At this appointment:
 - you can discuss any concerns in more detail
 - ask any questions you have about the diagnosis
 - we will give you information about local and national support.

What if my child does not receive a diagnosis?

Up to 1 in 5 children who come to the clinic for these assessments will not receive a diagnosis of ASD. This does not mean we do not take your concerns seriously. There can be lots of reasons why children present with different behaviours. ASD is only one possible cause.

Where a diagnosis is not given, the team completing the assessment will explain why. They might:

- be able to suggest sources of support to help your child.
- suggest an assessment for a different condition.
- arrange to see your child again after a period of time to check their progress.

What do I do if we cannot make our appointment?

If you cannot come to your appointment, please telephone the centre as soon as possible so we can arrange another appointment for you. The contact details for each centre are on the front of this leaflet.

Further information

Please contact your local centre before your appointment if you have any queries.

This leaflet has been produced with and for patients.

Please let us know:

- If you have any accessibility needs; this includes needing a hearing loop or wanting someone to come with you to your appointment.
- If you need an interpreter.
- If you need this information in another format (such as Braille, audio, large print or Easy Read).

You can let us know this by:

- Visiting the Trust web site (<https://www.ekhuft.nhs.uk/ais>).
- Calling the number at the top of your appointment letter.
- Adding this information to the Patient Portal (<https://pp.ekhuft.nhs.uk/login>).
- Telling a member of staff at your next appointment.

Any complaints, comments, concerns or compliments, please speak to a member of your healthcare team. Or contact the Patient Advice and Liaison Service on 01227 783145 or email (ekh-tr.pals@nhs.net).

Patients should not bring large sums of money or valuables into hospital. Please note that East Kent Hospitals accepts no responsibility for the loss or damage to personal property, unless the property has been handed into Trust staff for safe-keeping.

Further patient information leaflets are available via the East Kent Hospitals' web site (<https://www.ekhuft.nhs.uk/patient-information>).

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