Cleft.NET.East: The East of England Cleft Lip and Palate Network

Introduction to your Cleft Service

One in 700 babies is born with a cleft lip and/or palate; cleft means gap, and so babies may have a gap in either the lip, gum (alveolus), palate (roof of the mouth), or all three.

Cleft.NET.East is one of nine specialised cleft services across England and Wales. We are a regional network committed to providing high quality care to children and their families affected by clefts that live in the East of England (Cambridgeshire, Norfolk, Suffolk, Hertfordshire, Bedfordshire, Peterborough and Northamptonshire).

We aim to work together with you in your child’s care. As your child grows up, different members of our specialist team will become involved at different times.

The cleft team is based at Addenbrooke’s Hospital in Cambridge.

Where will my appointments be?

We hold a variety of clinics, both at Addenbrooke’s Hospital and across the East of England.

Addenbrooke’s Hospital:
- multi-disciplinary cleft clinic,
- preadmission clinic,
- dressing clinic,
- palate investigation clinic
- review clinic
- individual therapy clinic

Outreach clinics across the East of England:
- multi-disciplinary cleft clinic
- specialist therapy clinic

All surgery takes place at Addenbrooke’s Hospital where we have the full range of specialties and support services available.
When will my appointments be?

You should expect to attend for clinics according to the schedule shown. You might also need to bring your child for individual therapy appointments between these times.

<table>
<thead>
<tr>
<th>Age</th>
<th>Appointment Type</th>
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<tbody>
<tr>
<td>Initial Appointment</td>
<td>Multidisciplinary clinic</td>
</tr>
<tr>
<td>Post-Operative</td>
<td>Multidisciplinary clinic</td>
</tr>
<tr>
<td>18 Months</td>
<td>Nursing, speech &amp; language therapy (S&amp;LT), audiology, paediatric dentistry, psychology</td>
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<tr>
<td>3 Years</td>
<td>Multidisciplinary Clinic</td>
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<tr>
<td>5 Years</td>
<td>Full review with surgeons, speech and language therapy, audiology, psychology, orthodontics, dentistry and photography</td>
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<tr>
<td>7 Years</td>
<td>Dental review with paediatric dentist and orthodontist if alveolar involvement</td>
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<tr>
<td>8 Years</td>
<td>Alveolar bone graft clinic as appropriate</td>
</tr>
<tr>
<td>10 Years</td>
<td>Multidisciplinary clinic</td>
</tr>
<tr>
<td>12 Years</td>
<td>Orthodontic (If appropriate)</td>
</tr>
<tr>
<td>15 Years</td>
<td>Multidisciplinary clinic</td>
</tr>
<tr>
<td>18/21 Years</td>
<td>Multidisciplinary clinic</td>
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Who makes up the cleft team?

We are a multi-professional, specialist team of clinicians who work closely together to provide high quality care for all patients within our network. Our team includes:

- cleft surgeons
- clinical nurse specialists
- speech and language therapists
- audiologists
- orthodontists
- paediatric dentists
- clinical psychologists
- clinical geneticists
- paediatric dieticians
- ward staff
- administration staff
- paediatricians
- medical photographers
- restorative dentists
- research professionals

We work closely with your local healthcare team.

What happens after my referral to the cleft service?

We work with patients from diagnosis to adulthood providing the full range of healthcare recommended for a child with a cleft lip and/or palate. This is often described as a 20-year care pathway. We also provide a service to any child or adult who presents with difficulties with palate function.
As soon as an antenatal or postnatal referral is received you will be seen by one of our clinical nurse specialists. The clinical nurse specialist will provide support through your initial treatment pathway.

Sometimes we receive referrals for older children, from local speech and language therapy teams. Children are seen in a speech liaison clinic for further assessment and care planning.

**When will I meet different members of the cleft team?**

Families are introduced to the cleft surgeon and other team members at one of our multidisciplinary clinics. Your child will be seen by them for assessment, advice or treatment at regular intervals as they grow up. Often the appointments are set up according to national guidelines or protocols.

In the first year you are likely to have most contact with your clinical nurse specialist, audiologist, speech and language therapist (if your child has a cleft palate), cleft surgeon and ward staff. More regular treatment might be provided by your local health care team. We work closely with them to make sure your child is receiving the best care possible.

As your child gets older, you might find that you see other members of the team more or less often. This will vary from child to child but will always be planned to ensure the best possible care for your child at that stage of their development.

All babies have a newborn hearing screening test; babies with cleft palate will need ongoing audiology tests to monitor and optimise hearing.

Speech and language therapists are available in clinic to answer any immediate questions you might have, and also offer community visits to offer early advice and monitoring of your baby’s ‘babble development’.

Psychologists can become involved at any time if you feel you or your child need their support. Examples of ways the psychologists can help include: adjusting to the cleft diagnosis, managing other people’s reactions and coping with hospital appointments/medical procedures.

A paediatric dentist will also be involved in the early years, and as your child grows up other specialists from the dental and orthodontic teams might become involved.

**Will my child need surgery?**

It is highly likely that your child will need surgery to repair their cleft. However, the surgeon will discuss this with you when you bring your child for their appointment.
When will I know when my child’s surgery is planned?

We will arrange a date for your child’s surgery in line with national guidelines. You can expect your baby’s cleft lip to be repaired by six months of age (from the date they were due to be born) providing they have no other health issues; and you can expect your baby’s cleft palate to be repaired by 13 months of age (from the date they were due to be born) providing they have no other health issues. You will be informed of this proposed date by telephone or letter. Please note that this date is provisional and can be changed right up until your child is admitted. Hospitals have to provide both planned and unplanned care, so we may sometimes need to change the date due to bed capacity. We do understand that you will have made arrangements for your child’s admission, but if there are sick children in the hospital, they will take priority for beds. We ask that you phone the ward before setting off, to ensure that a bed is available on the day.

Your child needs to be well for their planned surgery, in order to minimise the risks of surgery and anaesthetic. Please let us know if your child is unwell so that we can rearrange a date as soon as possible.

Confidentiality

All information that you share with us is treated confidentially unless there are concerns that someone’s safety is at risk. Letters are exchanged between members of the team so that we can provide you with the best quality care. Copies of letters are also sent to you, your child’s GP (family doctor), health visitor and local clinicians. If there is information you do not wish to be shared with the rest of the team, then you can talk to us about this.

What information will be collected about my child?

We will record your child’s treatment in different ways, including written records, photographs, and video recordings of your child’s speech if their palate is involved. We may also take dental impressions and x-rays as your child grows older, which will help us plan your child’s care.

Information about children with a cleft is recorded on a special national cleft database called the Cleft Registry and Audit Network (CRANE) Database. This is so we can get an accurate picture of how many children are born with a cleft and also to record measures of your child’s treatment. This is part of a national audit process to help ensure that all children with a cleft receive high quality care. We will ask your permission (consent) to include your child’s treatment measures on the CRANE Database in order to report trends in cleft care. All information from the database is used anonymously; your child will not be named in any of those reports.
Will students be involved in my appointments?

As the cleft team is hosted by teaching hospitals, you may be asked if students can be present during your appointment. This is a way that students learn to care for families affected by cleft but you can choose not to have students present. This will not affect the care of your child.

Will my child be involved in research?

As a network we have benefited from research that has been done into cleft care, and this has allowed us to answer many of your questions. We continue to try to answer questions about cleft care and so we may ask you if you would like to be involved with research projects as your child grows up. Your involvement will help us to understand different aspects of cleft care but we will always ask your permission before involving your child. Your child’s care will not be affected if you choose not to be involved.

Who makes decisions about treatment?

As your child grows up we will increasingly involve them in the treatment options available to them. You can help by encouraging your child to ask the team questions from a very early age. We are always interested in how we can help your child learn about the condition and meet their needs as they move from childhood into adulthood.

What happens if I miss my child’s appointment?

It is important that your child is brought to appointments during the 20 year care pathway. We will see your child at regular, but not necessarily frequent, intervals in order to assess their progress in various ways.

If you do not bring your child for one appointment without letting us know, we will try to contact you by telephone but if this is not possible we may need to check your contact details with other professionals, like your GP. We will then write to you to offer you a further appointment. If your child fails to be brought for a second appointment, our policy is to discuss this with the safeguarding team, and this may lead to a referral to Social Care. We have a statutory duty of care to all the children treated by Cleft.NET.East and Social Care can help people who are struggling to attend appointments.

How do I give feedback to the cleft team?

We are always happy to receive feedback, please contact us via the co-ordinator on 01223 596272.
We are a smoke-free site: smoking will not be allowed anywhere on the hospital site. For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.

Other formats:

If you would like this information in another language or audio, please contact Interpreting services on telephone: 01223 256998, or email: interpreting@addenbrookes.nhs.uk For Large Print information please contact the patient information team: patient.information@addenbrookes.nhs.uk

Document history

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<td>Contact number</td>
<td>01223 596272</td>
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<tr>
<td>Publish/Review date</td>
<td>December 2019/December 2022</td>
</tr>
<tr>
<td>File name</td>
<td>Introduction_to_your_cleft_team.doc</td>
</tr>
<tr>
<td>Version number/Ref</td>
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