The Clinical Nurse Specialist Service: Information for Parents and Carers

This leaflet provides information about the Cleft Lip and Palate Specialist Nursing Service which we hope you will find useful.

What is a clinical nurse specialist (CNS)?

The clinical nurse specialist is often the first member of the cleft team you will meet. We are a team of senior nurses, led by a lead nurse, who specialise in caring for children and families affected by cleft lip and palate.

The team combines the skills of paediatric and adult nursing, midwifery, health visiting and counselling. We work closely with health professionals from your local community, specialist hospitals and other members of the cleft team. We are available to support you throughout your child’s treatment.

Who is my clinical nurse specialist?

Your CNS will be introduced to you at, or soon after, your initial referral to the cleft service. They work within the geographical area in which you live and will maintain regular contact with you. At times, you may meet or come into contact with other members of the CNS team during your child’s treatment.

How do I contact my clinical nurse specialist?

When you first meet your CNS they will give you their mobile telephone number. We welcome calls from you between the hours of 08.00 and 16:00, Monday to Friday. If your nurse is unavailable, please leave a voice message, including your child’s name and your contact number. If your named CNS is on leave, their telephone will divert your call to another member of our team. Out-of-hours or during periods of unavailability, the CNS team can be contacted via their secretary on 01223 596272. You will then be offered the telephone number for the CNS who is on-call for that period of time.

How can my clinical nurse specialist help me and my child?

We can help you:
- By providing information at a pace that you feel comfortable with.
- To understand and adjust to the news that your child has a cleft by providing support and counselling following diagnosis.
- To prepare for the birth of your baby if the cleft has been identified on an antenatal scan.
- To care for your newborn baby by assessing and supporting feeding after birth and throughout childhood.
• To care for your baby if they have additional needs.
• To cope with concerns about how others may react to your baby.
• By providing you with information to support you to make decisions.
• By making referrals to other professionals who may be able to help you or your child
• By liaising with other professionals involved in your child’s care.
• To make contact with other families who have had similar experiences.
• By assessing your child’s health and providing support and information around the time of your child’s surgery.
• By monitoring health, growth and development at regular intervals.

We welcome contact from you at any point as your child grows up.

**When will I see a clinical nurse specialist?**

Every family and child will be visited regularly at home during the first 18 months, or until the first operations are complete. The key times of contact are:

• Following an antenatal diagnosis.
• Between 32 and 35 weeks gestation to plan for the delivery of your baby.
• Following the birth of your baby and then weekly until feeding is well established.
• Around the time you will begin weaning your baby onto solid foods.
• Before and after surgery to repair the cleft.
• One year of age.

A CNS will be available to you at most outpatient clinic appointments or for further home visits at your request. We can also offer further contact should your child require further surgery.

**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, local paediatrician and other members of the cleft team. If there is information that you do not want to be shared with the rest of the team you can talk to your clinical nurse specialist about this.

**Suggestions/comments**

The staff are here to help and it is important for them to know if you have any comments or suggestions about the services you have received. If you wish to speak to a member of the cleft team please telephone us on: 01223 596272, Monday to Friday, 08:00 to 16:00.

Alternatively you can contact the Patient Advice and Liaison Service (PALS) on Tel: 01223 216756, Email: pals@addenbrookes.nhs.uk
External contacts and information

Cleft Lip and Palate Association (CLAPA)
First Floor, Green Man Tower, 332b Goswell Road, London, EC1V 7LQ
Tel: 0207 833 4883
Fax: 0207 833 5999
Email: info@clapa.com
Web: www.clapa.com

Changing Faces
The Squire Centre, 33-37 University Street, London, WC1E 6JN
Tel: 0845 4500 275
Fax: 0845 4500 276
Email: info@changingfaces.org.uk
Web: www.changingfaces.org.uk

Information leaflets about our service will be made available to download from Addenbrooke’s Hospital website.

This leaflet has been based on the NorthWest Regional Service leaflet.

We are now 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, large print or audio, please ask the department where you are being treated, to contact the patient information team: patient.information@addenbrookes.nhs.uk.
Please note: We do not currently hold many leaflets in other languages; written translation requests are funded and agreed by the department who has authored the leaflet.

Document history

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