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South Wales Cleft Lip & Palate Service

Antenatal leaflet



Welsh Centre for Cleft Lip and Palate
Morrison Hospital,
Swansea
Telephone: (01792) 703810
<http://www.wales.nhs.uk/cleft-team>

Welcome to the South Wales Cleft Team

The South Wales Cleft Team is based in Morriston Hospital in Swansea. The team looks after all children born with a cleft lip and/or cleft palate in South Wales and parts of Mid Wales. We are part of the South Wales South West Managed Clinical Network for cleft lip and/or palate.

The South Wales Cleft Team consists of a number of different professionals including Specialist Cleft Nurses, Cleft, Paediatricians, Psychologists, Paediatric Dentist, Orthodontists, Otolaryngologist (Ear, Nose & Throat Surgeon), Speech and Language Therapists, Geneticist and Restorative Dentists. We also have a Coordinator for the team. This booklet gives you some information about babies who will be born with a cleft and what you can expect from the team. We hope you find it helpful. You can also find further information from our website www.wales.nhs.uk/cleft-team.

Adjusting to your baby being diagnosed with a cleft

Congratulations on your pregnancy!

For most people reading this leaflet, you will have been told that your baby has a cleft lip and this will have been picked up on an ultrasound scan during pregnancy. For many people, this may be the first time you have really thought about clefts and you may feel it is something you don't know very much about. For other people, you may already know about clefts, maybe you or someone in your family or someone else you know was born with a cleft.

Some people find they come to terms with the news that their baby has a cleft lip very easily. For most people, however, it can take a little while to get used to the news and to feel that they have an understanding of clefts. You may find you experience all sorts of emotional reactions, from shock to worry to feelings of protectiveness. It is not unusual to switch from one emotion to another or to feel several emotions at once.

Many people report having worries about how they will react when their baby is born. These are very normal worries and if they apply to you, you may be reassured to know that almost everyone reports that these worries disappear once their baby arrives. It is also very common to have thoughts such as 'why us?' or 'why my baby?' As parents you are adjusting to learning that your baby will be born with a cleft. Some people adjust quite quickly, while for others this can be a more gradual process that takes slightly longer. These are all very normal reactions and are understood by all those people involved with your care and the care of your baby.

You may have lots of questions from the start, or these may take a while to become clear to you. You may find that the information given to you around the time of your baby being diagnosed with a cleft is confusing and just too much. Don't worry. We understand that this can be the case and will always be happy to discuss any of your questions when you feel ready. Please feel free to ask anything at any time if you have any questions or concerns. No questions are too small or unimportant. The best person to contact in the first instance is one of the Cleft Nurses on 01792 703810 .



Background Information - Cleft Lip and Palate

Some babies with a cleft lip will also have a cleft palate. This is the case for just over half of babies with a cleft lip. The palate forms the roof of the mouth. Almost always, it is not possible to tell before a baby is born whether they have a cleft palate or not.

What is Cleft Lip and Palate?

A cleft lip and/or palate happens very early on in pregnancy where the two sides of the baby's lip and/or palate do not join together properly. A cleft of the lip can be on one side (unilateral) or both sides (bilateral). It can be as small as a notch, or may extend up into the nose. The palate forms the roof of the mouth. It consists of two parts: the hard palate towards the front, and the soft palate towards the back. Some clefts only go part of the way through the palate while others may go through the lip, gum and palate.

Babies can be born with a cleft lip only or with a cleft lip and a cleft palate. Some babies are born with a cleft palate only but this is almost never picked up on an ultrasound scan during pregnancy.

How common are clefts?

In the UK, around 1 in 700 children are born with a cleft lip and/or cleft palate. Of these, about 25% have a cleft lip only, 40% will have a cleft palate only; and the other 35% will have both a cleft lip and palate.

The journey ahead

We have produced a separate chart that tries to show in simple terms the journey we will be sharing with you and your child over the years ahead. There are different charts for different types of clefts, so we will give you a copy of the one which will apply to your child when your baby is born.



Feeding babies born with a cleft lip and palate

An essential role of the Cleft Service is to work with the network of people involved in your baby's care to support you in establishing a good feeding regime that gives baby what he or she needs and is acceptable to the family.

All babies spend most of their early weeks feeding and sleeping. As well as satisfying hunger and thirst, feeding is a time of social interaction when a baby is most alert and parents and babies begin to get to know each other.

Normal breast or bottle-feeding takes place by a sucking action where the lips surround the nipple or teat. The milk is pumped out by the thrusting action of the tongue and a negative pressure built up in the baby's mouth by the closing off of the back of the nose with the soft palate. Babies with a cleft lip only do not usually have a problem with feeding, but some may find making a seal around the nipple or teat difficult. Babies with a cleft palate frequently have trouble getting enough intra-oral pressure for sucking because the cleft causes an air leak. They therefore often require some assistance to feed effectively. The specialist team will provide you with help and equipment to help you feed your baby. You can contact CLAPA on 02078334883 to order feeding bottles.

However you choose to feed your baby, spending time having skin to skin contact can be beneficial to you both. This will keep your baby warm and help to calm them, giving you time to bond together. If your baby is unable to breastfeed and you would still like to use breast milk, we still encourage you to put baby to the breast to encourage lactation.

Surgery

Babies born with a cleft lip usually have an operation to repair this at 3-4 months. Babies born with a cleft palate usually have an operation to repair this at 6-12 months. All surgery will take place in Morriston Hospital, Swansea. We understand that thinking about surgery can be quite a difficult thing for a parent to do. One of our specialist cleft nurses will visit you once your baby has been born to talk through what you can expect. When your baby is between 6-12 weeks you will be given an appointment to come to the new New Baby Clinic where you will meet members of the team involved in the early care of you and your baby. If you have questions in the meantime or would like to meet the team before your baby is born, please get in touch with one of the Specialist Cleft Nurses on 01792 703810.

Psychological support

The Psychologists are part of the Cleft Team. We are here to offer help and support to families in coming to terms with their baby having a cleft and to support them if they have any other worries or concerns. We also aim to work in a positive way with all families where a child has a cleft, looking at ways to help their child to grow up with good self-esteem, confidence and able to deal with life's 'ups and downs'.

There is support available to you, your child and other family members from the cleft psychology team at any stage. We are happy to talk with you on the phone to discuss how we can help and we can arrange appointments to meet up face to face. It doesn't have to be a big problem before you contact us. Contact us on 01792 703810.



What next?

If you have any questions or would like some more information, please contact one of the Cleft Nurses on 01792 703810. You can also find some information on the cleft team website www.wales.nhs.uk/cleft-team. The only other website we would recommend is the CLAPA (Cleft Lip & Palate Association) website www.clapa.com.

Contact Details

The members of the team who you will meet antenatally or soon after your baby is born are as follows:

Mrs Michaela Rowe	Specialist Cleft Nurse
Mrs Michele John	Specialist Cleft Nurse
Mrs Chuley Walton	Specialist Cleft Nurse
Dr Maha Mansour	Consultant Paediatrician
Dr Ingo Scholler	Consultant Paediatrician
Mr Tomos O`Neill	Consultant Cleft Surgeon
Dr James Farrant	Consultant Anaesthetist
Dr Sabelo Ndlovu	Consultant Anaesthetist
Dr Vanessa Hammond	Consultant Clinical Psychologist
Dr Danielle Dummett	Consultant Clinical Psychologist

If you would like to contact a member of the cleft team, we can be accessed via Andrea Thomas, our Cleft Coordinator, on 01792 703810.

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