## Welsh Centre for Cleft Lip and Palate, Morriston Hospital, Swansea

**Typical Patient Journey for a child with a Bilateral Cleft Lip and Palate (BCLP)**

### Ante-natal

- **Diagnosis**
  - Referral to Cleft Team
  - The Cleft Nurse Specialist (CNS) will make contact within 24 hours of referral.

### Birth

- **Maternity Unit**
  - Referral to Cleft Team on the day of birth
  - CNS visits baby within 24 hrs of referral to offer feeding help and information.
  - Newborn Hearing Screening test at local hospital and follow-up as appropriate.
  - Start Dynaceft for some clefts

### 0-2 months

- **New Baby Clinic**
  - Initial Assessment
  - Parents introduced to the Team which includes the Surgeon, Anaesthetist, Paediatrician, Psychologist, ENT, CNS. Referral to Genetics if indicated

### 3-4 Months

- **Inpatient stay**
  - Surgery: Lip Repair
  - Pre surgery Photos
  - Speech Development advice given.
  - Follow up at 6 weeks with CNS

### 6-12 Months

- **Inpatient stay**
  - Surgery: Palate Repair, follow up at 6 weeks with CNS.
  - Speech Development advice given
  - Hearing test locally at approx 8-10 months

### 5 years

- **Cleft MDT Clinic**
  - Assessment and review by:
    - Surgeon (+ photos taken)
    - ENT (+ Audiologist for hearing test)
    - Speech & Language Therapists (SLT) (+ recordings)
    - Orthodontic team (+ models taken)
    - Paediatric Dentist
    - Psychologist

### 3 years +

- **Hearing test at 3 years**
  - locally

### 18 months - 5 years

- **Speech & Language Assessment**
  - reviews at 18ths, 2, 3, 4 and 5 years
  - *From 18 months*: Some children will need therapy - this will be arranged locally.

### 9-24 Months

- **18 months: Cleft Review Clinic**
  - Review of Surgery
  - Post op Lip, Photos taken.
  - Appointment with Paediatric Dentist

### 9-18 Months

- **Babble Workshop at 9-12 months combined with advice given by the Dental Health Educators**

### 8 years

- **Cleft MDT Clinic**
  - Review by: Surgeon/Orthodontist
  - Assessment to see when an Alveolar Bone Graft (ABG) is best undertaken to repair the gap in the bone
  - X-rays
  - Paediatric Dentist
  - Psychologist

### 8-10 years

- **8-10 years Orthodontics**
  - Preparation for ABG if needed

### 8 - 10 years

- **8-10 years Inpatient Stay (if required)**
  - Surgery: ABG to repair gap in bone of upper jaw.
  - Appointment with nurse and psychologist to prepare for ABG
  - Outpatient 6 month follow-up of surgery with x-ray on Cleft MDT clinic

### 10 years

- **Cleft MDT Clinic**
  - Assessment and review by:
    - Surgeon (+ photos taken)
    - ENT (+ Audiologist for hearing test)
    - SLT (+ recordings)
    - Orthodontist (+ models taken)
    - Paediatric Dentist
    - Psychologist

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Joint Appointment at 12 yrs with Paediatric Dentist and Orthodontist

Orthodontics
Treatment appointments as required.

**Cleft MDT Clinic**
Assessment and review by:
Surgeon (+ photos taken)
ENT (+ Audiologist for hearing test)
Orthodontist (+ models taken)
Psychologist
Possible Discharge, open access to cleft service
Offer of Genetic Referral

**Cleft MDT Clinic**
Assessment and review by:
Surgeon (+ photos taken)
ENT (+ Audiologist for hearing test)
SLT (if required)
Orthodontist (+ models taken)
Psychologist
Possible Discharge, open access to cleft service
Offer of Genetic Referral

It is very important to recognise that every child is an individual and will follow their own unique journey. This is a guide, and all dates are approximate.

At any stage, please feel free to ask the Cleft Team "where have we got to?" or "what happens next?".

Additional Notes

**About Inpatient stays:** All inpatient stays will normally be in Morriston Hospital. You can expect to see the surgeon before and after the operation. The speech and language therapist and the cleft nurse specialist will visit you on the ward as well.

**MDT** = Multi-Disciplinary Team

**CNS** = Cleft Nurse Specialist

**SLT** = Speech and Language Therapy

**Alveolus / Alveolar** = the bone around the teeth

**Other Surgery:** Some children may require other operations during their patient journey. These might include an operation to improve speech, to improve the appearance of the lip or nose. These options will be discussed with you should the need arise.

**About Bone Grafts (ABG) and Osteotomies:** Most children with BCLP are recommended to have an alveolar bone graft. A smaller number of people, surgery to correct the position of the jaw or jaws will be discussed. This is called Orthognathic Surgery.

**Hearing Assessments:** In addition to the hearing assessments indicated above, further assessments will be carried out at intervals as appropriate throughout childhood.

**Speech and Language Therapy:** In addition to the speech assessments indicated above, further assessments may be carried out and/or your child may be referred to Speech and Language Therapy at any time.

**Psychology:** The Cleft Team Psychologist can be contacted at any other time during the patient journey to discuss any worries or concerns.

**Cleft Nurse Specialist:** Will support the family through regular contact in the early years.

**Cleft Coordinator:** Can be contacted on 01792 703810 (answering machine for outside normal working hours)

**The Welsh Centre for Cleft Lip and Palate Web Site:** [http://www.wales.nhs.uk/cleft-team](http://www.wales.nhs.uk/cleft-team)

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