

A patient journey of a patient with Cleft Lip and Palate*

This is a working document.
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1. First Symptoms

Cleft of the lip (unilateral or bilateral) and/or cleft of the palate (hard palate and/or soft palate)

2. Diagnosis

Diagnosis of a cleft lip can be made antenatally at around 20 weeks but it is rarely possible to accurately diagnose a cleft palate antenatally. Diagnosis at birth will involve an examination of the roof of the mouth with a torch.

3. Impact on child

There can be problems with feeding as a baby. Subsequently there can be speech difficulties, dental misalignment and missing teeth, hearing problems (glue ear) and appearance issues. Children and young adults with clefts may have low self esteem as a result of looking or sounding different, and may perform less well at school

4. Treatment ++

A cleft is repaired by surgery usually between 3 months to a year but can vary. Early speech assessment takes place around 18 months. Secondary surgery to repair the cleft in the gum (alveolus) takes place at around 9-11 years, and sometimes earlier. Speech therapy may be needed during the school years together with extensive orthodontic treatment. Further surgery may be required to improve speech and appearance in the teenage years. Psychological support should be available where needed.

5. Follow Up

While the majority of physical issues around clefts are 'sorted out' by adulthood, there needs to be an open door for someone to return to treatment if they need to. Often this is problematic because most cleft units are in pediatric hospitals

Needs: Information on condition and rapid referral to expert team. Initial difficulties are likely to be around feeding and these need assessing urgently by a specialist cleft nurse or equivalent

Needs: Is imperative that at diagnosis checks are made for any other associated abnormalities so these can be addressed.

Needs: Treatment pathway needs to be coordinated clearly by the cleft team with appropriate follow-up, checks and interventions at the right ages. Psychosocial adjustment and educational attainment should be monitored. Clear precise information and involvement of family in decisions around aspects of treatment is important.

Needs: Patient and family needs change with age of the child. All clinical interventions should be properly explained and should be decided by a joint multidisciplinary team. Psychosocial support is important for the whole family and especially at life change points such as changing schools. The teenage child should be involved in decisions about their care.

Needs: There may be some continuing physical needs (dentition, speech, fistulae – small holes in the palate). However it may be more on a psychosocial level that support is needed relating to looking or sounding different. This can potentially affect development of intimate relationships. There can also be issues around self esteem and in particular confidence at job interviews etc.

Ideally: Feeding established and normal bonding begins. Family positively adjusts to birth of a baby with a condition they did not expect and moves on to a place of certainty

Ideally: Child and family feel informed and involved in the care being given. They can explain clearly all aspects of treatment to the child's school and teachers. Absences from school will be inevitable for clinic visits and surgical interventions.

Ideally: At the end of treatment some young adults with clefts may feel they are alone facing the world with no further support. There need to be opportunities for the young adult to reconnect with the team or other relevant support networks so they feel supported in areas where they may continue to have needs.

* Completion was led by Gareth Davies (ERN CRANIO patient representative). Gareth represents the European Cleft Organisation (ECO). Gareth has been in contact with 5 patient groups in 5 European countries (Bulgaria, Finland, Slovenia, Spain and the UK) and their responses are reflected in this document. Content is also based on Gareth's personal experiences of receiving healthcare in the UK and working with hundreds of families and patients across Europe since 1995. The journey has also been validated by the European Cleft Organisation (ECO).