**Care Pathway encompassing Local Guidelines for**

**Children with Cleft Palate and/or Velopharyngeal Dysfunction**

The care pathway outlined below is designed for any child referred to the Speech and Language Therapy Service who presents with a cleft palate and/or velopharyngeal dysfunction (VPD), together with associated communication difficulties.

Children with cleft palate, and/or VPD are at risk of; articulatory problems, abnormal hypernasal resonance, hearing problems which impact on intelligibility and acceptability of speech (RCSLT, 2021). In the UK, approximately one thousand babies are born each year with a cleft lip and/ or cleft palate, or a sub-mucous cleft palate. There are many syndromic diagnoses also associated with cleft palate and velopharyngeal speech disorders. The most common are 22q11 deletion (known also as Di George), Sticklers Syndrome, Van der Woude Syndrome and Treachers-Collins Syndrome (CLAPA, 2020). In the UK, generally for a child with cleft lip and / or palate, typically the first lip repair takes place by 6 months old, and the primary palate repair takes place prior to 13 months old (NHS England, 2013).

Speech: Atypical speech development is common with the possibility of persisting speech and/or resonance problems into adolescence or adult life in about 20% of cases of Cleft Palate (Harding & Grunwell, 1996; Russell & Harding, 2001)

[**Hearing**](https://www.rcslt.org/members/clinical-guidance/deafness/deafness-guidance): There is often a mild/moderate fluctuating conductive hearing loss in 90% of children with cleft palate which may also contribute to the severity of speech difficulties. Repeated grommet insertion and/or hearing aids may be needed. There is also a risk of long-term conductive hearing loss.

**Teeth**: Atypical dentition and dental malocclusion are common and may impact speech. Impaired facial growth affects appearance, which may also affect speech and self-esteem. A child with Cleft Palate may require maxillary advancement surgery in their late teens. Children with clefts involving the alveolus require alveolar bone graft surgery at about 8 to 10 years of age.

Cleft lip and palate care is centralised in the UK with 11 Regional Services delivering highly specialist multi-disciplinary care, of which Speech and Language Therapists are based in these Regional (Tertiary Level) Cleft Services (CLAPA, 2020). The Regional Centres who support children with cleft palate and /or velopharyngeal dysfunction in the South East Essex are:

* The North Thames Cleft Palate Service, based in both Great Ormond Street Children’s Hospital, London, and Broomfield Hospital, Chelmsford.
* The South Thames Cleft Palate Service, based in the Evelina Children’s Hospital, London.

The Regional Multidisciplinary Cleft Team includes: cleft surgeons, ENT surgeons, Cleft SLTs, Audiologists, Orthodontists, Specialist Nurses, Dentists, Psychologists, Geneticists etc. The Specialist Cleft Speech and Language Therapists (SLTs) at these Regional Centres, liaise with the Local Cleft link SLT based in Essex Partnership University Trust, in South East Essex. The Local Link Cleft SLT offers therapy locally, close to home, with guidance from the Cleft SLTs in the Regional Centres. The SLTs manage and support early communication difficulties, to prevent the development of abnormal speech patterns (RCSLT 2021)

Where a child who is already being seen by a Community SLT for speech and language difficulties is subsequently diagnosed by with a submucous cleft palate and / or VPD, the Community SLT will contact the Local Cleft SLT to facilitate a case discussion to determine if this child should be transferred to the Specialist Cleft Caseload, with consent from parent/carer. If a child is identified by a Community SLT as having symptoms of a possible undiagnosed submucous cleft palate or VPD, they will seek the 2nd opinion of the local link Cleft SLT in the team for perceptual assessment, and onward referral to the Regional Cleft Service SLT for full highly specialist assessment and diagnosis where indicated.

Where Cleft palate is not a child’s primary need (i.e. children with significant complex needs, or requiring Special School Provision) it is likely that this child will join a different SLT care pathway.

1. **Referral**

Referrals for children with a diagnosed cleft palate and/or VPD should be made by a Specialist Cleft Speech and Language Therapist from the Regional Cleft Service e.g. The North/South Thames Cleft Service). Such referrals should be made by letter, detailing the case history of the child, together with their presenting difficulties. A referral can also be made by any other health professional, via a CAF or EHA/EHFSA form detailing on the referral form if there is a known diagnosis of cleft palate or velopharyngeal dysfunction, or highlighting any syndromic diagnoses also known to be associated with cleft palate and velopharyngeal speech disorders e.g. Sticklers Syndrome.

1. **Referral accepted**

Referrals received are screened by a Senior Paediatric Speech and Language Therapist using the information on the referral form or referral letter. The Care Aims model Section 1 form is used to prioritise referrals. Where it is obvious from the referral information provided that a child has a diagnosis of Cleft Palate or VPD, this will be allocated to an assessment appointment with the Local Cleft Specialist SLT. Where the above information or overall need is not clear, a video triage appointment will be offered prior to formal assessment. This triage appointment is 20 minutes in length and is provided via a video conference to the parents/carers. The child **MUST** be present for this triage appointment to take place.

1. **Diagnostic assessment**

The initial assessment will usually be completed in a clinic environment with the Local Cleft Specialist SLT, via observation, parental reports of their child’s needs and background information, informal and formal assessment as deemed appropriate by the Local Cleft Specialist SLT.

The purpose of the initial assessment is to gather information about the nature and severity of the child’s speech and language difficulties and how these impact upon their overall communication. During the initial assessment, the SLT will explain their role to the parents and complete a case history using the Paediatric Service questionnaire on SystmOne, to include when the palate was repaired, whether any further surgery is known to be necessary, whether the child has any associated hearing loss. If hearing loss is known then the severity of that loss should be detailed, together with mode of amplification, and details of any Teacher of the Deaf and Local Audiology Service involvement.

An informal and/or formal assessment of the child will be carried out, in order to look at the child’s play, speech, language and mode of communication, with assessment focus determined by the details provided in the referral form / letter or following a video triage appointment. A further assessment may take place during a separate, follow-up appointment. In discussion with parents, additional diagnostic information may also be gathered from the pre-school / school environment. This should be carried out through observation and discussion with staff.

The Therapist will ascertain whether any previous therapy has been accessed, and the outcome of any such intervention. Parental expectations for therapy will be discussed and motivation for change will be considered. Following the diagnostic assessment, the child / parents / carers will be given information about management options if assessment findings indicate the individual will benefit from Speech and Language Therapy intervention.

Those children who do not need the intervention of the Speech and Language Therapist to continue to develop communication skills will be discharged from the service at this point. For example, children who have a communication difficulty but for whom input may have no real benefit or effect on their skills and/or rate of progress.

At this point in the pathway, if appropriate to the individual’s needs, a child may be transferred to a different care pathway e.g. To the Community Clinic, or in discussion with another Specialist SLT, for a different Specialist Care Pathway e.g. Fluency.

Support to assess and develop Speech Skills is commonly associated with Cleft Palate and/or VPD. Where formal assessment of speech is deemed appropriate, it may include the following:

* Photos and / or video recordings with written consent
* Intra-Oral Examination
* Perceptual speech assessment of articulation, phonology, resonance, intelligibility, airstream etc:
  + connected speech e.g. GOS.SP.ASS Tool
  + word and sound level speech e.g. CLEAR / DEAP Speech Assessments

Assessment will include parents throughout the process, who will be kept informed of assessment results. Written reports will be completed as appropriate and copied to Parents, Referrer, GP and all relevant identified Professionals (including the Specialist Cleft SLT at the Regional Cleft Service).

1. **Intervention episodes**

Information from the diagnostic assessment is used to guide an informed decision about the level of clinical risk each individual child has at that time. Children may be offered indirect or direct treatment at any time based on their level of clinical risk and need, and the Local Cleft SLT’s informed decision about which intervention strategy is most appropriate at that time. Different direct treatment options are available, and may be provided by the Local Cleft SLT or where deemed appropriate one of the Community SLTs. as outlined on the care pathway flow chart. The Cleft Specialist may work alongside colleagues in Health and Education Services when working with this client group.

1. **Management commenced with goal negotiation**

Management is guided by assessment findings, and any target recommendations received from the Regional Specialist Cleft SLTs. Any intervention begins with an agreement of goals for each episode of care. All goal setting is agreed with the individuals involved in therapy. The Malcolmess Care Aims model is followed. It is likely that intervention will aim to maximise the child’s communicative potential, and minimise the impact of cleft palate on their interactions and educational success.

* 1. Indirect

The Local Cleft SLT may make an informed decision that an individual’s case is most appropriately managed by offering indirect input. This may involve providing advice and strategies via video conference and / or written advice to the child or parents / carers / support staff for implementation in the home setting and education setting, with monitoring at individually agreed intervals by the Local Cleft SLT. Such indirect strategies may also include Nursery / School visits to explain the targets and model the activities suggested to staff.

* 1. Direct

Direct therapy will be offered 1:1 in the clinic or the educational setting, at intervals agreed between the Local Cleft SLT, child and parents/carers. The period of direct intervention will be individualised based on a child’s presentation, the evidence base for intervention, carer support and motivation and therefore there will be variations between cases. Different therapy approaches are used as judged most appropriate for the individual, based on assessment findings and discussion with the child and / or parents/ carers. Therapists have responsibility to ensure intervention is evidence-based. Direct therapy will also be used as a means to diagnose further difficulties with a repaired cleft palate or concerns in regards to VPD.

1. **Reassessment**

Following an episode of care, the individual’s needs are reviewed (this may include further formal assessment) to monitor progress with the targets set out in the care plan. A consolidation period of up to 8 weeks is usual before the individual’s status and clinical risk is reviewed, to allow time for acquisition of new skills taught in the episode of care. If there is an ongoing clinical risk, they will continue with a further episode of care.

Where a child is slow to make progress or where there are further concerns in regards to the child’s palatal function for speech, information regarding input and outcomes will be communicated to a Regional Cleft Specialist Speech and Language Therapist at the relevant Regional Cleft Centre, who is overseeing this child’s long-term overall Cleft Palate or VPD SLT care. This information may be used by the Regional Cleft Service to support additional surgery or more Specialist SLT Intervention at the Regional Cleft Centre.

Where a child is awaiting revision surgery from the Regional Cleft Service, where advised, care locally will be placed on hold, until surgery is complete, and recommendations are received from the Regional Specialist Cleft SLT to advise that therapy can recommence.

1. **Discharge**

Local discharge procedure is followed when aims of intervention are achieved; no further difficulties present; discharge is requested by the patient (this may be implied when the child is not brought to sessions offered), or it is agreed that an individual is able to self-manage their own communication needs. Additionally, a child may be discharged at assessment if it is felt they do not present with communication difficulties and Speech and Language Therapy will not be of benefit to them.

1. **Referral for specialist assessment outside Trust**

At times a child with Cleft Palate and / or VPD may not as yet be known to the Regional Cleft Service e.g. due to moving in to the area, or moving in from overseas, or in cased of an undiagnosed sub-mucous cleft palate or undiagnosed VPD. These children will be referred to the Regional Cleft Service e.g. North Thames Cleft Service (Great Ormond Street Hospital and Broomfield Hospital, or the South Thames Cleft Team (Evelina Hospital).

**At any point in the pathway, referral may be instigated to other relevant agencies to support needs which go beyond the scope of Speech and Language Therapy, e.g. the Local Authority for Education, the Paediatrician, Ear, Nose and Throat Service etc**

References:

* CLAPA – Cleft Lip and Palate Association (May 2020) ‘Supporting People with Cleft Lip and Palate and Related Disorders’. Retrieved January 2022.
* Harding, A. & Grunwell, P. (1996). [Cleft palate speech characteristics: A literature review](http://www.tandfonline.com/doi/abs/10.3109/13682829609031326#.Ve2awdNVhBc). European Journal for Disorders of Communication, 31(4), 331-357.
* NHS England (2013) ‘NHS Standard Contract for Cleft Lop and / or Palate Services including non-cleft Velopharyngeal dysfunction (VPD) (All ages)’ Retrieved January 2022.
* RCSLT - Royal College of Speech and Language Therapists (2021) – [www.rcslt.org](http://www.rcslt.org) . Retrieved January 2022.
* Russell, J.R. & Harding, A. (2001). Speech development and early intervention in A. Watson, D. Sell, & P. Grunwell (Eds), Management of Cleft Lip and Palate. (1st ed). London & Philadelphia: Whurr.

Referral

**2nd Opinion**

Requested by discussion by another SLT in the team for a known child accessing a different care pathway who has a suspected sub-mucous cleft palate (SMCP) or VPD

Referral Accepted:

Identified with diagnosis of cleft palate / VPD / associated syndrome / possible red flags for undiagnosed sub mucous cleft palate and / or VPD

Video Triage

Not appropriate for Local Cleft SLT.

Transferred to Community clinic or other Specialist SLT Care pathway

Assessment with Local Cleft Therapist

Local Cleft Initial assessment

**Outcome =**

**No concerns / minimal concerns**

Internally transferred back to requesting SLT, or discharge from SLT Service if there are no further communication concerns.

Local Cleft SLT may review child’s progress in therapy with referring SLT at 6 months if monitoring is required

If relevant onward referral e.g. ENT.

**Outcome =**

**Yes concerns - Assessment identifies likely SMCP or VPD** Onward referral made to Tertiary Level SLTs at a Regional Cleft Service (North Thames Cleft Service or South Thames Cleft Service)

Intervention

**Local SLT input on Hold**

Await response letter from Regional Cleft Service SLT, following their assessment, in regards to next steps for local SLT input.

direct

indirect

Review

Discharge