



Factsheet 26

The Speech and Language Therapist working with children and young people with CHARGE syndrome

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Due to the wide variation of how CHARGE presents, it is unlikely that one speech and language therapist (SLT) will have sufficient skills to manage all of the presenting difficulties. To truly maximise the therapeutic value of SLT input, an inter-disciplinary approach to therapy will be required, working closely with appropriate colleagues such as occupational therapists, physiotherapists, medical and education colleagues.

Within the population of people with CHARGE syndrome an SLT may require knowledge of the following areas of speech and language therapy practice:

- Hearing impairment
- Visual impairment
- Craniofacial disorders
- Eating and drinking difficulties (structural, physical, and sensory)
- Gastro-Oesophageal Reflux
- Facial palsy
- Sensory integration issues
- Tracheotomy
- Learning disability.

Things to think about

The speech and language therapist will need to identify the diagnostic features that require consideration in the overall approach to management. In the acute neonatal setting, this will require initial diagnosis and intervention planning. There will need to be a co-ordinated hand-over to a community based SLT for ongoing support, and intervention.

Due to the complexities of management, a lead SLT should be identified to ensure a coordinated approach



to support and management is applied (from either community, acute or tertiary setting; depending on most appropriate skill set/service setting). The approach is likely to require collaborative working with other SLTs within specialist departments such as hearing impairment specialists, eating and drinking specialists; or engaging and liaising with specialist/tertiary services such as craniofacial, tracheotomy or eating and drinking specialists.

It is helpful for therapists to be clear about areas of clinical responsibility within management so as to prevent confusion and reduce delays in providing therapy. For example, if a child is seen at a specialist eating and drinking/dysphagia clinic it needs to be clear who has accountability for moving therapy forwards and developing the programme when



the child is also seen by the community based SLT. All therapy and management needs to be developed collaboratively and take account of fellow practitioners' skills and priorities.

No two children or young people with CHARGE syndrome are the same; the combination of features, severity of difficulties and approach to tackling challenges mean that every child and young person is unique. It is crucial to ensure that a child/young person is viewed holistically and not seen as separate entities when different parts of the child are managed discretely.

Due to the nature of Multi-Sensory Impairment (MSI) associated with CHARGE syndrome, children and young people may be supported by an intervenor, a specialist one-to-one support role trained in working with people with MSI. When this is the case, the intervenor is well placed to undertake direct SLT programmes under

the supervision of the SLT and provide consistent support across a range of situations. This allows the SLT to provide a consultation model of service delivery although there may still be aspects of therapy that require direct intervention.

Parental involvement

Parents have an important role in supporting children and young people. The experiences of parents during the early days can be challenging, as they may have to face many medical issues and complex support needs, often in a concentrated space of time.

Therapy and interventions need to consider the context of the whole family whilst balancing needs of the child or young person – bearing in mind the number of other professionals who may also be prioritising their goals and strategies alongside those of the SLT.

Critical periods to be involved

There are some critical periods when speech and language therapists will need to have an active role working with the child, supporting the family with a number of issues, decisions and developmental stages.

Critical Periods	
Neonatal	<ul style="list-style-type: none">• Supporting diagnosis and establishing interventions during the 'medical period' – particularly if identification of cleft, trache-oesophageal fistula, choanal atresia. Early management of eating and drinking issues will be essential, often naso-gastric (NG) or percutaneous endoscopic gastrostomy (PEG) tubes are inserted.• Critical period to provide parental support and a proactive approach to reduce potential later-development sensory-based eating and drinking difficulties.• Bonding may be an issue due to the 'medical period'. Ideas and approaches to support and establish early bonding between parents and child may be useful.
Early Years	<ul style="list-style-type: none">• Supporting the development of communication – mode selection and progress with language acquisition, role in supporting parents to make informed choices.• Development of eating and drinking skills – strategies, managing sensory issues.• Supporting the selection of appropriate education placement.
School age	<ul style="list-style-type: none">• Ongoing support and strategies to aid communication and language development and acquisition.• Focus on development of social relationships.• Identification of strategies that may be required to support later development of eating and drinking skills.
Transition into adulthood	<ul style="list-style-type: none">• Supporting young people in having their say in transition planning, ensuring adequate support for making informed choices (if required).• Focus on developing independence and social relationships.



Good team working includes valuing the parents' contributions when identifying priorities and setting appropriate therapy goals together.

With access to good information, parents are able to make informed choices. This is particularly relevant when it comes to decisions about communication, therapeutic interventions and eating and drinking strategies and approaches.

Parents tell us that they don't want to keep repeating their story, and systems for sharing information have a role in minimising this.

Do

- Involve families – provide opportunities for families to access information and support parents to make informed choices.
- Consider the priorities of the whole team and reach a consensus agreement.
- Be clear about areas of accountability.
- Work together, including making use of intervenors to deliver therapeutic support to ensure a consistency of approach throughout the day, not just in therapy sessions. Work with parents to put a plan in place to support the carry over of approaches into the home as well as other settings.
- View the child or young person holistically.
- Check in throughout the child's development – be clear about how to access SLT services and what to do if there are questions after a child has been discharged.
- Provide information about support networks for parents, young people and professionals working with people with CHARGE.

Don't

- Discharge without identifying potential risk factors and action to take if there are any concerns or changes.
- Panic if the child's skills are 'put on hold'; sometimes children need to hold the development of one area in order to focus on developing another. For example, a child may appear to stop using vision, or stop developing communication skills whilst developing the motor skills to learn to walk, and once achieved pick up on using of vision/communication again.

GLOSSARY

Choanal atresia: a blockage of the passageway between the nose and the pharynx.

Trache-oesophageal fistula (T-E fistula): an abnormal connection (fistula) between the oesophagus and trachea.

