Dysarthria

Dysarthria is the medical term for slurred or irregular speech

What may happen
As the neurological symptoms – those that affect the brain – of the disease progress, speech can be affected. Initially this may be just a slowing down or slurring of speech, especially when the person is tired. Most people will still be able to make themselves understood, although it can be very frustrating for a younger person. Over time, speech will become less clear, and the person may struggle to think of the words they are looking for. Eventually verbal communication may be lost.

What you can do
Introduce alternative means of communication while the child or young person is able to still talk. This may be through using keyboard skills, sign language, books with photos or words for likes and dislikes. You may wish to create a ‘personal passport’ with key information about the person and their family, the person’s likes and dislikes, and their preferred method of communication. This can be added to or adapted as time goes by.
How we managed ... one family’s story

We found that our son would often finish a sentence if you started it for him. By saying ‘I would like …’, he would be able to tell us what he wanted. Once he was no longer able or willing to speak, we found he was still capable of singing or reciting songs and rhymes learnt when he was young. This was a joy to hear.

Who can help?
Your speech and language therapist can offer advice and solutions to help with communication. The NPDG (UK) clinical nurse specialist will be able to provide information and ideas that have worked for other families. If your child is at school, the special educational needs coordinator will ensure that they receive individual help and appropriate aids that will maximise their ability to communicate.

This leaflet forms part of a resource pack published by the Niemann-Pick Disease Group (UK). It is intended to be read in conjunction with the other parts of the pack. If you do not have the other documents in the pack or you would like further information, please contact us at the email address below.

niemann-pick@zetnet.co.uk