



Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Families

Language and communication in Landau Kleffner Syndrome

This information sheet is part of a series on Landau Kleffner Syndrome (LKS) and focuses on language and communication. Other topics covered in this series include:

- An introduction to Landau Kleffner syndrome: information for families
- Landau Kleffner syndrome: abilities and behaviour
- Landau Kleffner syndrome: education

Children with Landau Kleffner Syndrome (LKS) experience a significant regression in their understanding and use of spoken language. This loss of skills often occurs at the onset of the disease and can be the first sign for families that something is wrong. Language difficulties may emerge suddenly or develop more slowly over time. Issues with language are most apparent during the active phase of LKS and can fluctuate during the course of the disease.

This information sheet from Great Ormond Street Hospital (GOSH) describes how Landau Kleffner Syndrome (LKS) can affect a child's language skills and outlines recommendations for input and support.

How can LKS affect a child's understanding of language?

LKS can cause significant difficulties in a child's understanding of spoken language. This means that they are no longer able to understand spoken words or sentences in the way they could previously. LKS can affect a child's understanding in different ways.

Some children continue to understand simple language, while others may lose the ability to understand any spoken words. Some children may also find it difficult to respond to, or recognise, sounds around them, such as a doorbell ringing or a dog barking. For this reason, parents may suspect their child to have hearing difficulties or to have become deaf. Hearing tests at this time would show that the child's hearing remains intact, however it is their ability to make sense of the sounds or words, and to know what they mean, that has been affected.

For some children, this loss of skills is less severe. Their understanding of spoken language may be limited to short phrases, simple sentences, or single words. Some children may also find it difficult to distinguish speech sounds within words and this can also affect their understanding of what is said.

Children with LKS will often require visual cues to help them understand language (for instance, signing, gesture, pictures). They may make use of lip reading to support their understanding or rely on strategies such as trying to guess what is being said from clues around them.

In what ways can LKS affect a child's ability to speak?

LKS can also cause significant difficulties in a child's use of spoken words and sentences. As with comprehension, children can be affected in different ways and their abilities may fluctuate over time.

Some children will stop using words altogether, and may become silent or produce short sounds and vocalisations. They may rely on gesture or sign to help them communicate with those around them.

Other children may retain some words but find it difficult to structure their sentences correctly. They might also make errors in their vocabulary, such as forgetting a word they previously knew or substituting one word for another. This is often referred to as 'word finding difficulties'. Their speech may seem more hesitant as they pause frequently while they try to find the right word.

Some children with LKS experience changes to the tone or quality of their voice. Articulation may become an area of difficulty and children might struggle to produce the correct sounds within words.

How do I help a child with LKS who has communication difficulties?

Children with LKS require support around their functional communication skills (that is, their ability to communicate with those around them in every day situations) as well as targeted input around their acquired speech and language difficulties.

In LKS, the brain's ability to process visual information can remain intact. This means that visual communication approaches (such as pictures, symbols, objects, signing, written language) are typically used to compensate for the difficulties a child has with understanding or using spoken language. These methods of communication do not require the child to interpret spoken language but will enable them to access their stored language knowledge and communicate with others using other approaches. Children will often benefit from access to signing at the onset of difficulties and some children will learn to use British Sign Language (BSL) as an effective form of communication.

As LKS affects children in different ways, a thorough assessment of a child's speech, language and communication should be carried out so that a personalised communication programme can be introduced.

Community Speech and Language Therapy

Children with LKS will require a comprehensive communication programme to support them throughout the day, at home and at school. They should access community speech and language therapy services as soon as possible after the onset of difficulties. Referrals can be made by parents, a GP or paediatrician, or the school Special Educational Needs and Disabilities Coordinator (SENDCo). It should be stressed in the referral that language regression is due to LKS in order to emphasise the need for immediate intervention.

Assessment

Once referred, the Speech and Language Therapist (SLT) will carry out a detailed assessment of the child's receptive language (understanding of words) and expressive language (use of words). They will also assess a child's strengths and needs in their functional communication skills (how they are communicating with those around them).

They will ask questions about the child's language development before regression. Any documentation of this (such as school reports, red book) will be very helpful so that the loss of skills is clearly appreciated and a label of 'language delay' is not given. Assessment usually takes place in the child's nursery, school or at a local clinic. The findings from the assessment will enable the SLT to set up an intervention programme.

As LKS is a rare condition, close liaison with teams that have experience in LKS will be essential. Community SLTs may find it helpful to contact the SLT team within the Developmental Epilepsy Clinic at Great Ormond Street Hospital for information on LKS, assessment and intervention.

Intervention

Speech and language therapy interventions should involve the SLT, parents and school. The timing of therapeutic input is important and intervention should begin as soon as possible after diagnosis. Owing to the fluctuating nature of LKS, therapy programmes may change depending on the child's needs. They are likely to focus on specific difficulties in understanding and using spoken language; introducing and developing the use of visual aids, including signing; and introducing strategies to the home and school environment to support a child's wider communication skills.

Monitoring

The SLT's role, alongside parents and education professionals, includes monitoring changes in a child's language skills over time and liaising closely with the medical team to alert them to these changes. For example, a child may lose skills if they experience a regression and the SLT may need to adapt interventions and highlight this change to the medical team. Equally, a child may rapidly regain language skills in response to medication and there will be a window of opportunity to use therapy input to build on these improvements.

Recovery from LKS – ongoing intervention and support

The degree of language recovery in LKS can vary. Some children will regain their language skills while others will continue to present with significant language difficulties. For this reason, children with LKS will often continue to require input from an SLT, even when the disease is no longer active.

Children who have experienced a language recovery may be left with some residual language difficulties which can be supported and targeted through intervention and appropriate support at school or college. Support may be needed around processing spoken language in noisy environments, keeping up with fast-paced conversations, and filling gaps with grammar and vocabulary knowledge. Children may also need strategies to help them remember large pieces of verbal information (such as to follow detailed verbal instructions or long explanations).

Examples of communication support at home and school

In addition to targeted input around receptive and expressive language, other interventions during the active phase of LKS will focus on providing wider communication support.

Signing

One of the most effective approaches for children with LKS is sign language. This is often used alongside spoken language and can be adapted depending on the needs and abilities of the child. For example, a sign supported system, in which the key words are signed alongside speech, may be introduced initially (e.g. Makaton™ or Signalong™). Children may then go on to use a more complex sign language such as British Sign Language (BSL).

Signing can support a child in continuing to develop their communication skills, their vocabulary knowledge and their understanding of language concepts during the course of their LKS. Signing

would not prevent a child from recovering their spoken language. Being able to communicate through sign and understand sign language may also help to reduce a child's frustration and can have a positive impact on their behaviour and interactions with others.

Signing can be discussed with the child's SLT so that it can be introduced into school and home settings as early as possible. It should be used consistently across the day and in all contexts, with the child, family, teachers and friends being given adequate opportunity to learn it. Signs can be introduced gradually to support the child's understanding and ability to express themselves. For children with LKS, it is often helpful to use speech alongside signs. Children typically sign less if their spoken language returns; however it might remain a useful tool to support communication in some environments.

Objects, photographs, pictures and symbols

Visual supports can be used at home and school, alongside speech, to help a child's understanding of language and to help them get their ideas across to others. Visual timetables, charts or lists can help children understand a series of tasks, follow verbal instructions, understand new situations, or know what is going to happen during the day.

The SLT and school can advise further on the use of these and other approaches as part of a child's individualised communication programme.

Strategies to support understanding and use of spoken language

As a child begins to recover some spoken language, they will continue to benefit from strategies to support their communication with others. It may be helpful to consider the following points:

- Make sure you have the child's attention before starting to speak
- Make allowances for the child to 'tune in' to conversations around them, especially if it is happening at a fast pace or if many people are talking at once.
- Some children find it difficult to process language when there is a lot of background noise. Tuning this out can be hard and support will be needed to help the child understand and follow what is being said.
- Children may find it difficult to retain large pieces of verbal information. They can be helped by breaking down long instructions or

explanations into shorter ones. Monitor and check their understanding – particularly in a classroom setting and provide clarification or repetition as needed.

- Using sign, gesture, pictures or written information helps children to understand what is being said and retain the information given. As they get older, they may continue to benefit from some of these strategies to support their communication and learning, for example writing their own checklists or organising verbal information into diagrams or charts.
- If a child presents with word finding difficulties, they can be supported by giving them the first sound in the word or asking them to describe what the word means in order to prompt their own recall. They may also benefit from some extra opportunities for consolidation of vocabulary learning in class.

Further information

A list of contacts for further information and support can be found in our leaflet *An introduction to Landau Kleffner syndrome: information for families*.