

Changes with Age in Kleefstra Syndrome

Research into Kleefstra syndrome is still limited, and so little is known about how the characteristics and behaviour of individuals with the syndrome develops over time.

Physical characteristics

As individuals get older, protrusion of the tongue improves.

Health

Epilepsy can be controlled with medication and improves with age. For some individuals, heart problems are still prevalent and require surgery.

In adolescence, individuals may develop a loss of interest and show increasingly unresponsive behaviour (known as catatonia). [Click here](#) to read more about this.

Behaviour

As children get older, outbursts of anger may become more common, as well as a variety of anti-social, compulsive and self-stimulatory behaviours. Research has also reported cases of individuals displaying autistic features and sleep disturbances, particularly in adolescence.

For some individuals, a decline in adaptive behaviour has been reported as age increases. Compulsive and inhibited behaviour and a loss of initiative are also reported to develop over time, and individuals may also experience a rise in anxiety and depression. [For more information on how to deal with anxiety and depression, download Cerebra's guide.](#)

For some individuals, speech improves with age. However, more research into this area needs to be done in order to determine the precise timeline of these changes.

Sleep

Recent research suggests sleep disturbance can sometimes begin during adolescence or adulthood. Some studies found remarkable sleep disturbances in participants. This is characterised by frequent night time waking and daytime sleepiness.

Mood and Sociability

There is also some evidence that mood, interest, pleasure, and sociability may decrease with age in Kleefstra syndrome; however, this is based on a very small number of individuals and these findings are yet to be published in a scientific journal.

The information on this website was developed in collaboration with www.kleefstrasynndrome.org. This is the parental support group for Kleefstra, a well-developed community with an active facebook group and parent support conference. Please visit their website for further information and to get in touch with families of individuals with Kleefstra syndrome.