

Stereotypes

Whilst this article is focused on a number of the similar repeated movements and behaviours that children and adults with CDKL5 can exhibit, it is important to recognise that these are just their versions of some of the odd behavioural quirks we all possess. Good examples of this in the wider world are nail biting, finger tapping, playing with one's hair, and even thumb-sucking as a common children's stereotype.

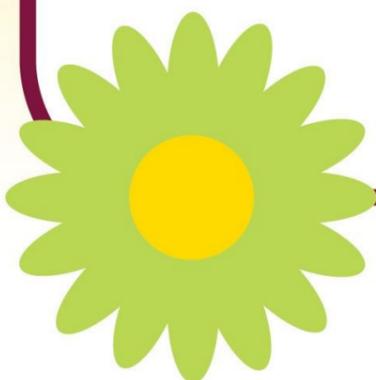
The generally accepted view is that these actions and behaviours provide a stimulus for the individual. They may be providing additional sensory stimulation or may in other cases be used to block out or inhibit excess sensory stimulation. They may indicate a positive or a negative emotion.

Children with CDKL5 can show typical repeat behaviours, some we have witnessed and recorded include: playing with hands and fingers; spontaneous hand clapping; sucking one or more fingers or even the whole hand; continual side-to-side head shaking; and odd verbal sounds such as moans, squeals, or screeches. Whilst most stereotypes are generally harmless to the child and those around them, many may be viewed as unpleasant or anti-social, so there may be a temptation to try to stop the child from what can be seen as obsessive, repeat behaviours. However, as with those stereotypes exhibited by the rest of us, this can be easier said than done, not least because the child will not understand that their particular behaviour(s) are anything other than normal and they are at least fulfilling a purpose or a need, even if we do not necessarily understand this.

The focus, therefore, is better placed on trying to understand what purpose each such behaviour is fulfilling for the child. As our children are generally non-verbal, this relies on our own observation and interpretation of the behaviour in the context of the child's mood, state of health etc. at any given time. Once the connection has been made, it may be possible to develop strategies for addressing the root cause rather than focusing on stopping the behaviour itself. Such strategies may, for instance, include taking steps to actively manage the child's sensory environment, either through providing an environment less likely to stimulate the stereotype, or even providing a safe, harmless environment in which the child can exhibit the stereotypical behaviour. Even where this is not possible, it is important for us all to recognise the circumstances or environment which may lead to a particular behaviour or action. This can at least help us to manage the situation to minimise the negative connotations sometimes associated with such behaviours. Even having the ability to explain the stereotype to others is an important step.

Parents and carers of children and adults living with CDKL5 report many repetitive behaviours. Here is a not-exhaustive list of some:

- Hand sucking, can include whole hand, fingers or thumbs
- Hand clapping, and arm flapping
- Rhythmic head shaking - this can be as a result of distress but likewise when happy.
- Self injurious behaviour - finger biting, hand biting
- Verbal noises eg shouting, or a back of the throat noise - appearing to like the feeling of the vibration at the back of the throat.



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