Interventions for Behaviours that Challenge

There are several key components for successful management of behaviours that challenge. Firstly, the intervention should be developed to maximise a person’s quality of life, rather than to simply suppress an unwanted behaviour. Secondly, the intervention should always be based on a systematic assessment of behaviour. It is important for those carrying out the intervention to have a good idea about the cause of the behaviours that challenge before trying to reduce it. Behaviour can be caused by different things for different individuals, so trying to change behaviour without fully understanding it can lead to the behaviour becoming more ingrained over time. Interventions should never be restrictive.

Managing behaviour that is underpinned by pain and discomfort

Treatment of underlying health difficulties followed by regular monitoring should help to reduce behaviour. It may be helpful to familiarise yourself with common health difficulties in Cornelia de Lange syndrome. It is important that families have a supportive GP who is willing to take the time to listen and understand the needs of children with Cornelia de Lange syndrome.

Managing behaviour that is underpinned by sensory reinforcement

There are numerous strategies to help reduce behaviours that challenge that are maintained by sensory reinforcement; for example, working out what kind of sensory reinforcement the person is receiving from the behaviour and trying to provide that via other means. Increasing the general level of sensory experiences the person has throughout the day may be another helpful strategy.

Managing behaviour that is underpinned by external causes

External factors that cause behaviour that challenge include access to social interaction, escape from a demand, access to a preferred object or activity, escape from social contact, and escape from an aversive sensory experience. Interventions for these behaviours typically involve teaching a person an alternative way to communicate what they want, and structuring the environment so that the thing they desire is available as much as possible. This might involve teaching a sign or helping the person use a communication system. It also involves making sure that the previous behaviour, for example self-injury, is no longer as effective as the new method of communication in gaining the desired outcome. Sometimes it is not possible for a person to have the thing they need when they ask for it and in these instances it is important to help the person discriminate when the thing they want is and is not available.
These interventions can be complicated and need to be monitored carefully. We advise that families seek the support of a professional such as a clinical psychologist, or behavioural team.

Don’t give up!

What is important to remember is that these behaviours may increase for a short time when teaching a new form of communication. This is because for the new communication to be successful the old form of communication (behaviours that challenge) needs to be less successful. Families may be advised to ignore the behaviour that challenges or respond in a way that gives as little ‘reward’ or reinforcement as possible. When families change the way they respond to behaviour the person with Cornelia de Lange syndrome may show more behaviour as they try harder to make their needs known. This is called an extinction burst and is a natural part of behaviour change. However, over time the behaviour will decrease. As a final note, it is very important that people do not ignore behaviours that challenge without teaching an alternative communication strategy because otherwise the person has no way to communicate their needs.

Managing other forms of behaviours that challenge

To read some tips on managing other forms of behaviours that challenge visit these pages:

Behaviours that challenge due to anxiety

Behaviours that challenge due to interruption of repetitive behaviours

Behaviours that challenge due to frustration due to communication difficulties.