

Down's syndrome and Complex Needs

Mental Health – Obsessive Compulsive Disorder (OCD)

August 2023

What is OCD?

Obsessions are thoughts that preoccupy the mind. Compulsions are acts that one feels compelled to perform. In classic OCD these compulsions are linked to a desire to lessen the anxiety arising from the obsessions.

Ordinarily, people with OCD realize that their obsessions or compulsions are extreme and not typical and would like to be rid of them.

Stress and other factors, such as physical health problems and life events can contribute to the development of mental health issues including OCD and anxiety disorders.



Sameness and Repetition (not OCD)

Many people who have Down's syndrome have a tendency towards sameness and repetition. Chicoine & McGuire refer to this tendency as 'The Groove' because people tend to follow well-worn paths or 'grooves' with set routines where they must do things in the same way. It is the absence of this behaviour that is notable because it is a rarity.

These tendencies can be especially marked in people who have a dual diagnosis of Down's syndrome and Autism Spectrum Disorder (ASD).

'Grooves' can be beneficial because they provide a sense of structure, order and predictability thus reducing anxiety and stress in daily life. They can help people to remember and complete self-care or work tasks and reduce the need for prompting and supervision from others. This may lead to greater independence which supports the person's positive self-esteem.

Here are some common examples of 'grooves':

Having a set order and timing to daily routines

Being quite meticulous in personal care and appearance

A set method for packing a bag.



People can also have 'grooves' in their personal preferences (e.g., music, activities, celebrities, or a favourite person).

'Grooves' can reduce the likelihood of a person having to deal with the stress of unexpected events. They may also be used as a calming mechanism when unforeseen stressful events occur. So, when stressed, people may, for example, use the following 'grooves' to relax:

- Repeating a loved activity in a quiet or private space such as reading, drawing, listening to music, or writing.
- Cleaning or grooming.

These repetitive familiar activities may provide reassurance and also respite from interacting with others.

'Grooves' can be a very positive tool in people's lives in terms of managing stress and anxiety. But there is a continuum where it is possible for a situation to develop where a person sticks too rigidly to a 'groove' and/or the 'groove' no longer serves a useful purpose.

'Grooves' and OCD?

'Grooves' can become an issue if they are interfering with a person's everyday life and their normal, essential, and previously enjoyed activities are disrupted. Stress and anxiety may result in thoughts or actions becoming stuck or rigid and a normally beneficial 'groove' can become an obsession or compulsion.

People may slow down, use more repetition, and display greater inflexibility than would be usual for them. In some cases, people may begin to use behaviours that are unusual for them such as hoarding items. This can lead to difficulties that are diagnosed as OCD.

The 'Grooves' Continuum

Most
Adaptive

Less
Adaptive

Maladaptive

OCD



Essential

No useful purpose

Interfering with day
to day function



OCD in people who have Down's syndrome

OCD seems to be more common in people who have Down's syndrome than in the general population, however it is still a rare occurrence.

Chicoine & McGuire point out the following in relation to diagnosing OCD in people who have Down's syndrome:

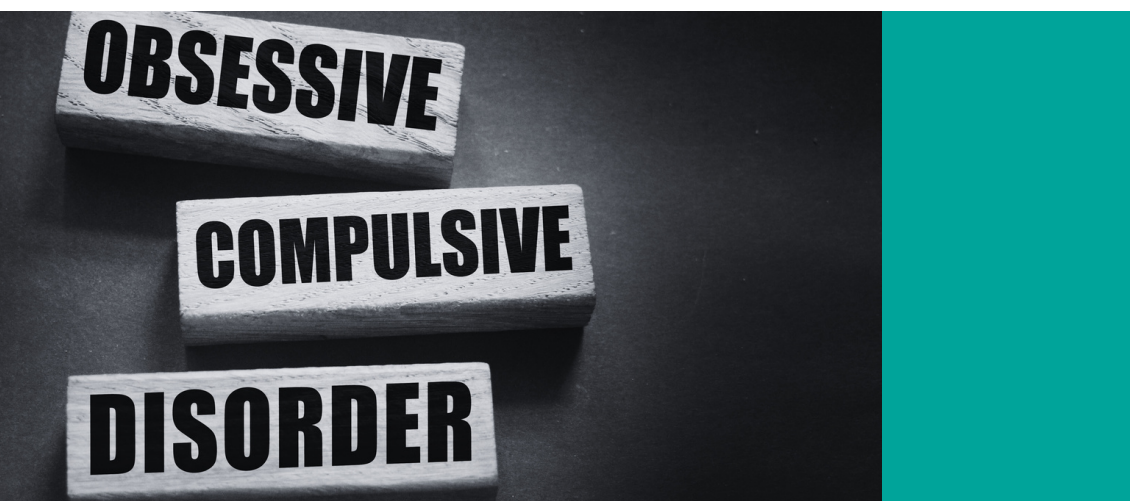
- There needs to be careful consideration of not diagnosing helpful 'grooves' as OCD.
- It is important to have a comprehensive case history that includes changes in behaviour and relevant stressors.
- OCD may be diagnosed even if the person seems to take pleasure in their compulsions or obsessions.
- For a diagnosis of OCD to be made the behaviour must interfere significantly with the person's ability to do day to day activities.

What helps

According to Chicoine & McGuire redirection should be the initial response, trying to interest the person in another activity either just before, or just after they begin a compulsive activity.

The following suggestions around redirection are taken from 'Mental Wellness in Adults':

- Select an interesting or preferred activity in advance.
- Do not get angry when trying to redirect.
- Suggest rather than insist that the person try the other activity (try over course of days; expect gradual, not instant changes)
- Offer rewards to do an alternate activity and use 'First...then' prompts with visual cues to help.
- Only work on one obsession/compulsion at a time
- Remember that physical prompts may make the person become more agitated



What do to next

Any treatment for OCD including medication and therapy would involve an assessment and discussion with a qualified health professional.

In the general population, Cognitive Behaviour Therapy (CBT) is recommended, sometimes in combination with medication (see link below for the website of the Royal College of Psychiatrists).



OCD and ASD

Obsessions and compulsions may appear more severe in people who have Down's syndrome and Autism. However, having severe obsessions and compulsions is not necessarily an indicator that the person has ASD. A proportion of people who have Down's syndrome and OCD do not have ASD.

References and further reading

Mental Wellness in Adults with Down syndrome, Chicoine & McGuire (Woodbine House, 2nd Edition, 2021) Mental Wellness in Adults with Down Syndrome: A Guide to Emotional and Behavioral Strengths and Challenges (2nd Edition) | Adult Down Syndrome Center (advocatehealth.com)

Complex needs resources books - Downs Syndrome Association (downs-syndrome.org.uk)

Emotional Wellbeing - Downs Syndrome Association (downs-syndrome.org.uk)

Obsessive-compulsive disorder (OCD) | Royal College of Psychiatrists (rcpsych.ac.uk)



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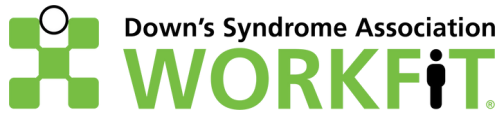
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