
The Cerebra Centre for Neurodevelopmental Disorders, University of Birmingham

Members of the Cerebra Centre for Neurodevelopmental disorders have conducted research to investigate the behavioural characteristics of people with Rubinstein-Taybi syndrome (RTS). This research has revealed that people with RTS often display repetitive behaviour.

‘Repetitive behaviour’ is an umbrella term for a range of behaviours including adherence to routines, insistence on sameness, stereotyped movements (e.g. hand waving and spinning) and restricted preferences.

The research study revealed that several repetitive behaviours occurred very frequently in people with RTS. These included repetitive speech (questions & phrases), wanting a specific routine, and repetitive movements of the body (stereotypies).

There are many different reasons why repetitive behaviour occurs and there is no single theory to explain this behaviour. It may be that different factors are involved for different people. Here are a few of the most likely reasons repetitive behaviour may occur:

According to Executive Function Theory (EF Theory), specific repetitive behaviours may occur as a result of difficulties with executive functions. ‘Executive functions’ refer to cognitive, brain-based processes, such as the ability to stop responses (inhibition), hold information in mind (memory), and mentally switch between tasks (cognitive flexibility). Evidence suggests that when a person with RTS who uses speech has difficulty remembering information and inhibiting responses, they are more likely to ask repetitive questions and repeat phrases. Findings also suggest that when a person with RTS has difficulty with cognitive flexibility, they are more likely to prefer routines.

Repetitive behaviours may also occur for other reasons. For example, a person may show repetitive behaviour as a way of increasing or reducing sensory input, reducing stress and anxiety.

Bear in mind that repetitive behaviours are not always problematic to either the person

with RTS or the people around them. Sometimes, though, repetitive behaviours can occur very frequently or be very intense; at this point the behaviour may start to interfere with the person’s day to day activities and well-being. It is then important to look at methods of reducing the behaviour, which may involve encouraging more flexible and adaptive behaviour.

We have developed this short guide to suggest methods of supporting people with RTS to reduce these behaviours. As the finding that repetitive behaviours occur in people with RTS is relatively new, there have been no studies examining the effectiveness of the following ideas for people with RTS. However, these strategies have been found to be effective for other people who show repetitive behaviour, such as people with an autism spectrum disorder, Prader-Willi and Williams syndromes.

Some of the following methods may work for some individuals and not others. Seek psychological support to help you implement these ideas.

Reducing adherence to routines.

-Let the person know when a change is about to happen in their routine by showing them a picture card for ‘change’ five minutes before the change occurs. While the change itself is unpredictable, the change picture card becomes a predictable warning that prepares the person to respond more flexibly.

-Teaching to person gradually to cope with more unpredictability in their routine. For example, first create a visual aid to provide **predictability** to the weekly routine, such as a visual schedule or timetable, and then very gradually introduce a ‘?’ time slot into this schedule which is a mystery or ‘uncertain’ activity. This is **planned uncertainty** and can help the person learn that uncertain events can be manageable, and even enjoyable.

Reducing repetitive speech/questions.

-If the person you care for with RTS can read, write the answer to the repetitive question on a sticky note or in a notebook when it is first asked, then redirect the

individual to that when the question is asked again. A memory aid like this could also use pictures.

-Insisting that once the person’s question has been answered once, they then answer their own repetitive questions. However, bear in mind that repetitive speech may be one of the few ways a person can initiate interaction so, while the repetitive question may not be answered, the person may still need to have their desire for social interaction met.

-If the repetitive questioning continues, explain that you have already answered that question but are willing to discuss their choice of one of a few topics with them.

-Allocating a special time of the day during which the person with RTS talks about their special interests or asks their repetitive questions.

-Use a scripted format to introduce better conversational strategies and practice these across various topics and situations.

-Teach self-control skills by encouraging the person to play simple games where they have to wait for their turn. You could provide a reward for when the person with RTS successfully demonstrates turn-taking.

Reducing repetitive movements:

-If the behaviour is underpinned by a need for sensory stimulation introducing fidget toys or stress balls may help to produce the same level of sensory stimulation or distraction.

-Prompts to stop the behaviour, combined with a reward system where the person is rewarded if they can spend increasing periods of time without displaying the behaviour. With this strategy, it is best to start with very small time periods.

If you have any questions regarding this intervention guide, please contact the Cerebra Centre for Neurodevelopmental Disorders via the following phone number or email address.

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