

Down's syndrome and Complex Needs

Regression in people who have Down's syndrome

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What is Regression?

Regression is a term that is used to describe the loss of previously acquired developmental skills in an individual. This can be in the areas of daily living, language, motor abilities/function, or social interaction. Regression typically occurs in adolescence/young adulthood and can occur over weeks to months or more quickly. There are some similarities with the presentation of autism and Alzheimer's disease however the age of the person would be the key indicator. Autism would usually be apparent at an earlier age and Alzheimer's at 40+.

Regression can also be referred to as Down's syndrome regression disorder (DSRD), Down's syndrome disintegrative disorder (DSDD) or unexplained regression in Down's syndrome (URDS) and these terms are sometimes used interchangeably.

The cause of regression is thought to differ among individuals and there is ongoing research to look at causation and treatment options.

The boxes below contain lists of reported symptoms.



Behaviour

Change in eating patterns (e.g., not wanting or not having interest in eating, extreme slowness with eating). This may or may not be associated with weight loss.

Insomnia and difficulty sleeping.

Compulsive and/or obsessive behaviors. (e.g., lining up toys, rigidity with routines not previously present, only talking about one specific show/activity/game)

Facial grimacing or repetitive movements of the mouth that can mimic chewing behaviour.

Loss of previously acquired developmental milestones or abilities.

Loss of independence in activities or need for significant assistance with activities. e.g., can no longer toilet or use the bathroom independently, feed self, dress self, or bathe self when previously able)

Aggressiveness towards self or others.

Displaying anger or frustration with or without behavioural outbursts.

General disinterest.



Movement

Repetitive hand or body movements.

Changes in motor activity. (stiffness, slow movements, freezing, tics and/or extra movements that are not purposeful)

Also, the following may be seen.

- **resistance to passive movement (stiffness),**
- **sudden loss of tone (cataplexy)**

'Freezing' or slowness in moving, this can sometimes look like a slow and shuffling gait where the feet don't lift off from the floor.

Movement changes as a result of catatonia. (see more about this below)



Communication

Mutism.

Loss of language or diminished language.

Decreased speaking, loss of certain word use, sentence structure changes, 'baby talk', speaking in a whisper.

Increased self-talk.

Social

Social withdrawal from friends, family, and school/classmates.

Development of autism-like features that were not previously present (onset over weeks, not chronic).

Decreased eye contact.

Repeating things that other people say or repeating lines from movies/television.

Decreased showing of empathy or emotions towards others.

Lack of interest in others



Mental health

Bizarre thought content or experiences (psychosis). This can include hallucinations (seeing or feeling things that are not there), delusions (belief in things that are not true), altered awareness, or distortions of memories/historical knowledge.

Inappropriate mood and affect. (crying for seemingly no reason, laughing uncontrollably to themselves even in an otherwise solemn situation)

These symptoms would typically have an onset of less than 3 months rather than there being a gradual decline.

There may be triggers that precede the onset of symptoms such as negative life events, changes in the home/school environment, and medical illness or hospitalisation.

If your loved one is experiencing any of these symptoms, it is important that they are seen quickly for assessment. Although we don't know for certain, it is presumed that early diagnosis and treatment, may improve outcomes

Cause of regression

Regression is a description of what is happening, the cause can be several things and will differ.

Below are some of the possible causes.

Medical

The symptoms of regression could be because of an undiagnosed medical condition. It is important that medical conditions such as obstructive sleep apnoea, hypothyroidism, coeliacs are ruled out as a contributing factor to the presentation of symptoms.



Neurological

People who have Down's syndrome can have neurological conditions such as epilepsy, a stroke, and mitochondrial disease and these should be ruled out as reasons for regression by a Neurologist.

Some families have been told that their loved one with Down syndrome and regression has 'early onset Alzheimer's disease'. This is very rare in persons less than 40 years old and other causes should be ruled out prior to arriving at this diagnosis.

Psychiatric/Psychological

Mental health conditions/significant life stressors are known to be factors in regression. Any diagnosis would require psychiatric or psychological assessment.

Catatonia has been recognized as a common feature of regression. Catatonia can be caused by psychiatric and/or medical conditions. It is not featured on any psychiatric screening tools and can be overlooked. Catatonia is important to detect as it may respond to treatment.

Immunologic/Endocrinologic

People who have Down's syndrome are at risk for inflammatory and endocrine disorders such as thyroid disease, coeliac disease, rheumatologic conditions (including inflammatory skin conditions such as psoriasis), and diabetes. Although these are less linked to longstanding regression, ruling in/out these diseases is of value as they are treatable

Genetic

Most people who have Down's syndrome have trisomy (three copies) of chromosome 21. It is possible for people to also have other genetic variations in addition to this.

Metabolic testing of blood or urine can sometimes detect genetic variation but not every person with regression requires genetic or metabolic testing.



Nutritional/Environmental

Regression can be caused by severe vitamin deficiencies, heavy metal or toxin exposure or infection. These are less frequently reported in persons with regression but can be evaluated as well, especially if there is a history of exposure or very restricted eating or diet.

Treatment

It is important to determine the reason(s) for the regression as this will inform any treatment. No case of regression is exactly like the next.

Any tests would be decided by a medical professional who may consult with relevant specialists. Testing is based on an individual's symptoms and determining the most likely cause of the regression. Sometimes a combination of treatments will be considered and discussed. A doctor may recommend treatment for an individual's symptoms while still waiting to get tests done.

There is no one singular treatment for a person with regression. Once a source (or reason) is found, medical professionals can work together to provide the best treatment options.

It may be necessary to seek consultation from an expert in psychiatry, neurology, and/or a provider familiar with treating people who have Down's syndrome and regression before starting a therapy.

How to support someone

We do not know the impact on the individual of regression. However, it is likely to be a frightening experience for the person.

Minimising other changes and retaining as much continuity and stability as possible may be helpful.

It may also be helpful to offer the person reassurance and an opportunity to express how they are feeling without pressure.

Seeking support from professionals is essential, the likelihood is that the person will be required to attend lots of appointments and have a number of tests which may be a trigger for stress. Where possible, maintain choice and autonomy, provide visual supports, and continue with daily activities unless this is detrimental to the well-being of the person.



DSA Research

The DSA is funding a research project into the cause, recognition and possible treatment of unexplained early regression. The team at the Cambridge Intellectual and Developmental Disabilities Research Group are recruiting participants through our usual channels.

If you know someone with Down's syndrome who is experiencing, or has recovered from, this type of regression, we would like to hear from you. Please email info@downs-syndrome.org.uk



References

This factsheet includes information adapted from the below
Regression in Persons with Down Syndrome: Current Consensus Update for Families -DSMIG USA

Helpful resources

[DSA Website - Emotional well-being resources](#)

[Dr Santoro video EDSA](#)

[Mental wellness book](#)

Research

Walpert, M.; Zaman, S.;Holland, A. A Systematic Review of Unexplained Early Regression in Adolescents and Adults with Down Syndrome. Brain Sci. 2021, 11, 1197.

Handen, B.; Clare, I.; Laymon, C.; Petersen, M.; Zaman, S.; O'Bryant, S.; Minhas, D.; Tudorascu, D.; Brown, S.; Christian, B., on behalf of the Alzheimer's Biomarker Consortium-Down Syndrome (ABC-DS). Acute Regression in Down Syndrome. Brain Sci. 2021, 11, 1109



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