DOWN'S SYNDROME ASSOCIATION

Regression
A DSA timeline

November 2024

Early 2000s

As an organisation we first became aware of people who had Down's syndrome presenting with a loss of skills that wasn't autism or dementia.

We supported a paper by Prof. Vee Prasher which was published in 2002 which talked about an awareness of an unclassified condition he was calling Disintegrative Syndrome in young adults.

2010 onwards

At a DSMIG meeting in 2010 Dr Deirdre Cahalane presented her findings around catatonic regression in adolescents with Down's syndrome discussing several case studies from her clinical work.

2018 World Down's Syndrome Congress in Glasgow

Several speakers presented around the issue of regression at the pre congress health symposium, confirming similar findings worldwide.

The DSA Journal Spring/Summer 2019 included the following:

'The increasing number of younger adults worldwide presenting with a non-Alzheimer type of mental regression. This is something that the DSA has been flagging up for some time with our psychiatric advisors in response to enquiries received from our families. We have started a closed Facebook group for families and we are looking at the possibility of a research study looking at this condition'.

Following this, the DSA funded Cambridge to carry out **A systematic review of unexplained early regression in adolescents and adults with Down's syndrome.** A paper was published in September 2021, abstract below:

'A proportion of young people with Down syndrome (DS) experience unexplained regression that severely impacts on their daily lives. While this condition has been recognised by clinicians, there is a limited understanding of causation and an inconsistent approach to diagnosis and treatment. Varied symptomology and little knowledge of the cause of this regression have impacted on clinician's ability to prevent or manage this condition. The purpose of this review was to examine the current evidence surrounding unexplained regression in adolescents and young adults, and to establish patterns that may be of use to clinicians, as well as raising awareness of this condition.

Four areas were specifically reviewed:

- *terminology used to refer to this condition*
- *the symptoms reported*
- *potential trigger events*
- *treatments and prognosis.*

A variety of terminology is used for this condition, which has constrained past attempts to identify patterns. An extensive number of symptoms were reported, however sleep impairment, loss of language and distinct changes in personality and behaviour, such as disinterest and withdrawal, were among the most frequently seen. Life events that were tentatively associated with the onset of a regressive period included a significant change in environmental circumstances or a transition, such as moving home or leaving school. Prognosis for this condition is relatively positive with the majority of individuals making at least a partial recovery.

However, few patients were found to make a full recovery to their previous level of functioning and serious adverse effects could persist in those who have made a partial recovery. This is an under-researched condition with significant impacts on people with DS and their families. There are no established treatments for this condition and there is relatively little recognition in the research community. Further studies that focus on the prevention and treatment of this condition with controlled treatment trials are needed.'

As well as the above paper, a member of the Cambridge team was involved in the publication of another paper about **Acute regression in Down's syndrome.**

In 2020 at a DSMIG meeting Dr Richard Newton presented Neurological approach to regression and poor progress in Down's syndrome.

With DSA support, Cambridge commenced a project in 2022 to look at the experiences of young people who have had regression.

Down Syndrome Act - Call for Evidence

As part of DSA's submission for the call for evidence, the following was submitted:

> *It is vital that GPs, Learning Disability Teams, Learning Disability Nurses, Psychologists, Psychiatrists and CAMHS services are knowledgeable about the presentation of early regression and are able to provide timely investigation and support, for the individual and the family. We know that awareness is highly variable and that parents have frequently had to be persist in order to obtain routes into public services and receive sympathetic management for their children.*

DSA led webinar on regression

In March 2023 the DSA hosted a webinar jointly with the Dept. of Psychiatry at Cambridge. The work of Dr Santoro in the USA was presented with several parents talking about their experiences. This resulted in an increased awareness of regression in young people who have Down's syndrome.

Current work

We have experienced an increase in calls and emails regarding this subject. In response we have developed a webpage where we are collating useful information and resources. We are also looking to gather case studies to inform further work in this area with continued collaboration with academic and clinical partners.

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