Depression in Down syndrome: a big problem?

The Committee for Science & Society of the Trisomy 21 Research Society (T21RS) regularly addresses issues raised by parents and Down syndrome associations through summarizing the state-of-the-art knowledge from a scientific perspective. The Committee for Science & Society* is strongly committed to introduce scientific research and explain recent findings in an understandable way. Today, the first edition of the T21RS Science & Society Bulletin: key issues on depression in Down syndrome.



FAQ on depression in Down syndrome

- Are changes in mood normal with aging?
- How does depression manifest itself in adults with Down syndrome? Is it different from depression in adults without Down syndrome?
- Is there anything we can do to prevent mood changes?
- How do you know when to seek help?
- What needs to be ruled out when assessing depression?
- What kind of therapeutic options are there?

While the transition from the teenage years to adulthood brings many new challenges for individuals with Down syndrome, one of the most common concerns expressed by caregivers regards changes in mood. 'When we see adults with Down syndrome in the clinic, they are typically brought in for the emergence of new symptoms,' says Dr. Michael Rafii from the Down Syndrome Research and Treatment Center of the University of California in San Diego, United States. 'In younger adults aged 20-40, there is usually a report of depression, anxiety, increased self-talk and rarely psychosis'. Rafii stresses that in many cases there is a change in social situation 'that precipitates the behaviors'. This concerns, among others, 'change in staff at day program, change in daily routine, moving to a new home, or loss of a family member.' Individuals with Down syndrome can thus experience psychiatric symptoms just as any other individual can. Among those symptoms, depression is a fairly pronounced one. However, the progression and signs of depression can differ from those in the general population.

Depression vs. apathy: not to be confused

Discussing depression in Down syndrome, it is essential to make a distinction between apathy and depression. Distinguishing these two may be fairly complex and apathy is often misdiagnosed as depression [1]. Apathy is generally defined as a loss of motivation and is mainly manifested by decreased interest, indifference, and blunted emotional responses. Various scientific studies have demonstrated that apathy is relatively omnipresent in individuals with Down syndrome. It has been suggested that continuous apathetic symptoms at adult age might be an early indicator for the development of Alzheimer's disease [2]. However, others found more apathetic symptoms, i.e. loss of interest, social isolation and increased fatigue in daily tasks, in older non-demented DS individuals compared to younger ones, which suggest that apathy is also related to normal aging in Down syndrome [3]. The lack of identification of apathetic behaviour might cause caregivers to misinterpret the symptoms as deliberate opposition or laziness [4].

Besides the commonalities between apathy and depression, depression includes unique symptoms such as: guilt, pessimism, self-criticism and feelings of worthlessness [4–6]. Because persons with Down syndrome may have difficulty expressing these feelings, the diagnosis of depression as opposed to apathy is complicated.

Is depression common in adults with Down syndrome?

Nevertheless, a particular vulnerability for depression has been suggested in adult persons with Down syndrome. A study in 1991 observed depression in 6.1% in 164 non-demented subjects with Down syndrome over 20 years of age, but found no depression in the 261 individuals below 20 years of age [7]. Others reported a three times higher number of depression in Down syndrome (11.3%) compared to aged-matched controls with intellectual disability of another aetiology (4.3%) [8]. With a prevalence of major depressive disorder of 4.7% in the general population [9], depression is likely more common in people with than without Down syndrome.

Issues in diagnosing depression

It is important to note that depression and dementia share various common symptoms, and depression can negatively affect cognitive and daily functioning. Therefore, depression might be misdiagnosed as dementia, pointing at the importance of careful differential diagnoses [10–12]. In addition to ruling out dementia, there are other factors which must be examined in order to best assess and treat depression. Many individuals with DS have difficulty with expressive communication. Because of this, medical issues that can cause pain and distress go undiagnosed, as the individual may not be able to disclose the problem. Thus, a physical workup should be done by a primary care doctor to explore the impact of health on mood and behavior. Once medical issues are ruled out, one must identify social triggers that may contribute to stress and anxiety. While life occurrences such as moving, a change in work or a family issue can cause significant stress in the general population, the effects of such occurrences may cause particularly exacerbated distress in individuals with Down syndrome. Thus, one must carefully assess any changes in social factors, as correcting these components may be an effective option to relieve stress and improve mood. Pharmacological treatment can be used in addition to medical and social treatment, though it may have limited success on its own [13].

In short, apathy and depression are fairly hard to distinguish. This is additionally complicated by depression's overlap with various symptoms of dementia. However, a careful diagnosis is essential, because it allows for adaptive caregiving and therapeutic interventions. For instance, a person with depression whose symptoms are incorrectly attributed to dementia may not receive the correct treatment and care. For dementia no pharmaceutical treatment is available, while depressive symptoms can be diminished by anti-depressive medication or behavioural intervention.

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T21RS is the first, and only, non-profit scientific organization of researchers studying Down syndrome, founded to promote research, apply new scientific knowledge to develop improved treatments and cures, and to explain (recent) findings to the general public. More information? Visit <u>www.T21RS.org</u> / <u>www.T21RS.org/nl</u> (Nederlands) or send a mail: <u>info@T21RS.org</u> (in English, Francais, Nederlands).
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Bibliography

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