**Regression in Adolescence and Early Adulthood experienced by people who have Down's syndrome**

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Regression is a well-recognised clinical presentation seen in people with Down's syndrome with multiple possible causes that requires investigation. By regression, we are referring to a loss of previously acquired cognitive and developmental skills in a person who has Down's syndrome. The many causes include underlying mental or physical health problems, such as depression or hearing loss. There is also a specific type of regression, called DSRD (Down syndrome regression disorder) where the underlying cause is not clear. DSRD usually occurs in adolescence and early adulthood and can appear within weeks or a few months. This type of regression is rare, and it is estimated that there is a 1-3% lifetime risk for all individuals with Down's syndrome. Note that dementia can present as regression, but it is highly unlikely to be the cause in a person aged 30 years or younger.

We do not expect all health professionals to be experts on this topic, but they should be able to identify when individuals change significantly and make appropriate referrals for assessment.

There is a wide range of treatment options that need to be considered that depends on the findings of a comprehensive physical and psychiatric assessment. We recommend that anyone who is showing a loss of skills or cognitive decline receives the following:

- GP review with relevant physical examination and routine blood tests including a thyroid function test
- Exclusion of the more common health conditions for people who have Down's syndrome including vision and hearing changes and dental problems
- Identification of possible transitions, environmental factors, life events such as change of school or carer, bullying, sibling leaving home, parental separation etc.
- Referral for further medical investigations as required
- Referral for psychiatric assessment (to assess for e.g. adjustment reactions, depression, catatonia and psychosis) as required
- Access to psychological support through a learning disability service if possible

We would like to see the formation of a regression working party and to facilitate a conference with a broad range of experts in the field sharing current findings.

We are committed to looking at what can be done to prevent regression including:

- Prioritisation of supporting mental wellbeing especially when people have experienced life changes or transitions such as loss
- Additional support for transition
- Access to individualised assessment, support and treatment including psychological support

A small number of individuals with regression may benefit from treatments not yet routinely available in the UK. This situation should be addressed with consideration of the current available research evidence.

We want to be involved in the development of UK guidance for health professionals on assessment and treatment of regression in Down's syndrome.

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