DOWN'S SYNDROME ASSOCIATION




# Round-up of meeting February 2026

## Meeting summary

### Changes in Behaviour

The group discussed concerns about changes in behaviour and abilities in their loved ones as they aged. Parents mentioned concerns around loss of skills and in some instances, aggression.

### Supported Living

Several parents expressed concerns around whether supported living placements were providing enough stimulation for their children and meeting their needs. Social care funding difficulties were mentioned, and a number of parents flagged up issues with high staff turnover and lack of consistency in support.

Another parent talked about the challenges her son had experienced and his vulnerability when going online. This parent talked of the tension between respecting her son's independence as an adult and knowing when she and his support staff (24 hour) should intervene. A parent suggested contacting a Vulnerable Adult Officer at the LA to alert them to the need to keep an oversight.

One parent mentioned that his daughter had had several different supported living placements in the last 15 years due to their not meeting her needs.

### Sensory Loss

A parent talked about her daughter's increasing support needs as she has experienced sight loss. They felt that her daughter's staff were not putting appropriate supports in place.

A sibling talked about her sister's sight (blind in one eye with a cataract in the other eye) and hearing loss and specifically the difficulties of finding

an optometrist with experience of testing someone who cannot answer questions.

A father talked about his daughter’s cataracts being detected by an optician and subsequently being removed. It was an issue they were unaware of.

**Sleep Issues**

A sibling shared her sister's experience of sleep apnoea and stressed the importance of ruling out underlying health issues as causes of behaviour changes. A parent described how her son's sleep issues were discovered through the use of an Actiwatch. A sleep support plan and dietary changes have led to an improvement in his sleep and behaviour. There was discussion about the challenges of convincing support staff of the importance of addressing sleep and other health issues in care settings.

Where people who have sleep apnoea are finding masks difficult to tolerate, the possibility of exploring alternative masks was mentioned. Jane talked about early-stage research into alternatives to masks.

**Dementia**

The group discussed challenges in distinguishing between dementia and other health issues.  We discussed the importance of a baseline assessment, particularly for individuals over 30, to monitor any changes in cognitive function and to rule out conditions like early dementia.

One parent shared his experience of his daughter in supported living undergoing a baseline reassessment which suggested she does not have dementia. They now believe she may be experiencing depression.

**Menopause**

A father brought up whether menopause may happen earlier in women with Down syndrome and this was confirmed. The father mentioned that NICE guidelines do not mention early onset menopause in Down’s syndrome. An article will be appearing in a future DSA Journal regarding this.

**Deputyship**

The group discussed the benefits of deputyship orders for managing the affairs of individuals with Down syndrome who lack capacity. A parent talked about the lengthy process of making an initial application and the

need to make a new application should other family members wish to become deputies. A sibling intends to apply for deputyship after a difficult experience in hospital where health professionals were not going to treat pneumonia until she intervened.

**Testicular Cancer**

A mother discussed her son's testicular cancer and the importance of advocating for individuals with Down syndrome during medical treatments.

Another mother said that her son was born with a testicular tumour. It was treated with surgery.

Both mothers talked about the importance of annual testicular checks. One of the mothers said that she had come across resistance from GPs to do a testicular check at the Annual Health Check, she felt this needed to be addressed.

**Next Meeting**




**Thursday 2nd April 10.30am**




**Wednesday 11th March 1.15pm**

In this webinar Maggie will discuss eyecare for adults and the changes in vision that occur with ageing. This webinar is aimed at family carers and professionals.

New Resource

A Guide for Family Carers Planning for the Future