DOWN'S SYNDROME ASSOCIATION

Down's syndrome with complex needs
support for parent carers

Round-up of complex needs meeting January 2026

Topic: Well-being and Winter

Meeting summary

We started the discussion with the following prompt questions.

- Do you notice a dip in mental well-being this time of year in the person you care for and yourself?
- Are there things that it is harder to do this time of year?
- What helps?

One parent shared her daughter's health challenges in winter, including thyroid issues and vitamin deficiencies, and sought advice on maintaining her spirits during this difficult time. The group shared various activities and programs that could help, including online dance classes and DS Engage discos.
Another parent shared her experience of her daughter's sensitivity to hearing others coughing, and the impact this has had recently. She would not be in the same room as a relative over Christmas who had a cold.
Two parents talked about their children's weather-related anxiety with one parent asking for suggestions of blocking out rain noise at night. Her fear seems to be because of a previous storm, suggestion of writing a story about the storm. Another parent talked about her son's sensory issues.

General discussion

One parent had joined to talk about his daughter and recent changes as she has been having falls/seizures, she has had several checks at the hospital, and they are now waiting for an outpatient appointment.
Another parent expressed frustration at trying to get a consultant appointment for her son for a recurring condition.
Putting things in writing was mentioned by a few people and using PALS.
Another parent talked about her daughter's behaviour at school and issues with how they are supporting her.

A parent asked if anyone knows of any behaviour therapists that can work with her daughter? Another parent recommended a service she had had locally.

One parent talked about her daughters sleep issues and how she doesn't seem tired at bedtime.

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Next Online Meeting



Tuesday 3rd March 10.30 - Midday

In person meeting Monday 8th June 10 –3pm London

For more information and booking:

Down's syndrome with complex needs - parent/family carer regional support meeting - London - Downs Syndrome Association

Useful Links and resources

To book any events please visit our Training Page - Training - Downs Syndrome Association (downs-syndrome.org.uk)

Complex Needs Webpage

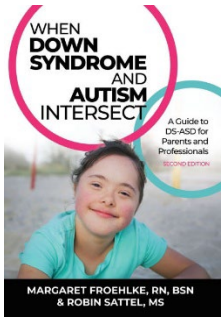
https://www.downs-syndrome.org.uk/about-downs-syndrome/lifes-journey/downs-syndrome-with-complex-needs/

Complex Needs Facebook

The DSA Complex Needs and Autism Group | Facebook

Books

When Down Syndrome and Autism Intersect is available at usual booksellers



Mental Wellness in Adults with Down Syndrome – link to free PDF:

DOWN'S SYNDROME ASSOCIATION



Mental_Wellness_full_book_final_2023.02.24.pdf (advocatehealth.com)

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