DOWN'S SYNDROME ASSOCIATION

Down's syndrome with complex needs
support for parent carers

Round-up of complex needs meeting September 2026

Topic: Transition after holiday/Open discussion

One parent raised concerns about her son who has been hitting his face during the summer causing bruising. Another parent shared her experience with her son, who also has self-injurious behaviour. We stressed the importance of ruling out underlying health issues/pain.

Another parent talked about her 18-year-old son's fixation on a teacher and issues with him leaving his classroom to find her. The group discussed strategies for this, including using visual supports and social stories

There was a lengthy discussion around two parents experience of a charity holiday club that has suddenly implemented tiered pricing based on children's needs, with charges increasing from £15 to £50 per day for higher needs children.

One parent mentioned how there was no holiday provision In the London borough she lived in and how difficult that is and how she has no support from social care. Some participants shared positive experiences with well-run charities who provide inclusive support without additional charges.

We talked about how our social care expert Chris Watson may be helpful.

One parent talked about her son having moved into 24-hour residential care and how this has been a very difficult decision.

Next Online Meeting

Down's syndrome with complex needs
support for parent carers

Thursday 5th November 10.30 - Midday

In person meeting Thursday 24th September 10 –3pm Sheffield

For more information and booking: Down's syndrome with Complex Needs Parent Family Carer Meeting Sheffield - Downs Syndrome Association

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Useful Links and resources

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

Complex Needs Webpage

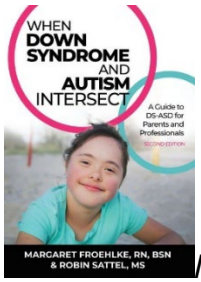
https://www.downs-syndrome.org.uk/about-downs-syndrome/lifes-journey/downs-syndrome-with-complex-needs/

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:

Mental_Wellness_full_book_final_2023.02.24.pdf (advocatehealth.com)