DOWN'S SYNDROME ASSOCIATION

Down's syndrome with complex needs
support for parent carers

Round-up of complex needs meeting June 2026

Topic: Open discussion

The group discussed several key topics.

Blood test phobia

A parent shared her son's difficulties with having blood taken and asked for advice. They have tried various approaches including giving choices, using distraction techniques, and creating themed environments, but these methods haven't been effective The group made suggestions such as accessing a desensitization programme and child specialist phlebotomists as well as asking for support from local CLDT.

Direct payments and transition

A parent raised concerns about the only option in her local area for respite care is direct payments which they do not feel is suitable. Her daughter is nearly 18 and recommendation made that they seek a formal transition assessment to ensure daughter is known for future support needs.

There was a general discussion around transition processes to adult services with one parent sharing how adult services have provided more support including monthly overnight respite.

Coeliac Disease

A parent shared her experience of her son's recent coeliac disease diagnosis and the challenges of managing a gluten-free diet, particularly around social aspects and cross-contamination.

She talked about what a big impact it has had on the whole family and how little she can find in the way of support for people who have Down's syndrome and coeliacs. It was recommended that she post in DSA Facebook groups. Also suggested she contact Coeliac UK to highlight need for more resources/support. Mum also mentioned that son had been prescribed beta blockers to help son's stress and anxiety.

Decision Making

A parent discussed her application for health and welfare deputyship and the requirements for documentation.

There was a discussion on consent and the best interest process and using the Mental Capacity Act properly.

Next Online Meeting

Thursday 16th July 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

Useful Links and resources

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

Complex Needs Webpage

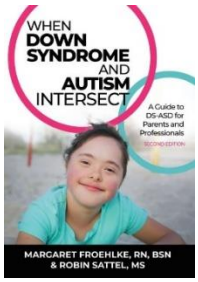
https://www.downs-syndrome.org.uk/about-downs-syndrome/lifes-journey/downs-syndrome-with-complex-needs/

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)

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