DOWN'S SYNDROME ASSOCIATION

Down's syndrome with complex needs
support for parent carers

Round-up of complex needs meeting December 2024

Topic: Round Up of the Year and Looking Forward

We asked everyone to complete a Zoom poll, and this was followed by a discussion about what people found most useful from the last year.

- *Feel like I belong*
- *I feel part of a group*
- *Grounds me*
- *Helps me understand my child better*
- *Helps me make sense of things*
- *Sharing experiences*
- *Hearing other people's experiences and comments really helpful*
- *It's not just me*
- *Snippets of advice/experience are helpful*
- *Makes me think about other issues not previously considered*
- *I am so grateful to have found the support group and complex needs page*

Several people mentioned that the meetings on sensory difference and communication were really helpful.

One parent said that the in-person meeting in Manchester really stood out for. The same person suggested that we could cut out some of the beginning/end of the online meeting as it is repetitive.

Complex Needs/DSA General

A parent attending for the first time said that she valued DSA advice, found our dual diagnosis webinars useful and had called many times over the last few years.

A couple of parents mentioned how useful the hearing/vision webinars had been.

General Discussion

The definition of complex needs and whether autism and Down's syndrome was the main dual diagnosis was discussed.

One parent had found *'When Down Syndrome and Autism Intersect'* very helpful.

One parent talked about their ten-year battle for a dual diagnosis which was received last year.

Some parents felt isolated from local support group.

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OCD Behaviours

A few parents talked about their children's anxiety and OCD like behaviours including:

- Moving other people's things including toiletries and piling toilet paper
- Covering wall spaces
- Lining things up
- Wanting to wear the same clothes every day

Helpful suggestions:

A parent talked about regulating her own emotions in order that she can help regulate her daughter.

Another mentioned creating a space within the home where the child can engage with their behaviours and not impact other family members.

With regard to obsessional behaviour and clothes some suggestions were:

- Involving son with laundry
- Buying identical clothes to replace worn out ones
- Having several of the same items

One parent commented that her daughter favoured older clothing possibly because it is softer.

It was recognised that behaviours serve a function and many are self-soothing helping regulate emotions. If the behaviour is not causing disruption to others, it is ok to let the person carry on.

Childhood Respiratory Issues

One parent asked if other parents had experiences of their child being very unwell as her daughter had picked up viruses on a regular basis including needing several hospital admissions. She has now been prescribed with low dose antibiotics during peak cold season.

Another parent was able to offer assurance as things had improved with her child as they got older.

One parent talked about how cranial osteopathy had worked well for her son when he was little.

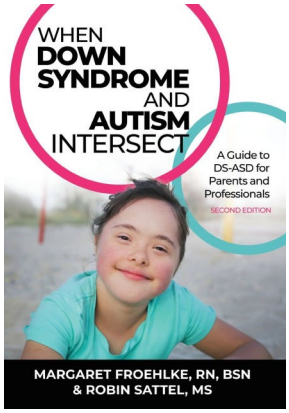
The point was made that parents should trust their own instincts if their child was unwell. There is sometimes a need to be a detective.

Useful Links and resources

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

Mental_Wellness_full_book_final_2023.02.24.pdf (advocatehealth.com)

When Down Syndrome and Autism Intersect is available at usual booksellers



COMING SOON

Tuesday 21 January 10.30am – midday



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

Complex Needs Webpage

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

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