

Round-up of complex needs meeting (Jan 2023)

Topic: Emotional well-being of people who have Down's syndrome and their parents.

Who attended: We had 11 parents attending from the UK and from the Republic of Ireland caring for people between the ages of 7-46

Points from discussion

- It is hard to look after someone else's well-being if your own well-being is not being nurtured.
- Caring for someone can impact negatively on my well-being and well-being of siblings.
- It is difficult to balance the needs of all in the family and spend quality time with siblings.
- Receiving a dual diagnosis has been helpful as it enables me to tune into my child's needs, to work within their child's boundaries, and to adjust expectations.
- The complex needs can mean that connections with others looks different.
- It can be hard coming to terms my child not wishing to socialise in a typical way of other children who had Down's syndrome.
- Taking time out for myself can make me feel guilty.
- Taking part in activities that are totally separate from other carers is helpful for well-being.
- Support groups where we meet other parent carers are helpful.
- Yoga, crafting, and paid employment are examples of things that help parent well-being.

Below is a list of resources that were mentioned during the meeting.

DSA

Emotional well-being resources for supporters and people who have Down's syndrome - [Emotional Wellbeing - Downs Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk/emotional-wellbeing)

Parent and carer well-being resource - [Parent and family carers well-being - Downs Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk/parent-and-family-carers-well-being)

DSEngage – free online activities for people who have Down's syndrome - [DSEngage - Downs Syndrome Association \(downs-syndrome.org.uk\)](https://downs-syndrome.org.uk/dseengage)

Other

Sibs – support for siblings - [Home - Sibs](https://www.home-sibs.org/)