Supporting Siblings

- Emma Durman – Autside Education & Training -



Having a neurodivergent sibling: considerations

- Being able to understand the diagnosis
- Feeling different
- Family unit being impacted
- Potentially adjusting their life to meet siblings needs
- Caring roles/responsibilities
- Parents may struggle to divide time and energy equally when one or more children have complex/additional needs
- Different schools, developmental trajectories, social opportunities etc.

How might siblings feel?

- Jealous
- Scared
- Proud
- Angry
- Loving
- Protective
- Guilty
- Embarrassed
- Lonely
- Overwhelmed



Can this sometimes be complicated where more than one sibling has additional needs?

- Conflicting sensory needs
- Needing different adjustments to meet individual needs
- Being triggered by each other's needs/behaviours
- Intense interests can be affected items may be touched/moved or broken
- Domino effect when overwhelmed and meltdowns affect the other sibling

Impact for siblings

Time

- Finances
- Difficult to take holidays/trips or enjoy certain activities
- Friends
- School
- Privacy and belongings
- Sleep disruption
- Coping with anxiety, anger, meltdowns/shutdowns
- Worries about parents and/or the future

There are positive impacts too:

- Positive attributes such as empathy, compassion, kindness and patience
- May be protective of their sibling and of others with disabilities
- May be mature and independent
- Understanding of difference
- Can lead to positive career choices

Explaining Additional Needs



- It is vital that we teach siblings about additional needs in an honest, factual way, relevant to their family member and age/developmentally appropriate
- Whilst acknowledging neurodivergence can sometimes bring challenges we should also highlight the positives, reinforcing that everyone has different strengths and challenges, likes and dislikes
- As parents/Carers we should be open to questions and able to validate concerns – if timing of these questions isn't ideal we can 'pop a pin in it' as long as we ensure we come back to the topic at a better time

Explaining Additional Needs

- We may not always have all the answers and that's ok! Be honest about that and explain you don't know, if possible you can find out or learn more together
- Everyone can experience different reactions to diagnosis – sometimes it is an emotional rollercoaster for family members including parents, siblings and the person with additional needs
 - Prepare yourself beforehand think about what questions might arise and what is important for them to know at this stage

This doesn't have to a big one-off conversation!

Drip feeding information over time is helpful, and being open throughout children's lives will normalise the conversations...

Use Resources to help you!

There are lots of resources out there that can help you explain and to help siblings understand including:

- Books
- Leaflets
- DVDs
- Media representation
- Internet
- Advocates/others
- Professional support
- Other parent/carers advice





Use Resources to help you!

- Even when you do not completely agree with the representation of characters and their lives on screen – they can be valuable discussion jumping off points – what do we relate to, what do we think they could have done better etc.?
- The resources you use will depend on your child's age, level of understanding and personal views.







Key concepts to explore

- Social differences
- Sensory needs
- Intense interests
- 'wired differently' brain works and develops differently
- Strengths and difficulties
- Equality doesn't always mean everyone gets the same thing – but that *everyone gets what they need*
- Explanations of why certain things can be particularly difficult – i.e. regulating emotions, completing tasks etc.

There can be lots of different questions.... Some of the questions might seem random or silly, but it is important to validate the sibling's curiosity and worries, and explore them openly, honestly and factually

Encourage ongoing discussion

- Encourage sibling(s) to continue to ask questions as they arise and come to you with any new thoughts or concerns
 - Give them a 'safe space' to share their emotions and feelings, and to discuss other people's perceptions and reactions positive or negative
 - It can be useful to arm siblings with handy responses or simple explanations to questions or comments they might come across when you are not with them
- Extend this discussion to any other diagnoses your child(ren) may have and the impact of these co-occurring conditions

Equip them with strategies for successful communication

- Use their brother/sister's name to get their attention
- Speak slowly and clearly and allow processing time
- Say one thing at a time/break down information into manageable chunks
- Say what you mean and mean what you say
- Use visual supports

Protected Time and Attention

- Set aside special time with sibling(s)
- Prioritise events and activities that are important to them where possible
- Respite as with parents/carers, siblings can benefit from their own time and space apart from their autistic brother/sister to decompress
- Encourage them to express their emotions and devote special time to this when you can focus on and engage without distraction if possible
- Relaxation strategies can be helpful for siblings, things like listening to music, mindfulness, ASMR etc.
- It is important to boost the sibling(s) self esteem whenever possible, and express appreciation for their support and understanding

Helpful Family Strategies

- Visual supports/schedules/communication aids, social stories
- Family rules
- Clear routines with calendars etc.
- Practice and promote turn taking
- Space and time when needed maybe before or after school, at bedtime etc.
- Rewards/motivators

Consistency is key for many neurodivergent people – so having siblings 'on the same page' with household strategies and rules is beneficial

Being with each other

- Dedicated spaces of their own, whether rooms or zones
- Rewards for being kind and compassionate with each other, or for modelling good behaviour
- Safely store treasured belongings
- Dedicated technology items or protected time for each sibling
- Encourage activities both siblings enjoy
- Promote games without focus on winning/losing

Managing/Expressing Emotions

- Create opportunities for sibling/s to talk about/express how they are feeling
 - Share your feelings with them too
 - Use books, TV shows, movies or experiences to explore feelings
- Make emotional toolkits, where the whole family engages in regular emotional literacy
 - Focus on positives as well as challenges
 - Use visuals to help you with this too

A Meltdown/Shutdown Plan

It can be helpful to have a meltdown/shutdown plan:

- where all family members have clearly defined roles for a sibling this might be removing themselves to a pre-allocated 'safe space' or pairing off with another parent/carer sibling etc.
- With information about things that can cause anxiety/overload
- What behaviours they might see/experience and why these might happen
- Considering that different actions/strategies might be needed in different environments

Even equipping siblings with simple knowledge around reducing sensory overload, talking, noise etc during meltdown / shutdown can have a big positive impact

Planning for the Future

- Siblings can sometimes think/worry about their role in their brother/sister's future
- It is important not to dismiss these feelings/concerns but to validate and explore them
- Explain that while it is impossible to know exactly what the future holds you can discuss likely outcomes and plans together
- This can be difficult for parents/carers, especially when discussing what might happen when they are no longer around, but it can be vital to make plans as children get older and begin to think about these issues

Look for local/online support

- Siblings can feel alone or different to their peers
- Having networks of others in their situation to connect with can be beneficial
- They may feel more able to talk openly about their lives, feelings or worries if they feel understood by others experiencing similar situations
- Local Carer's centres, NAS branches or social services may have sibling(s) events or support networks
- There may be online groups for information and support that could be helpful

Remember:

You cannot pour from an empty cup....

Self care is not a luxury but a neccessity... You are doing the most difficult job as well as you can - so try to be kind to yourself!



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