

NEURODIVERSE KIDS

SUPPORTING NEURODIVERSE KIDS

Here are some tips from experienced parents. Obviously, every child is different, and every situation is different so not every tip will work for every family.



GIVING THEM INFORMATION

- Keep information simple by using short sentences
- Less words the better. Use images, photos, or draw things on paper/tablet
- Use correct terms & words, e.g. scans, infections, infusions, chemo, cancer, steroids
- Think of the best place and time for your child (it might not be the best time for you), e.g. late at night
- Talking in the car is great as there is no eye contact so it is easier for them to focus
- Keep to facts
- Drip feed information so not to overwhelm or confuse them
- Let them know about appointments and any changes to appointments
- Don't push them if they don't want to know everything about your cancer and treatment
- Let them know that any question is a good question so don't be scared to ask
- If they have questions, use different methods to answer these, e.g Whatsapp conversations, or use a box to put questions in & reply in the same way
- If you ask them a question, give them time to think about it – sometimes this might take days. Say you will come back for the answer
- Be mindful that your child will be more exhausted and tired after an information session

HOW WILL THEY BE AFFECTED?

- Think about what they care about, e.g. going to school, swimming, drama
- Reassure them about the changes that are going to be made
- Design a plan (can be weekly or monthly) and put on all the things they will be doing
- Use visual prompts, e.g. calendars (online/paper), written planners, so they can see how each day/week looks

SUPPORTING THEIR WORRIES & FEELINGS

- Validate their worries (without using long explanations)
- Their feelings might not match what is going on with your cancer, or treatment.
- Recognise this and encourage emotional expression
- Confirm, if able to, that you are not going to die anytime soon
- Let them know that cancer can be treated, that people can become cancer free. Also talk about risks of relapsing/remitting but you will let them know if that happens
- Their emotions may be stronger than you think. Emotions may be different from what you think.
- Reassure them that it is no one's fault you have cancer
- For older kids, chat about a health check for them but reassure them that their health is ok
- Explore the book 'A Kind of Spark'

Try not to get upset or take it personally if your kids don't want to know anything about what is happening to you and your health, or if they are mean to you. These behaviours are often because they will be dealing with their own emotions.



Updated version with resources - not yet been through the graphic design mill!

SUPPORTING NEURODIVERGENT YOUNG PEOPLE (Autistic, ADHD and AuDHD (both Autistic and ADHD))

Here are some tips and insights from parents with lived experience. Every child is different. Every situation is different and not every tip will work for every family.

GOOD CONVERSATIONS

Understanding Neurodivergent Communication

- Aim to communicate with the child in the style that works best for them.
- For some it'll be short sentences, others may prefer longer sentences and some Autistic kids like bigger words!
- Some ND kids like pictures, some prefer bullet points, some work best with comic strips - so individualise it for the child
- One subject, one sentence; with a notable break between conversation topics to allow time "to switch to a new channel of focus"
- Avoid euphemisms, abbreviations and use correct terms and words e.g. scans, infections, infusions, chemo, cancer, steroids
- Say what you mean and mean what you say: many Autistic people don't do subtext, it just creates confusion and more panic around the vagueness and uncertainty
- If your kids have questions, use different methods to ask and answer these, e.g Whatsapp/ text conversations, or use a physical box with a lid to put questions in & reply in the same way
- Allow sufficient time for the child to reply, and don't hurry. Expect to revisit the topic as often as the child requires
- Allow much longer than feels naturally comfortable when waiting on a reply. If you ask them a question, give them time to think about it – sometimes this might take hours, days or weeks. Allow the young person to lead the conversation at a time that works for them.

Where, when and how?

- When you speak to your child, make sure that it's on a low demand day so that your child has enough mental energy (spoons!) to cope as best as they can.
- The best place and time for your child to ask questions or discuss topics to do with your cancer may not be the best time for you, e.g. late at night - but if you can, go with it and listen
- Talking in the car is great - there are fewer distractions, no direct eye contact and can be easier for them to focus on what is being discussed and sometimes the conversation can last a bit longer.
- Sitting side-by-side working on different passion projects can also ease communication whilst in the flow and safety of individual dedicated interests
- Many Neurodivergent (ND) people have sensory differences; getting the sensory environment right for difficult conversations can help alleviate overwhelm i.e. no noisy distractions, no strong cooking smells, subdued lighting, don't stand over them or sit too close, not too hot / not too cold. Conversely, some ND people prefer the exact opposite to regulate.
- Some sensory input can be particularly soothing so have a favoured cuddly toy, blanket, fidget toy etc at the ready. Perhaps a walk in nature, a bike ride or a good bounce on the trampoline may help to regulate?

Other Tips and Guidance

- Keep to the facts
- Give them as much information as they ask for so as not to overwhelm or confuse them
- Let them know about appointments, and any changes to appointments as soon as you can especially if it affects changes to their routine. As a reminder, maybe stick a change of plan reminder on a post-it note on the fridge/front of a jotter, send a whatsapp message etc
- Create a low demand approach - for example, don't push them if they don't want to know everything about your cancer and treatment.
- Reassure and validate that any question is a good question and to not to be scared to ask
- Be mindful that your kid will be more exhausted and tired after you have had a conversation about your cancer diagnosis / treatment or plan etc.

Autistic kids can have meltdowns especially if overwhelmed but some may have shutdowns instead.

- Be clear and don't give false hope. Keep school / college in the loop so that they can be aware of days the young person might be more dysregulated.

HOW WILL THEY BE AFFECTED?

- Think about their routines and what they care about, e.g. going to school, swimming, drama classes and will any of these things change for them ?
- Reassure them about the changes that are going to be made
- Design a plan (can be weekly or monthly) and put down all the things they will be doing and what may change
- Use visual prompts, e.g. calendars (online/paper), written planners, so they can see how each day/week looks
- Be mindful that some Autistic kids may have Aphantasia and don't see things in pictures. And other Neurodivergent people visualise in vivid technicolour and great detail i.e. are Hyperphants
- Furthermore, many Autistic people struggle to identify and name their emotions (Alexithymia), as well as reading and describing what's going on in the inside of the body (Interoception) - see more about this on Page xx
- ADHD kids may struggle to regulate their "big feelings" and impulsivity; at times like these, it's important to let them know their feelings and reactions are valid and to start each day with a clean slate.

SUPPORTING THEIR WORRIES & FEELINGS

- Validate their fears and worries (without using long explanations) Some children may need short explanations, and others may benefit more from using longer explanations.
- Their feelings may not outwardly match or appear reflective of what is going on with your cancer or treatment. They may mask their emotions in a bid to make others feel more comfortable
- Their emotions may be stronger than you think. Emotions may be different from what you think also.

- Confirm, if able to, that you are not going to die anytime soon
- Let them know that cancer can be treated, that people can become cancer free. Also talk about risks of relapsing/remitting but you will let them know if that happens or you have cancer like that.
- Reassure them that it is no one's fault you have cancer
- For older kids, chat about a health check for them but reassure them that their health is ok

Try not to get upset or take it personally if your kids don't want to know anything about what is happening to you and your health, or if they are unkind to you. Try to keep in mind, these reactions are often because they will be terrified of the unknown and are trying to process and deal with new and difficult feelings.

Remember your child has no social script for this and that they may not know whether or not to comfort you and they may look like they don't care but they may be scared, overwhelmed and not know how to make it better.

RESOURCES

Books:

- 'A Kind of Spark' by Elle McNicoll– good book from autistic girl (age 6) point of view and also a BBC drama
- Cancer Party!: Explain Cancer, Chemo, and Radiation to Kids in a Totally Non-Scary Way by Sara Olsher
- 'Standing up for Myself' by Evaleen Whelton
- 'Never let go - How to parent your child through mental illness' by Suzanne Alderson
- Link to Aucademy list of recommended Neurodiversity-affirming reads here www.aucademy.co.uk/books/

Websites (most advocates also on Facebook and other social media):

Full of excellent free resources and led by Autistic educators;

- Autistic Girls Network (www.autisticgirlsnetwork.org)
- Autism Understanding Scotland (www.autismunderstanding.scot)
- Aucademy (www.aucademy.co.uk)
- Kieran Rose - The Autistic Advocate (www.theautisticadvocate.com)
- Neuroclastic - (www.neuroclastic.com)

Autistic Advocates on Facebook and Instagram:

- Autistic and Living the Dream www.facebook.com/autisticandlivingthedream
- AUsome Training / Konfident Kidz www.facebook.com/ausometraining
- Jodie Smitten www.facebook.com/JodieSmittenWiltshire
- The Nurture Programme www.facebook.com/thenurtureprogramme
- Reframing Autism www.facebook.com/reframingautism
- Yellow Ladybugs www.facebook.com/yellowladybugs
- Autisticality www.facebook.com/Autisticality
- Neuroclastic www.facebook.com/NeuroClastic
- Laura Hellfeld Neurodivergent Nurse Consulting
www.facebook.com/LauratheNeurodivergentNurse
- Neurodivergent_lou www.facebook.com/profile.php?id=100091534964212
- Autistically Scott www.facebook.com/AutisticallyScott

Autistic Black, Brown and People of Colour:

- Scottish Ethnic Minority Autistics (SEMA) www.facebook.com/SEMA.Scot
- Autistic Typing www.facebook.com/AutisticTyping

PDA / AuDHD Resources

- Bridging the Neurodivide www.bridgingtheneurodivide.com/what-is-pda
- Kirsty Forbes www.facebook.com/inTunePathways
- Autisticality www.facebook.com/profile/100082562269700/search/?q=audhd
- Emergent Divergence www.emergentdivergence.com/?s=AUDHD

inside) is from Autistic “autism” educators and professionals.