## Setting boundaries and making space for ourselves

- 1. For some of our autistic brothers and sisters, it can be helpful to have clear (and familiar) rules or boundaries in place. Others, especially those with demand avoidance, really resist hard boundaries.
  - a) They might need to know (or struggle to grasp) the reason behind the rule.
  - b) The <u>PANDA method</u> is useful for setting boundaries that don't feel so much like boundaries. We also talked about making bargains (you do this and I'll do that) or offering choices (you can go yourself or I can go with you).
- 2. Parents or care staff can have a huge impact on our ability to set boundaries.
  - If they won't set or accept boundaries themselves, putting our own in place can feel like a real uphill battle. It can help to use strategies like the PANDA method here too.
  - a) If you want other people to change their behaviour, let them save face by assuming it's a mistake and of course they'll want to fix it. Present your boundaries as your own choices, which they are welcome to join you in.
- 3. Sometimes, it feels like our sisters and brothers (or parents) don't understand that we have lives of our own, outside of the things we do with/for them. They want us to make ourselves available on their schedule but will only decide at the last minute whether or not they actually want to do the thing we planned.
- 4. It can be equally frustrating when our friends and relatives don't understand that our autistic sisters' and brothers' needs and limits will be different. Many of us have set boundaries around how much (and how frequently) we are willing to explain.
  - a) We've had to accept that it's okay if our families need to do things differently. Our brothers or sisters might prefer to stay home from a family outing, and we set a mental boundary not to accept other people's judgement for that.
  - b) Sometimes, it is in our sisters' and brothers' best interests to recognise and uphold the boundaries that they have set. Other times, we may recognise that while they resist the transition, they will enjoy or benefit from the activity itself.
- 5. **It's important to put our own oxygen masks on first!** If something isn't sustainable for us, it's important that we draw that boundary so that other people know it. Otherwise, they will keep on assuming that things are okay as they are.
  - a) Sometimes, this means one of the balls we were juggling gets dropped but it's better to identify that then burn out and drop all of the balls at once.
  - b) It's important to recognise when something is not a good use of our energy. Even if we're not satisfied with the outcomes, sometimes we have to accept that this is all we can do (and it's better to save our energy for another day).
  - c) Read Sibs eBook 'Self-care for siblings' for more.
- 6. **Setting or enforcing a boundary can be scary.** We worry about both the tangible/safety impacts and the relationship impacts of things going wrong.
  - a) We see our brothers and sisters lash out when they are frustrated or angry and imagine the worst. But (especially if we are strategic), setting boundaries has often turned out much better than we expected.
  - b) If we know what our "red lines" are in terms of safeguarding/vulnerability, it can be easier to accept a situation getting a little bit worse in the short term so that the problem can be recognised and it can be improved over all.
- 7. More resources on boundary setting:
  - National adult sibling support group "Guilt is nothing to feel guilty about. Give yourself a break!"
  - East London adult sibling support group "Many of us have grown up feeling that we have to be the 'easy child" (tips on boundary setting)
  - Sibs guide Talking to parents (includes section on boundary setting)