

What should I say?

An educational resource to help clinicians and those that are prescribed valproate and have autism and / or a learning disability make informed choices about their sexual health

In the making of this resource, a variety of clinicians, patients with autism and / or a learning disability (along with their carers if necessary) and academic researchers were interviewed. Key points, repeated by multiple interview participants, are stated below:

Clinicians

- Professional anxiety around sexual discussions
 - Fearful of saying the wrong thing
 - Fearful of causing embarrassment or distress
- Assumption that those with autism and / or a learning disability do not have sex
 - Assumption that those that do have sex, do not have healthy relationships / intimate lives

Patients + Carers

- Sexual conversations are only embarrassing and distressing if they are unexpected, or we are unprepared for them
- Please use basic English not baby English
- Only ask one question at a time
 - It can take up to 30 seconds to process a question
- Ask for feedback on how appointment could have gone better, even if you think it has gone well

Academic Researchers

- Prepared patients can drive conversations
 - These result in higher quality conversations between patient and clinician
- Small studies have shown that those with autism:
 - Are more likely to be polyamorous than those who are neurotypical
 - But are also more likely to be asexual or aromantic than those who are neurotypical
- So do not make assumptions about sexual activity, just ask.

Top Tips

Before appointment: preparation is key

Ensure you are prepared:

- *Ask yourself:* Do I need to change anything to make this consultation go well?
 - What are their sensory preferences?
 - Have they had a communication assessment done recently?
 - Would this be better as a home visit or joint appointment with another healthcare professional?
- *Ask yourself:* Am I anxious to ask about their sex life?
 - What assumptions have I made about their sex life?
- *Ask yourself:* What information have I provided about the appointment?

Ensure the patient + carer is prepared:

- Send an appointment letter / email which provides easy-read top level questions to be discussed (example question 'do you have sex?' more examples below)
- If it is their first appointment then consider a visual appointment letter / email containing a photo of the building, the session space and the clinician.

During appointment

Environmental:

- Have as few distractions as possible
 - Think noise levels, odours, lighting, clutter
 - Don't assume, ask: "Is this too bright for you?"

Communication:

- Give at least 30 seconds to process a question after asking it
 - Do not ask another question in this time
 - Do not ask multiple questions at once
- Use basic English, not baby English
 - Are you infantilising?
- Use active listening techniques
 - Repeat back what you have understood from the patient

Feedback:

- At the end of the session, ask for feedback on how the session went and any changes for next time: *What can I as a clinician change to make this a better session next time?*

After appointment

Feedback:

- Give another opportunity for feedback (e.g. via email) on how the session went and any changes for next time

Language:

- Use neurodiversity affirmative language in report writing, case discussions, and support plans e.g. 'preference for predictability', 'special interests/areas of passion'
 - Use specific descriptions of challenging behaviour

Handover:

- Are there any sensory or communication tips you can pass onto your colleagues to help in future appointments with the patient?

Examples of easy-read top level questions

To be provided to the patient and carer before review appointment to help them prepare. These example questions are also on the [valproate review appointment letter](#).

Sex / Sexual health / Pregnancy Prevention:

- Do you have sex?
- Are you in a relationship?
- Would you like to be in a relationship?
- Do you use contraception?
- What contraception do you use?
- Have you had a pregnancy test recently?
- Do you know the risks to a baby if you get pregnant whilst taking valproate / your medication?

Valproate (or any medication):

- When did you start taking valproate / medication?
- Why did you start taking valproate / medication?
- How much valproate / medication do you take every day?
- Are there good things about taking your valproate / medication?
- Are there bad things about taking your valproate / medication?
- Would you like to continue taking your valproate / medication?