

Why the Notepad and How to Use it

The Notepad Resource is the outcome of a project funded by the British Society for Paediatric and Adolescent Gynaecology. It has been developed by the UK Charity dsdfamilies to be used as a clinical tool in the DSD (and related conditions) clinic to support young people in asking the questions they may have.

The Resources consist of 5 elements, i.e., the Notepad itself and 4 supporting resources. All have the same QR code which lands on the dedicated dsdfamilies resources/ Notepad page.

- A. Printed Notepads to be used in clinic with young people
- B. Supporting Resources
 - 1. Why the Notepad and How to Use it
 - 2. Guidance to Answering Notepad Questions – connect with <https://www.dssteens.org/> to find further supports and information
 - 3. ‘Talking about good sex’ for professionals
 - 4. ‘Through my eyes’ - recognising and investing in the diverse needs and challenges of young women from a black and Asian background

Why the Notepad?

We know from research¹⁻³ that young people attending the DSD clinic often do not get the chance to ask the questions that really matter to them.

Appointments can be busy and often address *typical medical* issues, without planning enough time to check-out the young person’s understanding. This approach can leave individuals with a belief that the body is something to be ‘fixed’. This interpretation of DSD, received at an individual level, can be linked to the way as a society we see positions of authority in medical teams. This means teams may not get to hear the worries or important questions the young person has. Further, the young person may want to ask personal or private questions and needs space to do so, while providers need to have confidence and knowledge to answer such questions.

We recognise that professional teams champion and want to meaningfully support our young people, like many parents. What we recognise is that providers (and parents) might not always be comfortable to speak openly about certain topics⁴. So, we generalise, stay on ‘safe ground’ and as a result -and as per research- can fail to address the questions young people have.

Young people might be uncomfortable about asking questions about sex or be afraid of asking ‘a stupid’ question. They may worry that ‘they should already know’ something or that ‘the doctor doesn’t have time’. Although most professionals will always ask ‘Do you have a question?’ it is actually quite hard to think about or articulate questions *in the moment* of high stress, such as at a hospital clinic appointment.

dsdfamilies was established in 2011 with an objective to help families and young people understand and live well with Differences of Sex Development and to signal at every opportunity that ‘they are not alone’. That means removing barriers to learn and talk about all aspects of having a DSD with children, family, friends AND in the clinic.

The **Notepad** has been designed to begin to equip young people with tools to ask the questions they really have. The questions have been developed by young people living with DSD working with dsdfamilies. They are intended to start a conversation – and to encourage them to voice their own concerns.

The additional supporting resources have been developed:

- to equip the professionals with guidance how to address some of these important questions young people have.
- to encourage professionals to move away from the safe ground of 'sexual function' to what maybe really important: intimacy and having good sex¹.
- to open a discussion on the failures to support young people from black and Asian background and how we can begin to address this.

How to use the Notepad in clinic?

- Every clinic is run in a different way. Consider when the best timing is to give a page of the Notepad to the young person: send by post or email, in the waiting room, in the consultation room.
- Put the young person at ease by explaining that professionals know they sometimes spend too much time on medical question or assume that some information is understood and remembered. Explain that the questions young people have are really the most important ones, and that you understand it is not always easy to ask a question out loud or that young people are not sure if they can ask a certain question.
- Give them a page of the Notepad and explain that young people with DSD have made a list of questions they had and feel other young people could ask.
- Ensure the young person is comfortable to tick all questions if that is how they feel, or tick a few, or none – commit to revisiting the list again at the next consultation and encourage them to add their own questions.
- Encourage the young person to write down answers and use visuals to help them remember and retain information. Remember to ask the young person if they have a preferred way of learning information (some like to read, others listen, others connect with people, there are lots of different learning styles). When in clinic, young people and parents, think remembering all the information shared will be easy, but after a few days, weeks, or months much can be forgotten.
- Use the questions to open conversations. The list is not exhaustive and will be different for each young person.
- Consider suggesting and signposting to a peer-to-peer support for young people. The literature supports that many young people become adults without having met others living with a DSD, which can increase loneliness and confusion⁵.

How to produce your own copy of the Notepad

The Notepad can be downloaded in print ready format from the dsdfamilies website.

We recommend for it to be printed double-sided and in colour and produced as a Notepad of 50 or 100 pages. The latter implies to the young person that ‘there are many others like me who need this type of information and support’.

Production team

Coordination: Ellie Magritte and Caroline Sanders for dsdfamilies and Megan Usipuk a Counsellor and graduate student in Counselling in Canada.

Notepad questions: Esme, Gabrielle, Jo, Claire – thanks to many others living with different sex develop and to professionals for reviewing and commenting on the questions.

Talking about Good Sex guidance: Nina Callens

Guidance to Answering Notepad Questions: Nina Callens, supported by Youth consultants Esme, Gabrielle, and by Jo and friends.

‘Through my eyes’: dsdfamilies Youth consultant Gabrielle

For feedback and suggestions: info@dsdfamilies.org

References

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3. Jones, T. (2016). The needs of students with intersex variations. *Sex Education*, 16(6), 602-618.
4. Reber, N., & De Clercq, E. (2022). Enduring uncertainties. Medical accounts on caring for young people with variations of sex characteristics. *Dialogues in Health*, 100014.
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