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Citation for final published version:

McKnight, Christine, Griffiths, Sarah Louise, Williams, Denitza , Phillips, Rhiannon, Brown, Sarah and James, Delyth 2025. Incorporating contraceptive shared decision-making into consultations for individuals with epilepsy: facilitating a holistic and dynamic approach. [Letter]. *BMJ Sexual & Reproductive Health* , bmjsrh-2025-202751. 10.1136/bmjsrh-2025-202751

Publishers page: <https://doi.org/10.1136/bmjsrh-2025-202751>

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Incorporating contraceptive shared decision-making into consultations for individuals with epilepsy: facilitating a holistic and dynamic approach

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Ethics Statement: This is a letter however quotes used were from a primary piece of research which had ethical approval from Cardiff School of Sport and Health Sciences granted ethical approval for the study under the Cardiff Metropolitan University Ethics Framework on 27/09/2022. Project reference number: PGT-6089.

Funding Statement: Commission by Welsh Government grant number MA/EM/0137/23

Patient & Public Involvement: Patients with epilepsy were involved in the full research process for the original research that this letter is based on.

Contributions of authors: Christine McKnight: Writing – Original Draft Preparation. All other authors: Writing – Review & Editing.

Valproate is a teratogenic drug [1], where gestational exposure is associated with a higher risk of congenital malformations, and cognitive, language and psychomotor delay [1]. In the UK, valproate is now contraindicated in women of reproductive potential unless a Pregnancy Prevention Programme (PPP) is in place [2] incorporating highly effective contraception. A person-centred approach through shared decision-making (SDM) may be helpful for women and girls making complex health decisions.

SDM is the process of a healthcare professional (HCP) and patient working together to facilitate preference-based decisions and is one of the six quality statements set by the National Institute of Healthcare Excellence (NICE) [3].

Valproate treatment for epilepsy can be detrimental to both fertility and pregnancy outcomes, it also impacts contraception choices resulting in consultations that are complex and nuanced [4]. Specialist sexual and reproductive health staff adopting a SDM approach to consultations are ideally placed to provide support for complex contraception decisions involving long-term conditions and high-risk medications.

A recent qualitative study [5] found a lack of person-centred approach to reproductive decision-making during valproate initiation where contraception choice was a major consideration for women. Indicative quotes (Box 1) illustrate the need for person-centred approaches and associated challenges of achieving person-centred care. Women discussed the nature of decisions surrounding taking valproate for their epilepsy as ‘crossing specialities’ including neurology, sexual & reproductive health and/or primary care services. Women also discussed the complexity of ‘managing information’, needing the appropriate amount to manage both their existing medical condition and to meet their contraception needs.

Box 1: Support with contraceptive shared decision-making: Example quotes from women with epilepsy.

Pseudonym	Topic	Example Quotes
Beth	Crossing specialities	<i>“Yeah, instead of having right, oh no, I prefer that so we're doing it this way. Then GPs are saying different things. Epilepsy specialists are saying different things, family planning can say different things and it can be quite confusing.”</i>
Lydia	Crossing specialities	<i>“And so, to have that multidisciplinary effect, you have got the consultant whose sole job is to talk about the epilepsy, and then, you know, someone, I think</i>

		<i>someone to talk about contraception would be a massive thing, and a huge help.”</i>
Oliva	Crossing specialities	<i>“So, to go over everything again and to look at contracept-, different, you know, methods of contraception and what might be right for you and then... so that can be done with the epilepsy nurse, and she could maybe sort that out with you. Or someone from family planning could also be there or refer you on to family planning. So, it’s all done...”</i>
Faye	Crossing specialities	<i>“Um, I think any sort of space outside of that neurological consultation. I think it's partly, I think I'm partly thinking because, I guess um, it sometimes feels like all the pregnancy prevention stuff distracts from, yeah, kind of, I guess talking about my epilepsy and things like that, and I think it eats into the consultation time and I think because appointments are so infrequent, it sometimes feels like that takes precedent over my health. And, so, I think any space outside of that consultation, I mean they're so short as well like 15 minutes and stuff by the time you go through that form, it's like you haven't really talked about epilepsy, you've talked about pregnancy prevention for ages and signed all these forms and stuff, and then you don't really get a chance, and yeah. So, I think basically I would prefer, any sort of space outside.”</i>
Chloe	Managing information	<i>“I think people need to be made aware, you know, for me, it was just a case of, oh, there's a risk of cleft lip, cleft palate, cleft palate and spinal bifida, but I think people need to be made aware of, you know, it can, it can impact babies more than that. You know? The fact that they didn't have this conversation about contraception with me, now, kind of, it's a bit of a red flag to me, you know, if you, you know, if maybe you're not considering pregnancy at that time, like I wasn't, maybe you need to be speaking to people about, you know, how it can interact with contraception, and you</i>

		<i>know, you need to be having those talks with people. And saying, you know, if you're not considering pregnancy, you do need to be considering long term contraceptive use."</i>
Kelly	Managing information	<i>"And so yeah, I think one of the other things obviously I looked at, cos I do, I have contraception, I have the implant now, epilepsy drugs really kind of minimise what you can have, you don't have much choice. So, I'm currently on Lamotrigine and Keppra, the only choice I had was the implant. I'm not able to have anything else, I was on the pill when I was on Epilim, which obviously is perhaps considered the easiest, but it was also taking another pill and then knowing that you already had this stuff going on with the Epilim [valproate]."</i>

To address these findings, a Valproate SDM Support Tool (see supplementary material) was co-designed with expertise from Cardiff Metropolitan University's School of Art & Design and input from a multi-disciplinary team including clinicians, pharmacists, health psychologists, academic researchers, illustrators, and women with epilepsy who had experience of being prescribed valproate. Two further phases of focus group discussions (virtual) were conducted with patients using an iterative approach in line with International Patient Decision Aid Standards [6] to enable person-centred and equitable discussions about the use of valproate. The tool aims to empower patients to engage in discussions with HCPs and make informed and preference-based decisions about valproate. Whilst outside the scope of this tool, that focuses specifically on valproate, use of the tool may assist in opening wider individualised conversations about other epilepsy medication and contraceptive choices.

The Valproate SDM Support Tool is a downloadable resource for women and girls who may need to decide about whether to take valproate or not, when their epilepsy specialist considers it to be a clinically appropriate option. The tool can be used with practitioners to discuss the options available to women and girls when deciding on valproate use. The Valproate SDM Support Tool has five sections including: about valproate, the benefits and risks of valproate, the valproate pregnancy prevention programme and highly effective contraception, planning for a pregnancy (if a future reproduction health goal) and thinking about what is important to you.

The project was commissioned by Welsh Government to improve patient safety for women and girls of reproductive age for whom valproate is a treatment option for epilepsy seizure control. The Valproate SDM Support Tool is hosted on the All Wales Therapeutic and Toxicology Centre (AWTTC) website, ([Sodium valproate - All Wales Therapeutics and Toxicology Centre](#)) available in English and Welsh for use for by healthcare professionals and patients throughout UK. Providing this on a website means that downloadable data will provide a proxy measure for usage. The tool is also accessible to international audiences acknowledging that contextual adaptation will be needed to fit localised health care systems and legislation.

There are future clinical implications for such tools including regulatory action for men who take valproate, and topiramate is now contraindicated with women of childbearing potential unless the conditions of a Pregnancy Prevention Programme are fulfilled.

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