

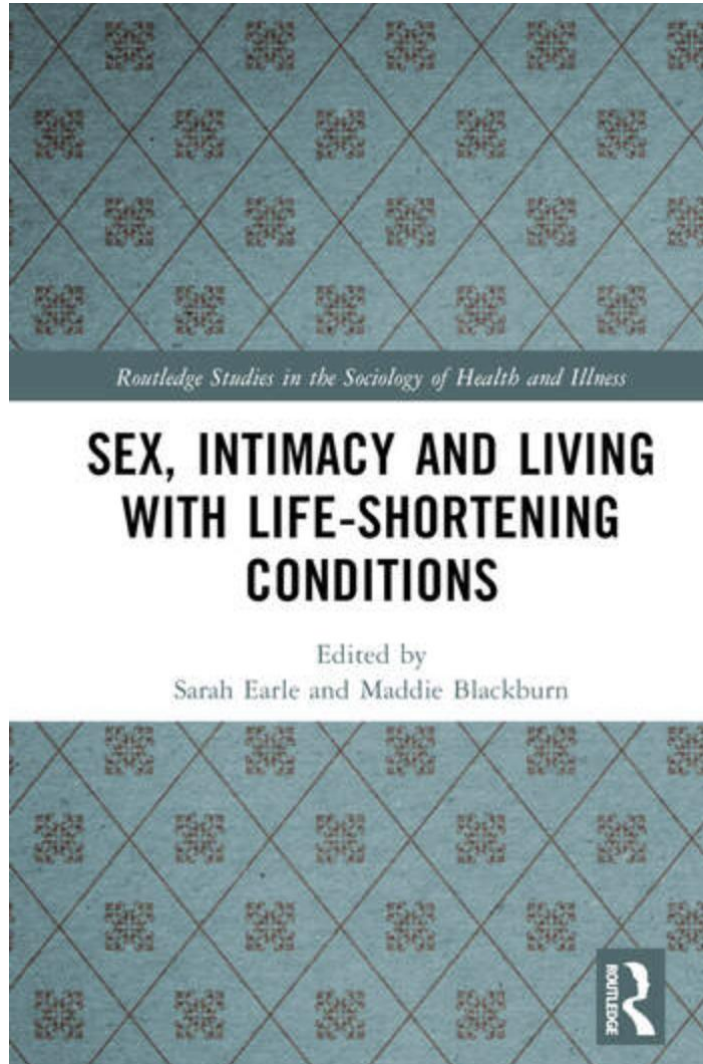
Sex, intimacy and living with life-shortening conditions

Sarah Earle & Maddie Blackburn

Department of Social & Political Sciences, Nottingham Trent University

Association of British Paediatric Nurses, 12th May 2025





Brings together over a decade of research

Research with young people, families, carers and professionals

Research was co-produced and collaborative

Part of the Sexuality Alliance

Our research findings: What do young people tell us?

Sex and relationships are normal and desirable

“most people expect it.”

“it’s like a rite of passage.”

“it feels like you’ve moved on another stage of your life. You feel like you’re stepping up a bit. “

“So you should be in a relationship by the time you’re 25 or something.”

“You don’t want to be 40 and still by yourself.”



Key to physical, emotional and social wellbeing

“having a girlfriend makes you feel like the happiest man ever!”

“Relationships give you a reason to live – they make you happy”

“I would have someone if my mum passed away – so I wouldn’t be on my own.”

“Loneliness is key to depression. In order to stay healthy, it’s important to have relationships.”

“In a relationship one may socially interact with other young people.”

Labelled as 'vulnerable'

"they (teachers) were on about us being extra vulnerable"

"I was told I was vulnerable because there weren't many disabled people there [in a mainstream school]"

"It's quite scary to be honest... because you don't think of yourself as a vulnerable person until someone says..."

"... because people are protective of me, that's made me feel more vulnerable. If they were like, 'oh, you're fine', then I would be, I'd feel fine."

"My parents don't want me to get hurt."

"My parents would be anxious someone might hurt me."

Missing out on sex and relationships education

'I was in and out of hospital and missed the sex ed.'

'Sex ed. was on the school curriculum, but it was designed more for a standard healthy person, not people like me.'

'I was discouraged from attending sex education classes, the content would be irrelevant because I was likely to die.'

'I don't often talk about relationships and sexuality with my parents. Too embarrassing.'

'I have used internet porn to learn about sex... I also have Facebook pictures of women.'

Research findings: top headlines

- Sex often at the bottom of list of priorities
- Young people see sex, intimacy and relationships as a normal part of the transition to adulthood
- Young people recognise its importance to physical, emotional and social wellbeing
- Most disabled people described sex education as absent or insufficient
- Ableist attitudes dominate how we think about sex and disability – young people are told they are ‘vulnerable’
- Important to recognise sexual and gender diversity (including asexuality)
- Avoiding topic of sex does NOT protect or safeguard disabled people: can lead to further vulnerabilities

Families need to be supported: enablers and barriers

Useful resources on sex and relationships

Standards and Guidance

- **8 underpinning principles** outlining what young people should expect
- **8 standards for staff** outlining their role
- **8 standards for organisations and managers** outlining their responsibilities



Let's talk about sex

- Online interactive resources
- Booklet for young people and supporters
- Easy-read guide
- Articles on talking about sex

All available free on Open Learn:

<https://www.open.edu/openlearn/>



The image shows a screenshot of an OpenLearn webpage and two booklets. The webpage header includes the OpenLearn logo, a search bar, and navigation links. The main content area features a colorful banner with icons related to sex, intimacy, and relationships, including a wheelchair, a stethoscope, and a heart. Below the banner is a dark blue box with the text: "LET'S TALK ABOUT SEX, INTIMACY AND RELATIONSHIPS... WITH A LIFE-LIMITING OR LIFE-THREATENING CONDITION".

The first booklet, titled "Let's talk about sex: a love & relationships guide", is an Easy Read guide for young people with a life limiting condition about sex, sexuality, love and relationships. It includes a section titled "You can ask someone to read this with you." and another section titled "This guide is to help people talk about how they feel, what they want and what support they might need." The booklet also features a section titled "Everyone has the right to learn about their bodies, sexual health, love and relationships." and another section titled "We want the sexual freedoms of people with a learning disability to be respected." The booklet has a yellow background and includes images of a person in a wheelchair, a person in a wheelchair with a stethoscope, and a person in a wheelchair with a heart.

The second booklet, titled "TALKING ABOUT SEX", is a booklet for young people with life-limiting or life-threatening conditions and their carers. It features a blue background and is filled with colorful icons related to sex, intimacy, and relationships, including a wheelchair, a stethoscope, a heart, and a person in a wheelchair. The booklet also includes a section titled "This guide has some tips about how to talk about sex and sexuality."

Five things to know about being disabled and LGBTQ

1: Disabled people don't just have sex, we have sexualities



People often assume that just because we're disabled, we don't have any sexuality, or any interest in sex whatsoever. It's a form of infantilising us – treating us like children – in which we're not understood to be the teenagers and adults we are. Even when people accept that we might want to date, the assumption is that we'd be straight. In fact, there are lots of disabled lesbian, gay, bi and queer (LGBQ) people out there, and we find partners and love the same way everyone else does.

4: Labels are there to support you, not constrain you



If you've found a label that describes you and helps you communicate yourself to other people, then that's brilliant – but if that label no longer fits, don't feel trapped in it. Labels work as a kind of social shorthand, but they shouldn't become a prison. If one set of words don't fit, you'll find others that do.

Talking about sex booklet

- Thinking about Sex
 - Believing in Yourself
 - Challenging Stereotypes
 - Expressing your Needs
-
- Advice for young people
 - Top tips for starting a conversation
 - Advice for carers
 - What the law says

EXPRESSING YOUR NEEDS

“If you talk to a professional, you’re gonna think they’re ‘above you’ and that they’re gonna judge you for talking about sex, but they probably won’t, just go for it!”


FOR YOUNG PEOPLE

It can be hard to think about talking about sex. For many people it is something private and you might feel a bit embarrassed at first. It's normal to feel like this but if you can find a way to express your needs you could have more fun and live life to the fullest!

For those who are becoming sexual it can be a really exciting time but you might also feel confused and have lots of questions. You might want to talk about what you wear or where you could go to make more friends. You might want to talk about dating, including online dating. You might have questions about how to masturbate, orgasm and other forms of sexual pleasure. You may have many other questions depending on where you are on your own sexual journey.

Whatever your needs and whatever questions you have, you have a right to information and support so never feel ashamed to ask for what you want! It is a shame when someone else cannot help but not your shame! Don't give up!

TOP TIPS FOR STARTING A CONVERSATION...

- Do you have a care plan? Sex and sexuality could be a part of it.
- Be strong and assertive! You have a right to information and to support but remember that your carer might feel embarrassed or might not be able to answer your question straight away.
- Don't leave it until the last moment– sometimes people worry about starting a difficult conversation so they don't say anything until the trusted person is about to leave! Say something like, 'I really need to talk to you about sex – can we make some time to chat next time I see you?'.

- Give a copy of this booklet to the person you want to talk to – it will help them know the kind of things you need to say.

Hearing from young people themselves

Intimate Not Intimidated: It's time to talk about sex



Explore subjects

What can nurses do?

Let's dispel some myths...

- Young disabled people aren't interested in sex!
- It's too embarrassing!
- I don't have the skills/knowledge!
- It's not my job!
- I don't understand the law but don't want to break the law!

Any questions?



Co-produced resources

1. Earle S, Blackburn M, Cooke A, de Than C, Sellar P, Walford C and Watts, L (2020) Talking about Sex: A booklet for young people with life-limiting conditions and their carers published with Hospice UK.
https://www.open.edu/openlearn/pluginfile.php/3278937/tool_ocwmanage/article/1/talking_about_sex_booklet_accessible_download.pdf
2. Blackburn M, Chambers L, Cooke A, Earle S, de Than C and Watts L. (2019) Talking about sex, sexuality and relationships: Guidance and Standards for those working with young people with life-limiting or life-threatening conditions published with Together for Short Lives.
https://www.open.edu/openlearn/pluginfile.php/3278728/tool_ocwmanage/article/1/tassr_very_final_web_151119.pdf
3. Blackburn M and Earle S (2021) Let's talk about sex: a love and relationships guide. An inclusive easy read guide produced by The Open University and Mencap.
https://www.open.edu/openlearn/sites/www.open.edu.openlearn/files/ou_mencap_easy_read_final_002.pdf
4. Earle S, Blackburn M and Watts L (2020) *Intimate not Intimidated: It's Time to Talk about Sex and Disability*. Short Film.
https://www.open.edu/openlearn/health-sports-psychology/health/intimate-not-intimidated-its-time-talk-about-sex-and-disability?in_menu=1023912
5. Earle S, Blackburn M and Watts L (2019) *Let's talk about sex, intimacy and relationships ... with a life-limiting, life-threatening or another disabling condition*. Learning interactive <https://www.open.edu/openlearn/talkaboutsex>
6. Earle S and Blackburn M (2019) *Nine top tips on talking about sex... for young people with life-limiting or life-threatening conditions*. https://www.open.edu/openlearn/health-sports-psychology/young-peoples-health/9-top-tips-on-talking-about-sex-young-people-life-limiting-or-life-threatening-condition?in_menu=1023912

References to the research

1. Blackburn M and Earle S (2015) 'Why young people with life-threatening conditions also need to talk about sex' *The Conversation*. <https://theconversation.com/why-young-people-with-life-threatening-conditions-also-need-to-talk-about-sex-51340>
2. Blackburn M, Chambers L and Earle S (2016) 'Talking about sex, relationships and intimacy: New Guidance & Standards for nurses and other health and social care professionals working with young people with life-limiting and life-threatening conditions', *Journal of Advanced Nursing*. August. <https://dx.doi.org/10.1111/jan.13089>
3. Earle, S. (1999). Facilitated Sex and the Concept of Sexual Need: disabled students and their personal assistants. *Disability and Society*, 14(3) pp. 309–323.
4. Earle S (2001) 'Disability, Facilitated Sex and the Role of the Nurse', *Journal of Advanced Nursing*, Vol. 36(3), pp. 433-440.
5. Earle S (2024) People with disabilities have sex too – so why do some doctors think otherwise? *The Conversation*, <https://theconversation.com/people-with-disabilities-have-sex-too-so-why-do-some-doctors-think-otherwise-229581>.
6. Earle S (2024) Disrupting normativity: Understanding reproductive loss in the lives of young adults with shortened lives. In: Earle S and Blackburn M (eds) *Sex, Intimacy and Living with Life-Shortening Conditions*. Routledge, London.

References to the research cont.,

6. Earle S and Blackburn M (2020) Young adults with life-limiting or life-threatening conditions: sexuality and relationships support, *BMJ Supportive & Palliative Care*, 11(2), DOI: [10.1136/bmjspcare-2019-002070](https://doi.org/10.1136/bmjspcare-2019-002070)
7. Earle S and Blackburn M (2021) Involving young people and adults with life-limiting conditions in research on sex: The intersections of taboo and vulnerability, *International Journal of Social Research Methodology*, 24:5 545-551
8. Earle S and Blackburn M (2024) *Sex, Intimacy and Living with Life-Shortening Conditions*, Routledge, 195pp
9. Earle S, Blackburn M, Chambers, L, Downing J, Flemming K, Hale J, Marston H, O'Dell L, Sinason V and Whitney S (2024) Disruption, Relationships and Intimate Futures: The unintended consequences of pandemic control. In: Earle S and Blackburn M (eds) *Sex, Intimacy and Living with Life-Shortening Conditions*. Routledge, London. [80% contribution]
10. Earle S, Blackburn M, Watts L and Whitney S (2024) Involving Young People with Life-Shortening Conditions in Research: A conversation on the politics of co-production methods. In: Earle S and Blackburn M (eds) *Sex, Intimacy and Living with Life-Shortening Conditions*. Routledge, London
11. Earle S, Blackburn M, Cooke A, de Than C, Sellar P, Walford C and Watts, L (2021) *Talking about... Sex and Relationships: Young People Speak Out*. Final evaluation report presented to Together for Short Lives.



Nottingham Trent
University

Thank you

Please get in touch!

Sarah Earle, Professor of Social Science

Nottingham Trent University, UK

Department of Social & Political Sciences

Email: sarah.earle@ntu.ac.uk

Follow me on [LinkedIn](#)

Dr Maddie Blackburn, Visiting Scholar

Nottingham Trent University, UK

Department of Social & Political Sciences

Email: Maddie.blackburn@ntu.ac.uk