

FOREWORD

Talking about sex for anyone, be they a young person or an adult, can feel uncomfortable and intrusive. But sex is part of life! This booklet creatively draws out how an essentially private and sometimes challenging matter can be talked about in a respectful and helpful way. For example, it opens up the potential for young people to question their identity and reassures carers it is OK to support and facilitate a person with a life-limiting or life-threatening condition to find satisfaction.

The 'Top tips for starting a conversation' are designed to help people to talk openly and honestly. None of this is easy, especially at the beginning. But the 'what the law says' sections help unpick the tricky, potentially complicated experiences that might be encountered in a practical, reassuring way.

The need for the booklet is summed up for me by the quote, 'We need to know about how to make friends and have a social life. We need to understand about sex and relationships, but people don't think we need it because of our life-limiting conditions'. I believe we can all learn from the content of this booklet which has been informed by inclusive research carried out by the Open University Sexuality Alliance. It helps ensure a more supportive approach is taken to enable young people with a life-limiting or life-threatening condition to enjoy a full life.

The authors recognise that a booklet of this length cannot address all issues relating to this complex subject. So, at the end there is a useful list of resources and a link to online interactive materials for young people.

It is a wonderful addition to the now growing body of literature on this subject. Thank you.

Professor Dame Elizabeth Fradd, DBE. DL.

High Sheriff of Nottinghamshire (2020/21)





HOW TO USE THIS BOOKLET

One of society's greatest taboos seems to be that disabled people are not sexual beings. Many non-disabled people cannot entertain the idea that us disabled folk can actually have sex, let alone that we maintain intimate relationships or that we have sexual needs and desires in the first place. We have the same needs and desires as our non-disabled peers. We also have the ability to form deeply connected, loving relationships – and indeed find happiness. Our need to explore our sexuality is completely natural, whether we are disabled or non-disabled, and whether we are heterosexual or LGBTQ+ (lesbian, gay, bisexual, trans, queer or questioning). We, as young people have every right to explore sexuality, intimacy and relationships as these are a normal part of life — and a basic human right. However, we often face additional barriers and can struggle to open up and talk about our wants and needs.

This booklet is intended to be used by young people, carers and professionals to facilitate conversations around sexuality, sex, intimacy and relationships, providing a starting point. It contains lots of useful hints and tips for how to approach talking about these topics and explains some of the law.

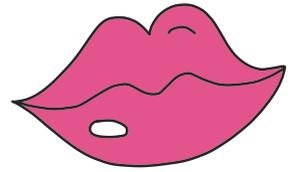
If you are a young person, this booklet can help you to discuss your needs, wishes and desires with others. You must be able to explore your sexuality and to fulfil your sexual needs, experience intimacy and pleasure, have relationships and fulfil your desires, and to be respected as a sexual being.

If you are a carer or professional, we hope this enables you to have conversations with young people like us about this important topic, giving you the skills, conversation starters, legal overview and confidence to have open and honest conversations about this vital and often neglected part of our lives.

Rhys Bowler and Lucy Watts

Young people living with life-limiting conditions

THINKING ABOUT SEX



|| Sex... it's a bit of a taboo thing. It's not something that people talk about regularly is it? ||



FOR YOUNG PEOPLE

Everybody is a sexual person whether they have a boyfriend, girlfriend or are single. Whatever your sexuality it is **NORMAL!** Whatever other people think! Are you gay, straight, bisexual, queer, asexual or unsure? Look up the words at the end of this booklet. Gender is also an important part of sexuality: are you female, male or 'non-binary' - neither male nor female. Sexuality is about other things too, like: what clothes do you like to wear and what turns you on? How have your views been affected by family, other people, friends, or religion?

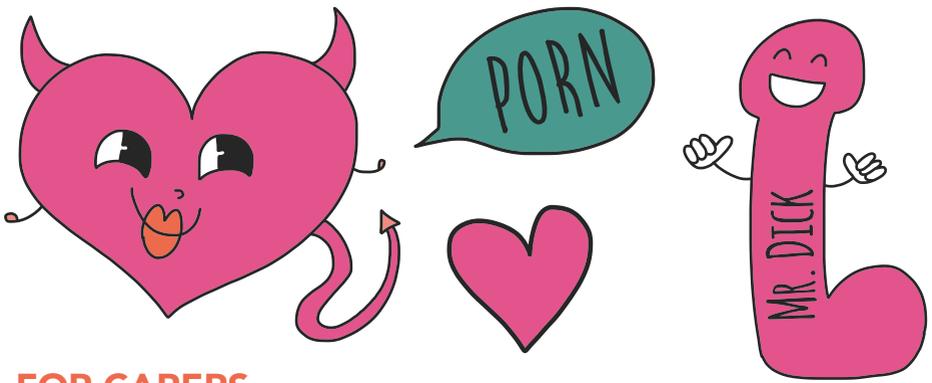
Our sexuality can change. It doesn't have to stay the same. In our lives new experiences happen (good and bad) and these can all change the way we feel and think.

Sadly, we live in a society that doesn't always accept that disabled, life-limited or life-threatened young people are sexual beings with sexual feelings, needs, fantasies and desires – just like anyone else.

Whatever your feelings, know that they are **YOUR** feelings and that's it's OK to have them and talk about them.

TOP TIPS FOR STARTING A CONVERSATION...

- Do you want to talk about sex? It's private and you don't have to. It's up to you. Think about it first. Only you know when it's the right time to talk.
- Plan ahead. Think about when it might be the best time to talk about sex.
- Some people can talk about sex easily but many people, with or without a disability, find it hard to talk, and that includes carers, friends and parents too! If one person doesn't listen in a helpful way, don't give up! Show them this booklet.



FOR CARERS

Sexuality is an important part of EVERYONE'S life, including people that are disabled, life-limited or life-threatened. It is a human right. For some individuals this will mean that they will identify as either male, female or non-binary. It is for them to tell us what type of relationship they might want, if any. For others, these issues may not be clear at all.

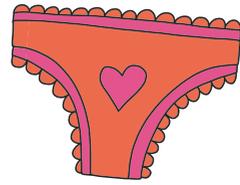
For most people sex and sexuality can remain private but when someone is disabled and needs help, it can rarely stay that way. As someone who supports young people, it is right to consider your own personal feelings. Reflect on the following:

- How does your sexuality affect your everyday life? How does it contribute to your wellbeing? How do you deal with a negative effect?
- How do you relate to young people with the same or different sexual experiences to you?
- Are there issues about sex that make you feel uncomfortable? Why do you think that is?

WHAT THE LAW SAYS

Sexual expression is a human right. When sex involves more than one person, consent is crucial, so there must be clear records of how a person communicates consent, including any technology used. Many carers are understandably concerned about the legal implications of clients having sex or asking for help with sexual issues. Unless the carer actively encourages sexual activity to take place, they are unlikely to be committing a crime. However, they or their employer could be sued if they knew that sexual abuse was taking place and did nothing.

BELIEVING IN YOURSELF



|| You have to believe in yourself and know that you are worthy of love and attention ||

FOR YOUNG PEOPLE

Becoming a young person can be hard work! Most young people feel shy or confused sometimes. If you are LBGTO+ it can feel even harder. Having a life-limiting or life-threatening condition means that it can be harder to make your own choices, especially if you have additional health needs and physical or learning disabilities. Maybe some people say you are vulnerable and should be protected. Maybe you feel your body and your life are not your own and that includes your sexuality too.

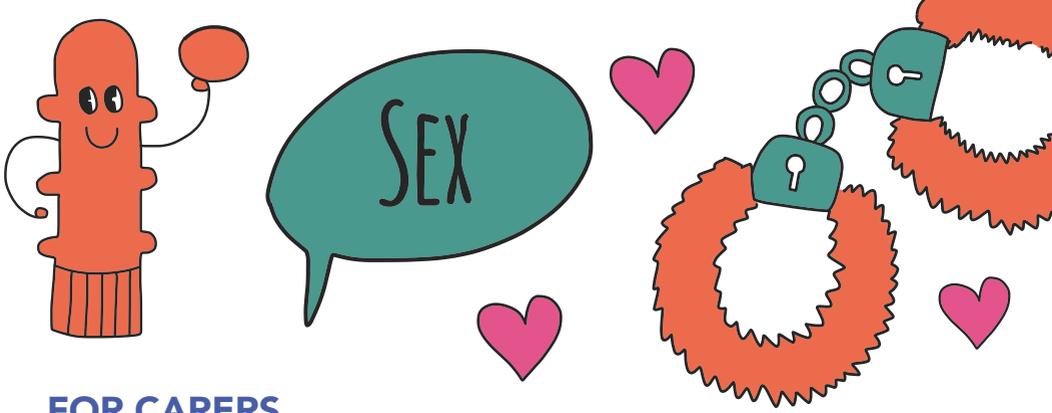
You may have been lucky and had great friends, supportive parents or inspiring teachers in the past. But bad experiences (such as being abused, becoming very unwell or being let down by someone close to you) can affect you badly too.

You **DO** have the right to be who you want to be, and you **CAN** believe in yourself even when other people do not help you.

TOP TIPS FOR STARTING A CONVERSATION...

- Talk to someone you trust. You could say *'I want to tell you something private, but I feel shy'* and see how they respond.
- If you're anxious about what you want to talk about, try making a note or a picture to remind you.
- Find an easy place to start. What clothes do you feel comfortable wearing? Do you want to meet or find people who have the same interests as you? How hard would that be to talk about?
- If you've had bad experiences that affect you, ask to speak to a counsellor.





FOR CARERS

It can be hard for young people to find the courage to ask about sex and sexuality. They may not know how to begin. Young people with life-limiting or life-threatening conditions have often had limited access to sex education which makes it harder. They might also feel ashamed or embarrassed. They may lack confidence or have low self-esteem.

Young people with life-limiting conditions can often feel unattractive. They may have had a lifetime of illness, operations and interventions. You can help them to feel valued as a whole person. Try the following:

- Ask how they feel and if they want to talk. Leave it up to them.
- Try humour to break the ice but always be respectful!
- Encourage them to share their views.
- Help them to be involved in decision-making.

All of this will help to develop self-confidence and self-belief.

WHAT THE LAW SAYS

UK laws are based on age, mental capacity, the nature of any disability and whether a disabled person lives at home or in residential care. This often makes issues about sexual expression so complicated that many people don't understand their rights. But young people with life-limiting or life-threatening conditions have the same right to sex and relationships as anyone else as long as no harm will be caused. Everyone should be supported to make as many decisions as they can for themselves (See [Useful Resources, page 11](#)).

CHALLENGING STEREOTYPES AND ASSUMPTIONS



|| We need to know about how to make friends and have a social life. We need to understand about sex and relationships, but people don't think we need it because of our life-limiting conditions!! ||

FOR YOUNG PEOPLE

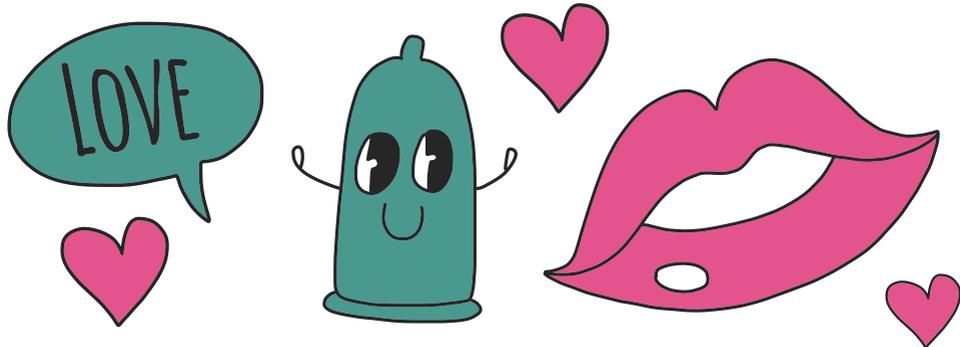
People sometimes think that young people with life-limiting or life-threatening conditions are 'all the same'. They think they know you, but they don't know what it's like to be you. Sometimes they think they are protecting you and don't realise that is not helpful.

Young disabled people are often asked unhelpful questions like... *Can you have sex? Do you want a relationship? Do you have to pay for sex? Can young people who are life-limited or life-threatened have children?* These questions come from a lack of understanding and training.

Relationships and sex (at the right time, if you want and consent to it) are basic needs. These are just as important to you as anyone else.

TOP TIPS FOR STARTING A CONVERSATION...

- When people think they know you but they have got you all wrong. How does it affect you?
- Remember you don't need to answer people's questions if it makes you feel uncomfortable or unsafe. Only talk about sex and relationships if you feel safe and it's with someone you trust.
- Decide if it is easier to talk about sex on-line or face to face. How much do you want to share about your private feelings? Think about your safety on social media.
- If you would like to have children and become a parent, make sure you get help and advice from your doctor and others before planning this.



FOR CARERS

Relationships and sex can and should be enjoyed by people living with life-limiting or life-threatening conditions BUT some advanced planning may be required. Always remember, that providing this support is an important role and a privilege.

Feeling confident and competent may reduce embarrassment and taboo. Consider whether you are the right person to have the conversation and ensure that you have enough information to do so. If you feel that you're not the best person (for example, on account of your own personal or religious views and beliefs) find the right person. If you're not sure who that might be, speak to your manager. NEVER leave the young person with no-one to talk to.

Think about the following:

- Have you ever received training in this area? Many people haven't, but it might be really useful.
- Do you feel confident? If not, the Talking about Sex: Sexuality Guidance and Standards will help. See [Useful Resources on page 11](#).

WHAT THE LAW SAYS

Under the Mental Capacity Act 2005, take all practicable steps to enable an individual to make their own decisions.

Under Article 10 of the European Convention on Human Rights, give people access to all relevant information needed to make decisions about their own lives.

Under the Sexual Offences Act 2003 it is not a crime for an adult to communicate with young people about sex and sexuality if they are genuinely acting in their best interests and fulfil certain criteria.

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.





FOR CARERS

You support young people with life-limiting or life-threatening conditions to live their lives as fully as they can. Sexuality is an important part of that. It may be difficult for a young person to express their needs either because they are shy, haven't previously had sex or a relationship, or have had a bad one. If the young person has a communication difficulty or is non-verbal you may need to pay close attention to other cues – they may need sexual support but may find it hard to tell you. This is what you can do to help a young person express their needs:

- Be open minded and listen to the young person – it will have taken a lot of courage to start this conversation and it's important that they feel safe, supported and respected.
- Don't be afraid to ask questions and explore their concerns.
- If you don't know how to help – say so – but find out what you can do and get back to them. If you really can't help, find someone who can!
- Check out the additional resources at the end of this booklet.

WHAT THE LAW SAYS

People aged 16 + may legally have sexual relationships. Caregivers should be prepared to support them within the current legal framework. If everyone involved in sexual activity is all of the following things: an adult; not a regular carer for the other person; not in a position of power, control or trust over the other person; can communicate consent, does consent, has capacity to consent, and the sexual activity takes place in private, then the activity can be supported. If not, it may be illegal, so you need to get more advice.

USEFUL RESOURCES

Council for Disabled Children Growing up, sex and relationships <https://councilfordisabledchildren.org.uk/sites/default/files/uploads/documents/import/growing-up-sex-and-relationships.pdf>

Griffith R & Tenginah C (2014) Assessing capacity to consent to sexual relations: a guide for nurses, *British Journal of Community Nursing* Apr18(4):198-201.

Hale J Five things to know about being disabled and LGBTQ www.open.edu/openlearn/health-sports-psychology/young-peoples-health/five-things-know-about-being-disabled-and-lgbtq

Hollins S, Perez W & Abdelnoor *Falling in Love*. Books Beyond Words <https://booksbeyondwords.co.uk/bookshop/paperbacks/falling-love>

Hollins S & Sinason V *Jenny speaks out* Books Beyond Words <https://booksbeyondwords.co.uk/search?q=Jenny%20speaks%20out>

Makaton: Sex Education Symbols Book www.makaton.org/shop/shopping/stockDetails/SexEducation-SymbolsBook

MENCAP *Sexuality and Relationships* www.mencap.org.uk/sites/default/files/2019-02/Easy%20read%20Relationships%20and%20Sex%20Vision%20Statement.pdf

Nursing Midwifery Council (2018) *The Code: Professional standards of practice and behaviour for nurses, midwives and nursing associates* www.nmc.org.uk

SCOPE (2020) *Talking about intimacy, sex and relationships* www.scope.org.uk/advice-and-support/talking-about-intimacy-sex-relationships/

The Open University Sexuality Alliance (2019) *Talking about sex, sexuality and relationships: Guidance and Standards for those working with young people with life-limiting or life-threatening conditions* https://www.open.edu/openlearn/sites/www.open.edu.openlearn/files/tassr_very_final_web_151119.pdf

RELEVANT LAW

European Convention on Human Rights www.echr.coe.int/Documents/Convention_ENG.pdf

Human Rights Act 1998 www.legislation.gov.uk/ukpga/1998/42/contents

Mental Capacity Act 2005 www.legislation.gov.uk/ukpga/2005/9/contents

Sexual Offences Act 2003 www.legislation.gov.uk/ukpga/2003/42/contents



Let's talk about sex, intimacy and relationships...

Try our interactive video experience to explore the challenges around sex. It doesn't have to be embarrassing!

www.open.edu/openlearn/health-sports-psychology/young-peoples-health/lets-talk-about-sex-intimacy-and-relationships

RELEVANT TERMS

LGBTQ+ an 'inclusive' way to represent different sexual identities.

L – lesbian: a woman who is attracted to other women.

G – gay: a man who is attracted to other men.

B – bisexual: a person who is attracted to men and women.

T – transgender: a person whose gender identity is different from the sex the doctor put down on their birth certificate.

Q – queer: originally used as a hate term, this word has been taken back to show strength. Generally, the word is used for someone who is not rigidly one thing or another. (male v female, homosexual v straight).

Q – questioning: a person who is still exploring their sexuality or gender identity.

I – intersex: a person whose body is not either male or female. This may be because they have chromosomes which are not XX or XY or because their genitals or reproductive organs are not considered 'standard'.

A – allies: a person who identifies as straight but supports people who are LGBTQ+.

A – asexual: a person who is not sexually attracted to people of any gender.

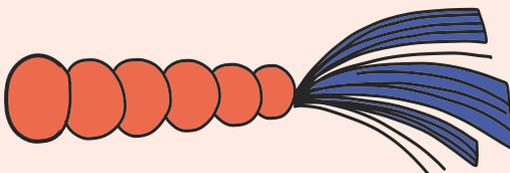
P – pansexual: a person whose sexual attraction is not based on gender and may themselves be fluid when it comes to gender or sexual identity.

I – identify: what kind of sexuality or gender do you see as being like yours? What sexuality or gender do you identify with?

B – binary: means seeing gender as two rigid opposite things like male and female, rather a variety or range.

This list is not exhaustive, and some people may identify with more than one of these terms.

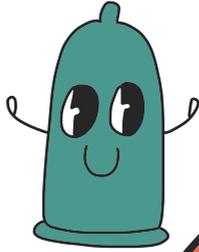
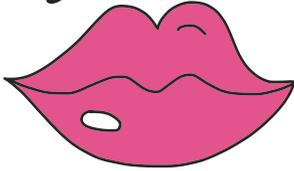
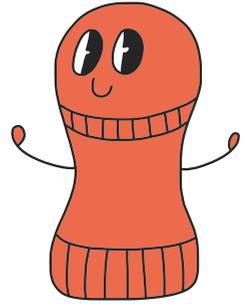
Adapted from: <http://www.bbc.co.uk/newsbeat/article/33278165/we-know-what-lgbt-means-but-heres-what-lgbtqiaap-stands-for>



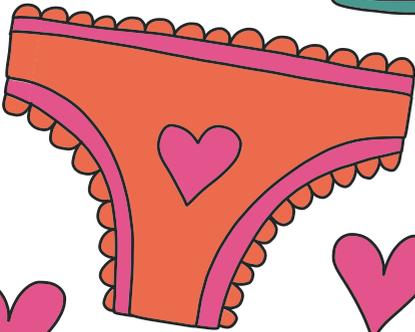
MAKE SOME NOTES

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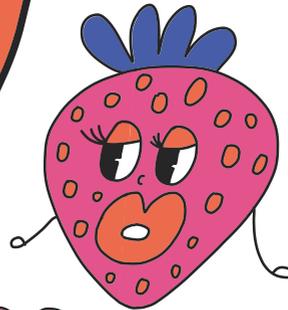
"sex is for anyone who wants it"



"it's challenging to share your sexual needs when people think we are not interested in sex"



"when you're having conversations about sex, people need to be open-minded"



"we are sexual beings with needs like everyone else, we might need some practical help to reach our goals but it doesn't make us any less human!"



THIS BOOKLET

This booklet has been produced by The Open University and Hospice UK as part of the Talking about... Sex and relationships: Young people speak out Project

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The Open University and Hospice UK.



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