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Sexuality in young people
with life-limiting and or life-
threatening conditions, on an
uncertain life-course'.

With thanks to Dr Sarah Earle
and young adults with life-
limiting and or life- threatening
conditions who have
contributed to all the research.



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Aims of this session

- Brief overview of findings from 4 projects related to people with life-limiting life-threatening conditions,
- **Project One:** Thesis: *Sexuality, relationships and reproductive choices in young adults with life-limiting and /or life-threatening conditions*
<http://oro.open.ac.uk/61843/>
- All four projects focus on sex, intimacy and relationships in young adults, age 16-40, whose life-course maybe uncertain and shortened but want to live life to the fullest.
- Two projects used an inclusive, action research model and two projects did not.
- Reference to interview data and the on-line education resources below
- <https://www.open.edu/openlearn/health-sports-psychology/young-peoples-health/lets-talk-about-sex-intimacy-and-relationships>



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Intimacy, Relationships and Sexuality

Sexuality is:

- “...a central aspect of being human throughout life encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction.....” (WHO, 2006a)
- Sexuality is a major component of our spiritual, psychological, social and physical identity
- More people with LL or LTCs *now* living into adulthood (Fraser, Lidstone et al, 2014; Beresford & Stuttard, 2014; Craig & Lidstone, 2012,)



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Sexuality, relationships and reproductive choices in young adults with life-limiting and /or life threatening conditions
(Blackburn, M C 2019)

- 13 young adults aged 16-40 years, nine males, four females, with some, but not all, life-limiting or life-threatening conditions, mean average age, 26 years.
- People with Duchenne Muscular Dystrophy, (n=six), cystic fibrosis ,other progressive neuromuscular and rare conditions, certain cancers and other genetic conditions.
- Explored the views and contributions of family supporters. (Two non-disabled partners, ten parents and ten care practitioners).
- 35 participants, one focus group. Some participants interviewed on more than one occasion.
- In-depth semi-structured f-to-f interviews. No co-researcher involvement.



<i>Participant</i>	<i>Participant type</i>	<i>Sex</i>	<i>Age Group</i>	<i>Country of Birth</i>	<i>Education Level</i>	<i>Faith</i>	<i>Household</i>	<i>Medical Condition(s)</i>	<i>Occupation</i>
<i>Alfa Romeo</i>	YA	Male	30 up to 40	UK	Special College	Christian	Lives with parent(s)	DMD	Volunteer
<i>Austin</i>	YA	Male	20 up to 30	UK	University	Christian	Lives with parent(s)	Benign recurring brain tumour	Volunteer
<i>Diamond</i>	as a Young Adult	Female	30 up to 40	UK	Mainstream College	Christian	Lives with partner	Leukaemia	Mixed
<i>Fiat</i>	YA	Male	20 up to 30	UK	Special College	Christian	Lives with parent(s)	DMD	Not working
<i>Jaguar</i>	YA	Male	20 up to 30	UK	Special School	Christian	Lives with parent(s)	DMD	Volunteer
<i>Jane</i>	YA	Female	10 up to 20	UK	Mainstream School	Other	Lives with partner	Rare life-limiting condition	Volunteer
<i>Lamborghini</i>	YA	Male	20 up to 30	UK	Special College	Christian	Lives with family	DMD	Not working
<i>Lily</i>	YA	Female	20 up to 30	UK	Mainstream School	Christian	Lives with family	Rare life-limiting condition	Volunteer
<i>Marmaduke</i>	YA	Female	20 up to 30	South Africa	Special College	Unassigned	Lives with parent(s)	Rare life-limiting condition	Special college
<i>Maserati</i>	YA	Male	20 up to 30	UK	University	Unassigned	Lives with parent(s)	Brain tumour- cancer	Volunteer
<i>Mini</i>	YA	Male	20 up to 30	UK	Special College	Christian	shared parent scheme	DMD	Special college
<i>Morris</i>	YA	Male	20 up to 30	UK	Special College	Jewish	Lives with parent(s)	Adrenoleukodystrophy	Not working
<i>Vincent</i>	YA	Male	20 up to 30	UK	University	Jewish	Lives with partner	Cystic Fibrosis	Postgraduate Student
<i>Dee</i>	Partner	Male	40 up to 50	UK	Mainstream School	Unassigned	Lives with Jane	N/A	In full time employment
<i>Smidge</i>	Partner	Female	20 up to 30	UK	University	Christian	Lives with Vincent	N/A	In full time employment
<i>Daisy</i>	Parent	Female	30 up to 40	UK	University	Unassigned	Unassigned	N/A	In part time employment
<i>Emerald</i>	Parent	Female	40 up to 50	Jamaica	University	Episcoplian	Lives with family	N/A	In part time employment
<i>Goldie</i>	Parent	Female	30 up to 40	UK	University	Episcopalian	Lives with partner	N/A	In part time employment
<i>Liliana</i>	Parent	Female	40 up to 50	UK	Mainstream College	Christian	Unassigned	N/A	Main Carer
<i>Pear</i>	Parent	Female	40 up to 50	South Africa	Mainstream College	Christian	Lives with family	N/A	Main Carer
<i>Precious</i>	Parent	Female	30 up to 40	UK	Mainstream College	Christian	Lives with partner	Leukaemia	CNS
<i>Primrose</i>	Parent	Female	40 up to 50	UK	University	Christian	Lives with family	N/A	Care assistant
<i>Ruby</i>	Parent	Female	40 up to 50	UK	Mainstream College	Christian	Lives with family	N/A	In part time employment
<i>Diamond</i>	as a Parent	Female	30 up to 40	UK	Nursing School	Christian	Lives with family	Leukaemia	In part time employment
<i>Topaz</i>	Parent	Female	40 up to 50	UK	University	Jewish	Other residential care	N/A	Main Carer
<i>Millie</i>	Social Worker	Female	50 up to 60	UK	Mainstream College	Christian	Lives with husband	N/A	Social Worker
<i>Peach</i>	Med Student	Female	20 up to 30	UK	Medical School	Roman Catholic	Unassigned	N/A	At University
<i>Oak</i>	GP	Female	30 up to 40	UK	Medical School	Unassigned	Unassigned	N/A	Doctor
<i>Ellie</i>	GP	Female	40 up to 50	UK	Medical School	Unassigned	Unassigned	N/A	Doctor
<i>Apple</i>	Carer	Female	20 up to 30	UK	Mainstream College	Christian	Lives with partner	N/A	Main Carer
<i>Cherry</i>	Care Practitioner	Female	40 up to 50	Ireland	Nursing College	Christian	Lives with family	N/A	Full time employment
<i>Elm</i>	Care Practitioner	Female	30 up to 40	UK	Mainstream College	Unassigned	Unassigned	N/A	Youth Leader
<i>Spruce</i>	Care Practitioner	Female	40 up to 50	UK	Nursing College	Unassigned	Unassigned	N/A	CNS
<i>Walnut</i>	Care Practitioner	Female	40 up to 50	UK	Nursing College	Unassigned	Unassigned	N/A	CNS
<i>Pine</i>	Care Practitioner	Female	40 up to 50	UK	Nursing College	Unassigned	Unassigned	N/A	Main Carer
<i>Focus group</i>	YA	Male	20 up to 30	UK	Various	Various	Various	Multiple life-limiting conditions	Various

Observations

- **The topic**, sex and sexuality- taboo
- **The language**; intercourse ‘making love’, ‘having sex’. ‘Bonking’ “f....ing”

(Abbott, D. W. F., Jepson, M. and Hastie, J. (2016)

- **The researcher**- who does it, where is this taking place, how long will it last?
- **Is it safe?**
- **HREC and individual Hospice RECS- do their views differ?**
- Undertaking qualitative research raises a variety of ethical issues on sensitive subjects, such as death and dying, sexuality, homelessness, HIV/AIDS or cancer
(International Journal of Social Research Methodology, Special Edition)



Posthumous Consent

- **Mini:** *What happens if I die during this research, what will happen to what we've talked about together. Will my interviews be shared?*
- **Maddie:** *What would you like to happen?*
- **Mini:** *I want you to use whatever you wish from my interview. It will be my living legacy and means my contribution will not be wasted. I want people to know what I feel about sex....*
- *(Mini who DMD, died whilst I was 'writing up'. His discussions regarding sex, death and dying, end of life are included in the thesis. His parents contacted me, following his death. They did not wish me to publish his findings) Discuss!!*
- GDPR issues. Obtaining consent to use data before death. Parental intervention with a young adult.

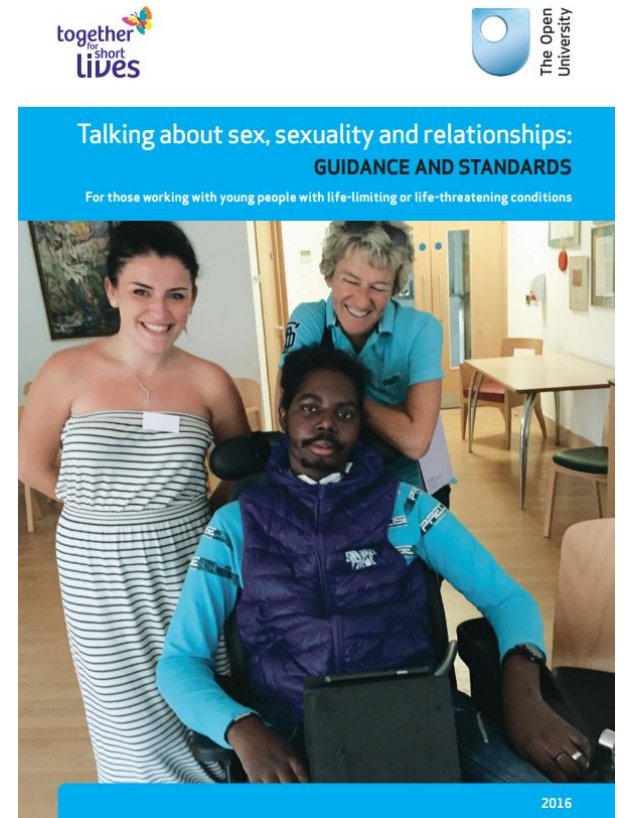


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Recommendations

- Access to life-long and specialist information about relationships, intimacy and sex- not just at school or college (both young people and their carers, (particularly requested by men with DMD))
- Sustainable, dedicated services for young people with LLTCs which address their holistic needs, including sex and intimacy, sexual gratification, masturbation
- Guidance and governance about relationship choices and sex for staff working in hospice settings.





Project Two: Co- researchers.
The Adversi Team working with The Open University Sexuality Alliance: First
Edition of the Sexuality Guidance & Standards



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Lucy Watts, MBE, Master of The Open
University

Chair of the AdversiTeam and member of
The Open University Sexuality Alliance



Young people talking about Sex

Project Three

- https://www.open.edu/openlearn/health-sports-psychology/health/intimate-not-intimidated-its-time-talk-about-sex-and-disability?in_menu=1023912



How to talk about sex

Project Four: Talking about sex

**A booklet for young people with life-limiting or life-threatening conditions
and their carers**

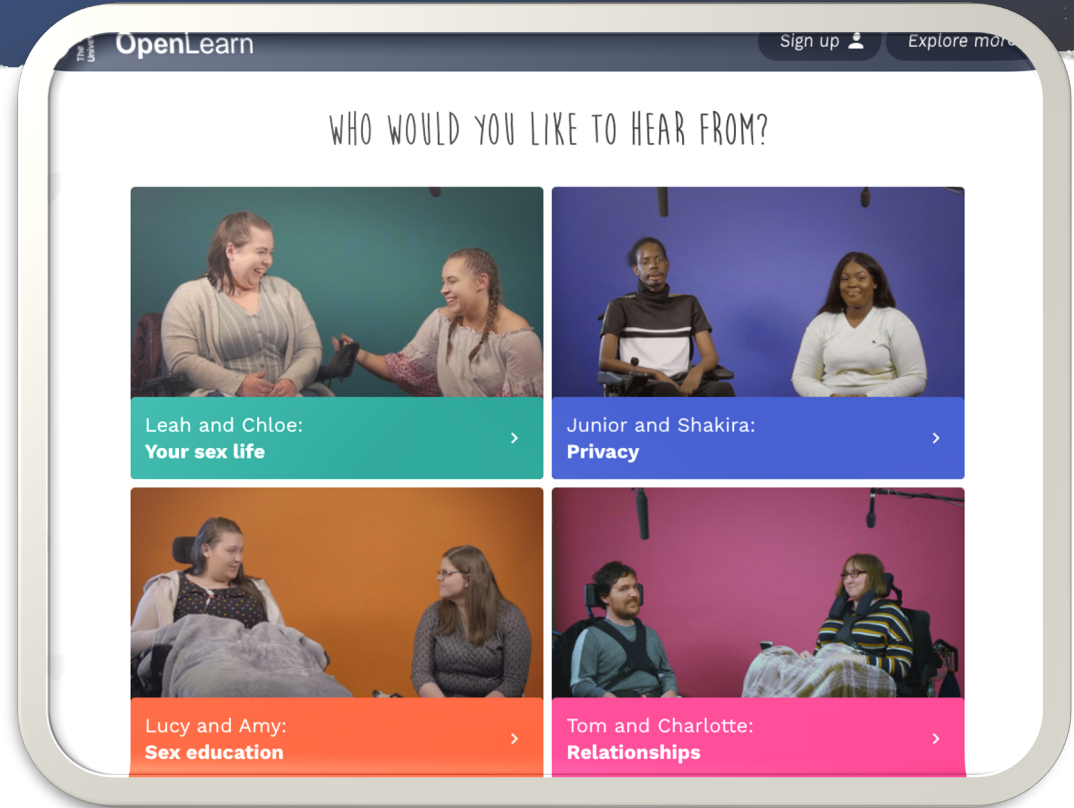
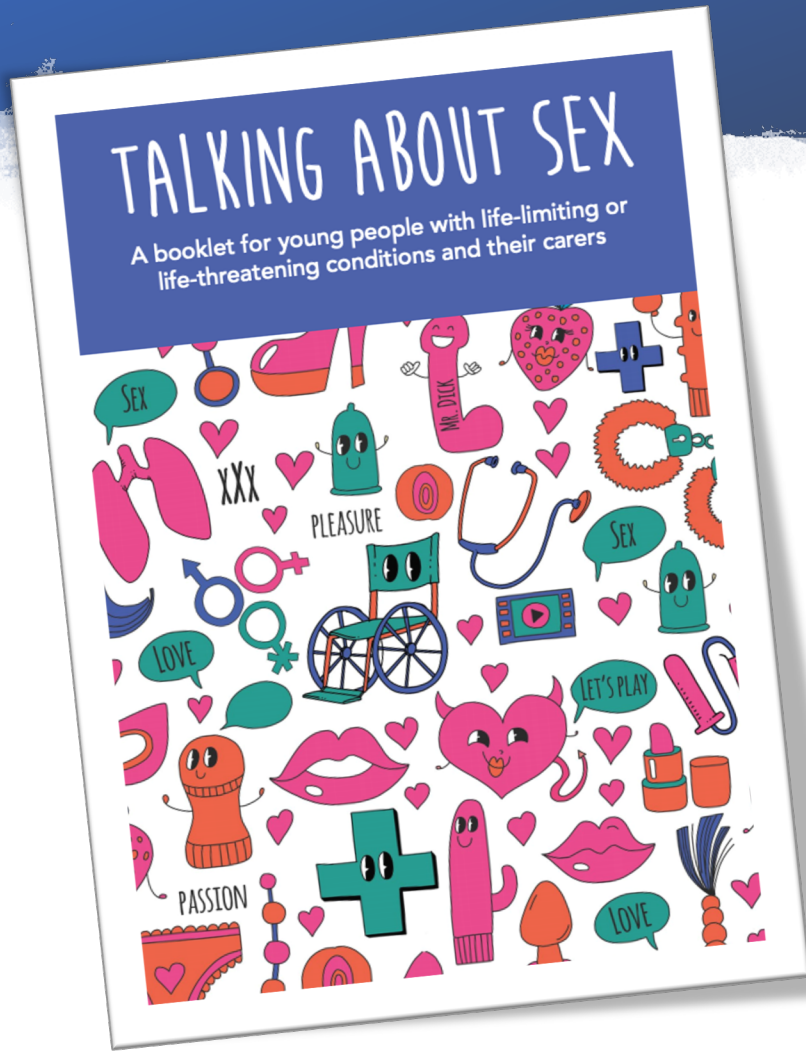
The Open University Sexuality Alliance &
Hospice UK



*Funded by the Improving Transitions
for Young People Fund, Together for
Short Lives and The Open University*



The “Talking about... sex and relationships” Project

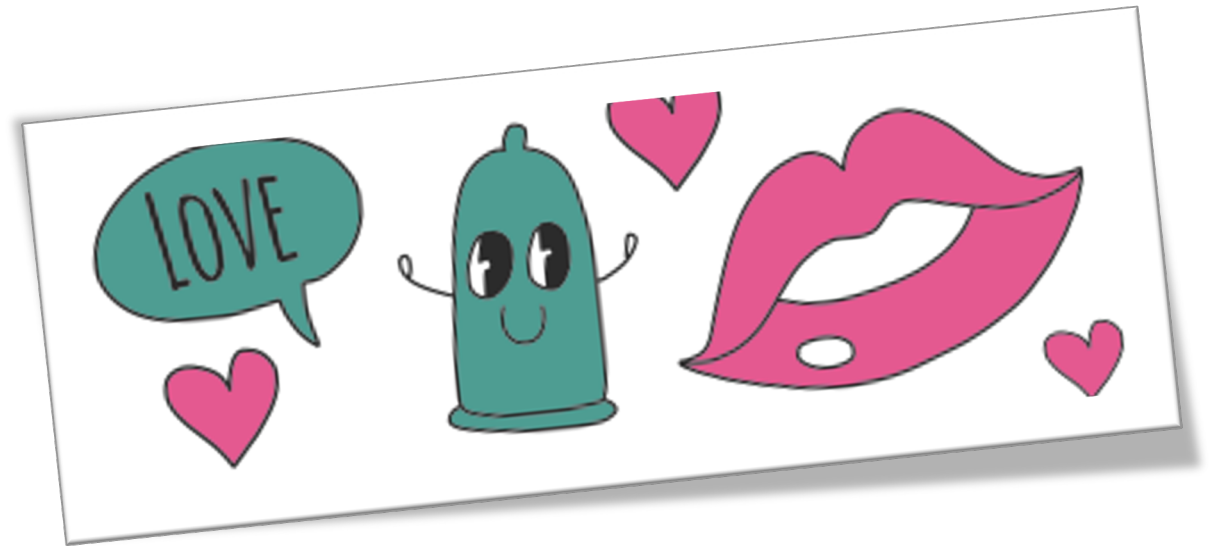


- Young people see intimacy and relationships as a desirable **part of 'normal' transition**
- Significant component of **emotional wellbeing**
- Disabled and LLTC young people not always seen as having a **sexual identity**
- Young people sometimes **have limited experience, confidence and self-belief**
- Young people **seldom** get to talk about sex, intimacy and relationships with anyone
- Young people's needs are **not** being met

**Informed by
research with
young people
with LLTCs,
Including those
with DMD**

How to use the Booklet

- Information for young people
- ‘Top tips’ for starting a conversation
- Information specifically for carers
- Signposting to the law
- Other useful resources



YOUNG PEOPLE'S PERSPECTIVES



Summary of key issues

THINKING ABOUT SEX



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



BELIEVING IN YOURSELF



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

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!! ||

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! ||

Projects three and four

These have recently been completed. They were inclusive, action-research projects, designed to support the transition of young people who are life-limited or life-shortened, by developing their confidence in talking about sex, intimacy and relationships through developing, on-line education resources (OERS) via The Open University's, Open Learn Portal (Together for Short Lives, 2018).

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



Learning from all the projects: Clinical Governance

- Clinical Governance underpins, sustains and improves high standards of care. The CQC and RCN suggest 5 key considerations:
- **Young People** – how support around sexuality is based on individual's needs and engagement by the young person
- **Information focus** – how sexuality information is discussed and presented.
- **Quality Improvement** – how these sexuality standards will be reviewed and attained.
- **Staff focus** – how staff are supported to address issues of sex, intimacy and relationships.
- **Leadership** – how improvements can reduce taboos and improve knowledge and confidence in staff.



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Summary

- Multiple taboos and 'sensitivities' encountered when researching sex with young people with LLCs who may or may not be approaching death.
- We have tried to overcome some of these by encouraging young people to talk about sex and intimacy.
- Included the unexpected, unanticipated and unimagined 'sensitive' encounters on the research journey, such as access and gatekeeping, posthumous consent
- The affective aspects for addressing these
- Certain taboos maybe viewed as 'sensitive' by both participants and researchers and be more prominent on different stages of the research journey



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THANK YOU



Access“ Talking about... Sex and Relationships” project on- line resources. Please complete our on- line surveys at:

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

And for the Booklet:

<http://tiny.cc/BookletEval>

Other useful references:

Earle S and Blackburn M (2020) Young adults with life-limiting or life-threatening conditions: sexuality and relationships support *BMJ Supportive & Palliative Care* Published Online First 02 April 2020. doi:10.1136/bmjspcare-2019-002070.

<http://oro.open.ac.uk/70021/>

Earle S & 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*

DOI: <https://doi.org/10.1080/13645579.2020.1857968>

Q & A

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