



Lucy Watts MBE MUniv FRSA

Sexuality for young people with life-limiting conditions

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 **@LucyAlexandria**

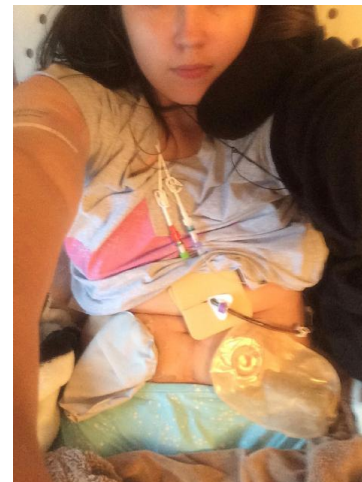
Open University Sexuality Alliance

Open Educational Resources from the
“Talking about....sex and relationships: young people speak out” project

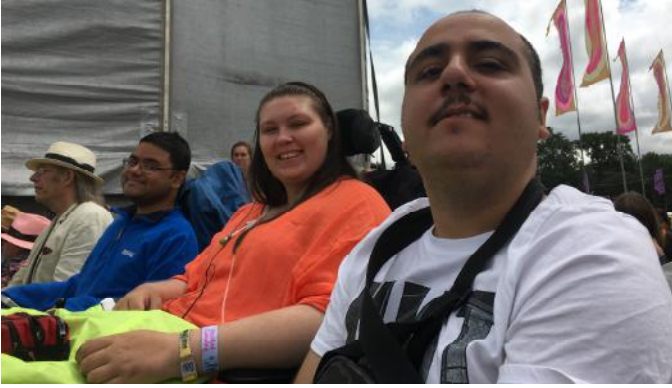
Co-produced, co-designed and co-led by the **AdversiTeam** Young Advisory Group



Funded by Together for Short Lives in the Improving Transitions for Young People Fund



**I want to love and be loved, to be seen as attractive, to feel worthy,
and to share my life with someone who chooses to be with me.**



**However, I rarely have the opportunity to be in social situations
with other young adult men, disabled or non-disabled.**

Talking about sex, sexuality and relationships: Guidance and Standards

For those working with young people with life-limiting
or life-threatening conditions



Staff Contract

Lucy Watts PHB

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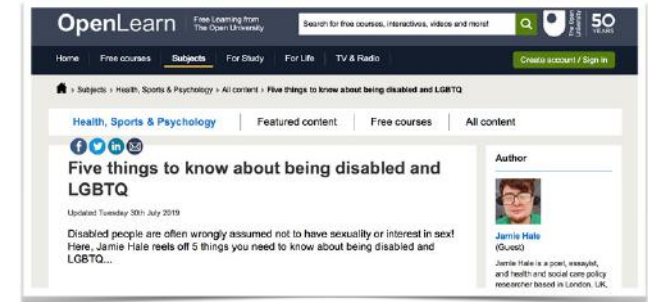
When assisting the employer, the employee should:

- Respect the employer's home. The employee will be expected to leave things as they found them
- Treat items of equipment with care. If uncertain how to use any equipment, please ask. If the employee accidentally breaks or damages any property, it is their responsibility to notify the employer immediately
- Not knowingly or deliberately putting at risk the health and safety of any person. The employee must inform the employer or others of any health and safety or other matter that could put either of them at risk
- Arrive at work in a fit state. The employee must be able to perform the agreed tasks
- Remain awake throughout the duration of the shift. Sleeping on shift is not tolerated and will be subject to warning and if it continues, to disciplinary procedures
- Turn mobile phone off while working, unless during downtime periods, however priority always must remain with the employer and no telephone calls are to be made during certain periods (such as overnight or whilst in a meeting) or whenever requested by the employer
- Not smoke in the place of employment
- Maintain professionalism when outside of the home with the employer
- Understand that the dog is a working Assistance Dog, therefore there is to be no feeding of the dog, no playing with her, no disrupting her or doing anything that will jeopardise her role and duties or her training
- Support Lucy to participate in friendships and personal relationships, including intimacy, within legal boundaries (Royal College of Nursing-endorsed Sexuality Guidance and Standards for professionals available on request).

It is vital to realise that young people like me with life-limiting conditions have wants, needs and desires like any other young person.

We must not be infantilised, we must be treated as emerging and maturing young adults, and whilst we must ensure that we keep young people safe, we must do so without preventing them from exploring sex, sexuality and relationships within their own lives.

Thank you for listening, I'll now hand over to Maddie



“Let's talk about sex, intimacy and relationships...” interactive resource

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

“Nine top tips on talking about sex... for young people with a life-limiting or life-threatening condition” listicle resource

<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>

“Five things to know about being disabled and LGBTQ” listicle resource

<https://www.open.edu/openlearn/health-sports-psychology/young-peoples-health/five-things-know-about-being-disabled-and-lgbtq>



HEALTH & WELLBEING
RESEARCH



The Open
University

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Practical issues in supporting people with life-shortening conditions: Sex and Sexuality

Dr Maddie Blackburn

Visiting Fellow & Chair of The Open University Sexuality Alliance.

Sexuality , relationships and reproductive choices in young adults with LLTCs

- Maddie's PhD thesis focused on the emergence of a third group of young people with LLTCs who are on the threshold of adulthood (not children or older adults)
- Over the last century, palliative care has developed as a unique and explicit specialism for all age groups, creating its own philosophy and often rendering it different from services provided in NHS health-care setting
- The young people (age 16-39 years) in Maddie's thesis emerged as adults at different chronological and physiological stages. This was often compounded by their LLTCs.



Four intersecting areas of sexuality research

- Sexuality
- Disability
- Uncertainty along the life course
- Death, Dying, End of Life





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2019

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)
- Sustainable, dedicated services for young people with LLTCs that address their holistic needs, including sex
- Guidance and governance about relationship choices and sex in hospices for young people in hospices and those who support them.



Recommendations



- Young people and their families should be made aware of the policy, processes and support available, and consulted about ongoing needs or concerns.
- Support should be offered to families who struggle to understand the reason for this work.
- There should be ongoing review of needs – of young people, families and staff to ensure that the policy remains robust and fit for purpose.

- All young people have the right to receive information and support to develop their self-esteem, a positive body image and self-confidence in relation to their sexuality and relationships.
- This can be particularly challenging for young people with life- limiting conditions or complex health conditions and for their parents / carers.
- Professionals should recognise that avoidance of discussing issues around sex and sexuality can cause deep unhappiness and distress.



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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.
- **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.

- Managers and organisations should work towards achieving a culture in which sexuality issues can be openly discussed within the team, and that young people are encouraged and supported to talk about their sexuality and sexual needs.
- Support should be provided to help young people develop skills such as decision making; communication; assertiveness and understanding personal safety to underpin their ability to develop relationships.
- Wherever possible young people should be assisted to understand their sexual feelings and learn about acceptable and appropriate behaviour and respect for others.



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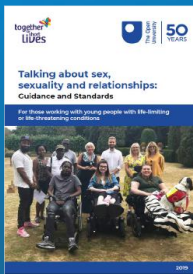
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- Addressing issues about sex and sexuality is both appropriate and legitimate, and there is a professional and clinical responsibility to do so.
- Issues relating to sex and sexuality are most appropriately addressed within a wider context of health and well-being, including sexual health.
- All young people should be able to enjoy and control sexual and reproductive behaviour with freedom from fear, shame, guilt and false beliefs.



- If individual professionals feel uncomfortable in supporting young people with issues around sex and sexuality it would be in no party's best interests to insist that they participate in this aspect of personal care. They can't be forced to.
- Professionals who feel strongly about this should inform colleagues, their manager and the person receiving care that they have a conscientious objection to a particular procedure and arrange for a suitably qualified colleague to take over responsibility for that person's care.





Robust Sexuality Policies



- Identify clear processes and clear reporting lines.
- Fit within legal frameworks.
- Be informed by evidence and research.
- Identify a named person/ individuals to lead on sexuality who can be responsible for supporting staff members.



Thank you for Listening...

Any Questions?

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