LET’S TALK ABOUT SEX: LET’S TALK ABOUT YOU AND ME!

Relationships, sexual health and sexuality guidance for those working with young people with life-threatening conditions and their families

Authors: Corine Koppenol, Katrina McNamara-Goodger, Trudy Ward, Peter Wells
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ACT (Association for Children’s Palliative Care) is the only organisation working across the UK to achieve the best possible quality of life and care for every life-limited child and their family. Registered Charity No: 1075541 Company Registration No: 3734710
Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors. (World Health Organisation 2002.)

Everyone has 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 and the right to experience and explore their sexuality, however ACT recognises that for young people with life-limiting conditions or complex health conditions this can present a wide range of obstacles, both for the young person, their parents/carers and families and some will need additional help and support in exploring this. This guidance has been devised with the understanding that most young people will have an interest in relationships, sex and sexual relationships.

It aims to:

- Provide the family and carers of young people with life-limiting/life threatening conditions, and organisations involved in their care with useful information and other resources.

- Assist parents and those working with young people to be able to support young people as they develop relationships and their own sexual identity.

- Act as a signpost for young people to useful resources.

We know that there are a number of useful sources of information and resources for young people; these are described at the end of this document. Friendships and relationships with other people are important. Friendships can be some of the most important things about growing up; growing up is not just about having sexual partners. Everyone can sometimes find that feeling good about yourself can be difficult, but friends can help you understand what they value about you and how special and unique you are.

Experience tells us that the time when young people start to develop relationships and their own sexuality can be a difficult time for parents - their child may be approaching puberty but this may appear to parents that this is an empty or ‘purposeless’ state. Sometimes the total lack of a ‘sexual being’ is very distressing for parents, it may bring to the fore, fears that their child will not grow up having a physical relationship; never have a partner; they will not be a grandparent. Parents may find themselves re-visiting their loss at this stage in their child’s life as the physical manifestations of adulthood accent all that a young person may miss out on.
This guidance is based on the core principle that the welfare of the child or young person is paramount, and emphasises the need to work together to reduce a young person's vulnerability to harm/abuse, while balancing the young person's right to sexual expression and their right to protection. It aims to explore what parents, professionals and organisations need to know and what resources are available to support them as they in turn support the young person as they develop their sexual, adult identity. ACT believes that:

- All young people with life limiting/life threatening conditions 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.
- Support should be provided to help them develop skills such as decision-making; communication; assertiveness and understanding personal safety to underpin their ability to develop relationships.
- They should be assisted to understand their sexual feelings and learn about acceptable and appropriate behaviour and respect for others.
- Information, advice and support should be given to parents and carers to enable them to deal with their child's emerging sexuality.

We urge parents, carers and organisations parties to work towards this Sentinel Standard and this guidance aims to offer issues to consider, suggests key actions and details some resources to support this activity.

**Goals**

1. All young people have the right to privacy and confidentiality.
2. All young people, regardless of gender, or sexual orientation who are believed to be engaged in, or planning to be engaged in, sexual activity should have their needs for health education, support and/or protection assessed by agencies involved.
3. All young people should be able to enjoy and control sexual and reproductive behaviour with freedom from fear, shame, guilt and false beliefs.
4. Young people should be supported to minimise their vulnerability to risk.
5. Parents and carers should be provided with resources and information to enable them to be equipped to support the young person.
6. Young people should be provided with resources and information to enable them to be able to explore and develop their own sexuality.
7. Organisations should have a policy to enable young people to develop their own sexuality and for the young people and their parents/carers to be provided with resources and information they need.

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8. Professionals should have access to training and support to enable them
to be able to support young people and their parents/carers in matters of
sexuality.

Parents:

What does the Standard mean for you?

Parents are key people in teaching their children about sex and relationships, helping
them cope with the emotional and physical aspects of growing up and preparing
them for the challenges and responsibilities that sexual maturity brings. Parents of all young people face a range of issues around sex and relationships. Adolescence is
recognised as a period of turmoil and stress: the secure world of childhood existence is left behind as a new search for adult identity begins. Some, but not all, young people often challenge authority or the rules as a means to establish their individuality. It can be difficult to accept that your child is a young adult, with his or her own values and opinions.

Many young people who have learning difficulties and/or communication difficulties may present challenges for parents to cope with a child’s or young person’s inappropriate behaviour around siblings/visitors; lack of inhibition and an emerging but socially inappropriate interest in the opposite/same sex. There is often a presumption by carers of young people with very complex needs, that there is an asexuality about the person and an assumption that sexuality is not important.

Staff and families need to be helped to understand that a person with a learning disability might become sexually aroused during intimate and personal care and to respond to sexual arousal in appropriate ways. Carnaby (2006)

What do you need to know?

- Be prepared: talk to others to build up your confidence to help you deal with your child’s emergent sexuality. Find information and resources to help you find out what you need to know to support your child as they develop for example there are many different types of contraception available, you may want to discuss these options with your GP or your child’s consultant so that you are aware of the options if your child asks you for advice. There is a list of resources in Appendix 1.

- Be prepared to deal with intimate care: sometimes you can’t ignore it, and carers need to be prepared for e.g. involuntary erections and ejaculations. Your care team should be able to help you prepare to deal with this, and to provide advice on how reassure the young person.

- Intimate care of young people: young people often want privacy; sometimes this can be difficult if you are the main carer for your child. Involving your child in their care and maintaining their personal dignity can help the young person develop a sense of ownership of their own body. Your key worker should be able to provide advice on how to deal with this.

Contact a Family suggests some ways of providing intimate care:

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- Knock before entering a bedroom or bathroom.
- Ask permission on each occasion before providing intimate care – e.g. Is it OK if I help you take off your pyjamas now?
- Discuss personal care plans and any changes to these with the child or young person as far as possible.
- Reassess whether intimate personal care is still necessary and whether it could or should be provided in a different way. Are there aids and equipment that could enable the young person to manage alone?
- Reassess how many different people need to be involved in a young person’s personal care and keeping this to a minimum.
- Clear communication and explanation of why a procedure is necessary.
- Use consistent language for genitals and for bodily functions. Ensure any new care workers are informed of the appropriate language used.

(Contact a Family. *Sex and Relationships information for young people, parents and professionals.* (2005).

**Protecting your child:**
By providing your child with information and education this will help to empower them and reduce their vulnerability. Young people need to understand “appropriate touch” and have access to sex education to help develop the life skills and confidence to protect themselves.

**Do parents have a ‘right’ to know?**
Decisions to share information with parents and carers will be taken using professional judgement, consideration of legal guidelines. Decisions will be based on the young person’s age, maturity and ability to appreciate what is involved in terms of the implications and risks to themselves.

**Culture and religious beliefs:**
Beliefs are hugely important to many people and there may be occasions when parents and young people share different interpretations or understanding. In order for discussion to take place it may be important to recognise the differences and to respect such differences in order for dialogue to take place. If the differences seem too great it may be important to find someone who can help with a conversation; such a person may be a professional health care worker already involved in providing care or someone that they might recommend.
Professionals

What does the Standard mean for you?

• At all times staff are required to work within the boundaries of their Professional Codes of Conduct.

• Confidentiality:
The duty of confidentiality owed to a person under 16, in any setting, is the same as that owed to any other person. This is enshrined in professional codes. It is considered good practice for workers to follow the Fraser guidelines when discussing personal or sexual matters with a young person under 16. The duty of confidentiality is not, however, absolute, where a professional believes that there is a risk to the health, safety or welfare of a young person or others which is so serious as to outweigh the young person’s right to privacy, they should follow locally agreed child protection protocols, as outlined in Working Together to Safeguard Children. In these circumstances, the over-riding objective must be to safeguard the young person.

• Communication:
Professionals should establish rapport and give a young person support and time to make an informed choice by discussing:

  o The emotional and physical implications of sexual activity, including the risks of pregnancy and sexually transmitted infections.

  o Whether the relationship is mutually agreed and whether there may be coercion or abuse.

  o The benefits of informing their GP and the case for discussion with a parent or carer. Any refusal should be respected. In the case of abortion, where the young woman is competent to consent but cannot be persuaded to involve a parent, every effort should be made to help them find another adult to provide support, for example another family member or specialist youth worker.

  o Any additional counselling or support needs.

1 Fraser Guidelines: It is considered good practice for doctors and other health professionals to follow the Fraser guidelines; these give guidance on providing advice and treatment to young people under 16 years of age. These hold that sexual health services can be offered without parental consent providing that:

  o the young person understands the health professional’s advice;

  o the health professional cannot persuade the young person to inform his or her parents or allow the doctor to inform the parents that he or she is seeking contraceptive advice;

  o the young person is very likely to begin or continue having intercourse with or without contraceptive treatment;

  o unless he or she receives contraceptive advice or treatment, the young person’s physical or mental health or both are likely to suffer;

  o the young person’s best interests require the health professional to give contraceptive advice, treatment or both without parental consent.

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• **Duty of Care:**
Health professionals have a duty of care, regardless of patient age. A health professional is able to provide contraception, sexual and reproductive health advice and treatment, without parental knowledge or consent, to a young person aged under 16, provided that:

- She/he understands the advice provided and its implications.
- Her/his physical or mental health would otherwise be likely to suffer and so provision of advice or treatment is in their best interest.

However, even if a decision is taken not to provide treatment, the duty of confidentiality applies, unless there are exceptional circumstances.

- Safeguarding young people.

- Legal issues: there are a number of guides available to explore the legal issues e.g. the Children's Legal Centre produce a range of legal guides that are regularly updated. E.g. Mental Capacity Act and the Children Act.

**What do you need to know?**

**Training** should be offered to enable staff to manage any conversations relating to sexuality in a sensitive and responsible way. No member of staff should be expected to engage in prolonged discussion about matters that they find personally difficult, but staff should be expected to respond initially in a professional, non-judgemental manner and, with the young person's permission, refer them to another member of staff who feels more able to address the issue. You may find it helpful to arrange joint training or placements with others such as Family Planning Staff or School Nurses.

**Confidentiality:** protecting and providing information. Professional bodies have addressed this issue in detail and a training resource ‘Confidentiality and young people: improving teenager’s uptake of sexual and other health advice’ is a useful resource. The duty of confidentiality is not, however, absolute. Where a health professional believes that there is a risk to the health, safety or welfare of a young person or others which is so serious as to outweigh the young person’s right to privacy, they should follow locally agreed child protection protocols, as outlined in *Working Together to Safeguard Children.* In these circumstances, the over-riding objective must be to safeguard the young person.

**Be Aware:** Your own cultural beliefs/attitudes and upbringing will influence your ability to deal with this area of care. Supervision and education and training, such as specific training on Sexual Health, can help prepare you for this. Ensure that this is covered by the care plan.

**Be Prepared:** Parents often relate that no one discusses their child’s sexuality with them. The care plan should ensure that parent's are prepared to deal with their child's emergent sexuality and how to deal with practical aspects of care e.g. dealing with periods/erections- involuntary or otherwise.

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Organisations

What does the Standard mean for your organisation?

Organisations should respond sensitively and appropriately to the holistic needs of all young people, including their sexuality. This is recognised as being a challenging area. Organisations should recognise the rights and needs of young people and to ensure that they experience a non-judgemental, non-prejudicial approach from members of staff, and a willingness to engage in discussions relating to relationships and any aspect of their sexuality that they wish to discuss. Organisations need to recognise the challenge this may present to the staff and offer training and support to enable them to appropriately deliver this aspect of care e.g. matching genders; cultural/spiritual beliefs and sexuality.

Be aware that sexuality and sexual activity can be a very important part of a young person's life and that it is appropriate to be explicit in having a policy rather than not have a policy which can lead to uncertainty for everyone. Such a policy should be discussed by the Executive Team and others e.g. Directors/Trustees and involve staff and users in establishing and reviewing a policy. The Directors/Trustees need to be clear about what is and what is not acceptable in terms of expression, and practice for everyone. It will be important to realise that the 'daily' staff will be responsible for carrying out the policy whilst the Directors/Trustees will be responsible for upholding the policy to the public.

Given the emotive and sensitive nature of discussing sexuality and sexual activity it may be best to arrange for an outside consultant/agency to assist the process of discussion. Often sexual policies are written to prepare staff in the eventuality of the young person wanting to discuss ‘having’ sex rather than the organisation being proactive in discussing a young person’s needs for expression in a variety of ways, one of which might be to ‘have’ sex.

What do you need to do?

Develop a Statement of Care:

This is a statement of practice in terms of how the organisation sees its care in relation to looking after the needs of those in their care. You may wish to consider:

- Why organisations will find such topics difficult to discuss.
- How organisations might go about the discussions.
- How organisations can review and audit their policy.
- When will the organisation discuss/make clear to young people and their relatives and friends that sexuality and sexual practice can be discussed and with whom and when?
- Will the discussion be held at assessment of both the young person and relatives?

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Will staff ensure that the subject is something that although not discussed at assessment will be proactively reviewed on a regular basis?

How will staff discuss constructively discuss a young person's needs if the staff member feels negative towards a young person and their needs?

How to provide appropriate supervision and training for staff.

Whether the appointment of a designated member of staff will assist with these processes - by ensuring staff/young people's advice is available, supporting policy development and advocacy.

Whether there is potential to share expertise with other professionals, for example professionals caring for young people with life-limiting conditions sharing expertise with professionals from School Health/Family Planning.

**Define sexuality, sexual practice and relationships:**
A definition of terms is essential in being able to give everyone – patients, relatives, friends and staff – clear boundaries within which to work which can reduce ambiguity and assumption as to what is meant by sexuality and sexual practice. The usual assumption is that discussions of sexuality and sexual practice automatically refer to ‘gender’ and penetrative sex. In reality sexuality includes the way someone expresses their gender in a variety of ways and sexual practice equally includes a wide spectrum of practice.

**Develop a sexual health policy:** It is essential to include:

- A clear statement as to what the organisation understands by sexuality and sexual health and to express this in a positive way as part of the young person's persona and its relevance to health care.

- How and when does the organisation discuss sexuality and sexual practice with the young person and relatives and as a staff group?

- What will the organisation do in terms of offering support to young people and relatives and which members of staff are available to discuss a young person's needs.

- How will the organisation assist some staff who do not feel it is appropriate for them to discuss a young person's sexuality or sexual needs if the member of staff thinks that some beliefs and practices are fundamentally against their own beliefs.

- Be clear about what is acceptable for the organisation e.g. is a gay young person allowed to have a gay disco, or a young woman allowed to have her male friends to stay?

- What will the organisation do if a young person wishes to engage in sexual activity with a partner/sex worker/friend? How far will the organisation go in terms of facilitating the activity on the premises/in the young person's home?
- How staff can support young people to access specialist services/clinics.
- The role of the key worker in supporting the young person to access information and services if they are not able to attend outside clinics.
- Be prepared to have resources available if necessary: literature, website address, external consultation.

**Schools:**
Ensure sex and relationships education (SRE) is accessible to all young people. School governors have a statutory responsibility for SRE in their school. There are resources; guidance and training activities to help governors fulfil this role. School governors should ensure that parents, pupils and staff work together to develop a policy which meets students needs, reflects the school's individual ethos and takes on board local sexual health concerns. A lot of young people with special needs may miss out on SRE due to their condition or their level of understanding.

**Confidentiality:**
The duty of confidentiality owed to a person under 16, in any setting, is the same as that owed to any other person. This is enshrined in professional codes. All services providing advice and treatment on contraception, sexual and reproductive health should produce an explicit confidentiality policy which reflects this guidance and makes clear that young people under 16 have the same right to confidentiality as adults.

Employers have a duty to ensure that all staff maintain confidentiality, including the patient's registration and attendance at a service. They should also organise effective training which will help fulfil information governance requirements. Any disclosure should be justifiable according to the particular facts of the case and legal advice should be sought in cases of doubt. Except in the most exceptional of circumstances, disclosure should only take place after consulting the young person and offering to support a voluntary disclosure.

All services providing contraceptive advice and treatment to young people should:

- Produce an explicit confidentiality policy making clear that under 16s have the same right to confidentiality as adults.
- Prominently advertise services as confidential for young people under 16, within the service and in community settings where young people meet.
- Health professionals who do not offer contraceptive services to under 16s should ensure that arrangements are in place for them to be seen urgently elsewhere.
- Directors of Social Services should ensure that social care professionals working with young people are aware of the Teenage Pregnancy Unit guidance – "Enabling young people to access contraception and sexual health information and advice: the legal and
Ensure that training and supervision is available for staff.
Appendix 1: Resources and useful organisations

For young people

- Brook Advisory Centres are the only national voluntary sector provider of free and confidential sexual health advice and services specifically for young people under the age of 25. They run a unique network of 17 centres across the UK, delivering innovative services, designed with the help of young people. The centres provide contraception, advice and counselling to young people about sexual health, as well as outreach, education and satellite services in response to local need. Helpline (recorded information): 0800 0185 023. www.brook.org.uk

- Contact a Family. Sex and Relationships information for young people, parents and professionals. Spring 2005. www.cafamily.org.uk

- Need2know: advice on useful info, relationships, sexual health www.need2know.co.uk

- Like it is. Information for 11–15 year olds on sexual health information and related subjects. Marie Stopes Information Line: 0845 300 80 90. www.likeitis.org


- Outsiders Club: A self help group for isolated disabled people, to offer the change to contact others in the same situation, gain more confidence, make friends and perhaps find a partner: www.outsiders.org.uk Email: info@outsiders.org.uk


Sexuality


- Paul Cambridge: The Sexuality and Sexual Rights of People with Learning Disabilities

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Sex and relationships education

- Teenage Pregnancy Unit - [www.teenagepregnancyunit.gov.uk](http://www.teenagepregnancyunit.gov.uk)
- Brook - [www.brook.org.uk](http://www.brook.org.uk)
- Sex Education Forum. Produces a range of resources to support Sex and Relationships Education. E-mail: sexedforum@ncb.org.uk. [www.ncb.org.uk/sef](http://www.ncb.org.uk/sef). T: 0207 843 6000  F: 020 7843 6053
- Family Planning Association: [www.fpa.org.uk](http://www.fpa.org.uk)
- The Shepherd School produces a range of leaflets for carers and young people with learning difficulties. [www.shepherdschool.org.uk](http://www.shepherdschool.org.uk)
- *Picture Yourself*—192 picture cards with teaching notes. A flexible teaching resource designed for young people and adults with learning difficulties who are participating in programmes about life skills, personal relationships, etc. Supplied by: Hilary Dixon & Ann Craft, Me-and-us Publications, Sedbergh, LA10 5JN, UK. Download and buy from the website: [www.me-and-us.co.uk](http://www.me-and-us.co.uk)
- Contact a Family. *Sex and Relationships information for young people, parents and professionals*. Spring 2005. [www.cafamily.org.uk](http://www.cafamily.org.uk)

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Need2know: advice on useful info, relationships, and sexual health
www.need2know.co.uk


- Local Health Promotion services often have useful resources that you can borrow.


Professional issues

- Department of Health, Best Practice Guidance for Doctors and other Health Professionals on the provision of Advice and Treatment to Young People Under 16 On Contraception, Sexual, and Reproductive Health.


- Best practice guidance for doctors and health professionals on the provision of advice and treatment to young people under 16 on contraception, sexual and reproductive health. (Department of Health July 2004).


- Royal College of Nursing. 2000. Sexuality and sexual health in nursing practice. An RCN discussion and guidance document for nurses who want to develop their nursing practice in the field of sexuality and sexual health. Publication Code 000965. Published by the Royal College of Nursing.

Safeguarding Children and legal issues

- What to do if you are worried a child is being abused: Children’s Services Guidance. (Department of Health, Home Office, Office of the Deputy Prime Minister, Lord Chancellor, Department of Education and Skills).
• **Handling Allegations of sexual offences against children.**  

• Guidance on offences against children.  (Home Office Circular 16/2005)

• Disability Discrimination Act, 1995. published by HMSO.  

• Children's Legal Centre http://www.childrenslegalcentre.com

• McCarthy and Cambridge: *Your Rights about Sex, a booklet for people with learning disabilities*

• Fernstone and Andrews: *Learning disabilities, sex and the law: a practical guide*

**Other organisations**

• Like it is. Information for 11–15 year olds on sexual health information and related subjects. Marie Stopes Information Line: 0845 300 80 90.  
  [www.likeitis.org](www.likeitis.org)


• FPA (formerly the Family Planning Association). Provides specific information booklets, information on contraception and sexual health and your nearest clinic. Helpline: 0845 122 8690  [www.fpa.org.uk](www.fpa.org.uk)

• Disabled Parents Network. Offers information to disabled parents and those planning to become parents. Helpline: 0870 2410 450.  
  [www.disabledparentsnetwork.org.uk](www.disabledparentsnetwork.org.uk)

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  [www.brook.org.uk](www.brook.org.uk)

• Respond. Organisation working with people with learning disabilities on issues around sex education, vulnerability and abuse. Resources list available from website.  
  [www.respond.org.uk](www.respond.org.uk)

• Ann Craft Trust. Provides resources and training for staff on sex, relationships, abuse and related issues. Tel: 0115 951 5400.  
  [www.anncrafttrust.org](www.anncrafttrust.org)