Sex and young disabled people with progressive conditions

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This paper was created specially for the Sexual Respect Tool Kit in 2013
based on Darja's work done in 2011,
since which time she has sadly, retired due to the onset of MS

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Introduction

In this paper, Darja presents a picture of what young disabled people with short life expectancy feel about their bodies, sexual selves and desires.

She then makes suggestions and gives all the references possible to give you guidance to help you understand, and help you move forward to do what you can to enable those needs to be met.

The material discussed covers some things that may be already familiar to you, as well as more thought-provoking, challenging and controversial matters.

The area of sexuality, almost unlike any other area in health care, deals with a field which is highly sensitive and personal in nature, strongly influenced by social, cultural, moral, ethical and religious factors, and prone to eliciting strong emotional reactions in health professionals as well as in the lay person.

You, the reader, are urged to tread carefully, to remain curious about your own reactions to the material presented, and to keep as open a mind as possible, thereby allowing yourself to meet disabled clients from within their frame of reference and experience.

More specific issues arising in the care of children and young people living with learning disabilities, brain injury, or mental health problems are not specifically discussed.

The difficult topic of sexual abuse, and child protection and the protection of vulnerable adults in this context, are also not included.

World Health Organization (WHO) definition of Sexuality

— from Defining Sexual Health (2006)

"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 influence 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 and religious and spiritual factors."

World Association for Sexology (WAS) — Declaration of Sexual Rights (1999)

Sexual Rights are universal human rights based upon the inherent freedom, dignity, and equality of all human beings. Since health is a fundamental human right, so must sexual health be a basic human right:

1) The right to sexual freedom. Sexual freedom encompasses the possibility for individuals to express their full sexual potential.
2) The right to sexual autonomy, sexual integrity, and safety of the sexual body.
3) The right to sexual privacy**.**
4) ***The Right to Sexual Equity***: *This refers to freedom from all forms of discrimination regardless of sex, gender, sexual orientation, age, race, social class, religion, and physical or emotional disability.*
5) ***The right to Sexual Pleasure.*** *Sexual pleasure, including autoeroticism, is a source of physical, psychological, intellectual and spiritual well-being.*
6) The right to emotional sexual expression.
7) The right to sexually associate freely.
8) The right to make free and responsible reproductive choices.
9) The right to sexual information based upon scientific inquiry.
10) ***The Right to Comprehensive Sexuality Education***. *This is a lifelong process from birth throughout the life cycle and should involve all social institutions*
11) ***The Right to Sexual Health Care.*** *Sexual Health Care should be available for prevention and treatment of all sexual concerns, problems and disorders.*

Sexuality, therefore, is a key component of human nature from birth. Individuals, in an age-appropriate manner, have the right to comprehensive sexual education, sexual health care, and indeed the right to sexual pleasure. These rights may be all the more important to safeguard and consider when dealing with a young person for whom interpersonal and sexual development may be at the forefront and who may have little time left.

Development of Body Image, Sexuality and Sexual Identity in Children, Adolescents and Young Adults

“Human beings are sexual from the time of their birth until the time of their death, and being sexual is a primary part of being human.” (Shell, 1997)

“All people can love and all people can make human contact with other people.” (Hingsburger, 1990)

Infancy

Children are sexual even before birth. Males can have erections while still in the womb. Babies build their sexuality by mouthing, sucking, touching and being touched, deriving enormous satisfaction from their bodies and from interactions with others. The tenderness and love babies receive during this phase contributes to their ability to trust and to eventually

receive and show tenderness and affection. First relationships have a huge impact on emerging sexuality and are a determinant for future sexual life.

In terms of self awareess and identity development, infants begin the process of discovering themselves as separate and unique individuals.

Toddlerhood

This is the time in development of new motor and language skills. This includes

- learning names of body parts
- early expectations about what boys/girls do
- increased self awareness and concepts of the self focused on concrete physical characteristics and competencies

Children are curious about their body and touching of own genitals for pleasure or self-soothing is common. Both little boys and girls can experience orgasm from masturbation, although boys will not ejaculate until puberty. The child may begin to learn about what are appropriate or inappropriate environments or situations for self stimulation. Depending on caregiver reactions, they may also experience their body as “bad” or “shameful”. The child also begins to form early ideas about affection and relationships from early observations. Children absorb early lessons about human interaction. These ideas may last a lifetime and be reflected in later behaviours and expectations.

Relatively little is known about the body image of toddlers but, by 2 years, a child recognizes their mirror image as a reflection of themselves.

Preschool/Early School Years

Children are often fascinated to discover that the bodies of opposite-gender parent or siblings are different. They will develop an interest in “how babies are made” and will be interested in sexual content in the media and from peers and other adults. Early sex education is appropriate at this stage, including preparing girls for menstruation.

Children are highly affectionate and enjoy hugging other children and adults. Their ideas about gender and gender roles are being consolidated at this time and their gender identity is developed. They may imitate adult social and sexual behaviours, such as holding hands and kissing. Most children talk about marrying or living with a person they love when they are older and may role-play being married.

Either rejecting or showing an interest in the opposite gender is normal during the early school years. Friendships, playmates, games and activities are important during this period. Sexuality is often expressed by interest in sexual jokes, stories and songs. Sexual play with siblings and peers (“playing doctor”) at this time is mostly motivated by curiosity.

Self concepts begin to include less concrete ideas about feelings and about how they fit into the social world. During early childhood, overall body esteem is closely correlated with global self esteem. However, childeren as young as 3 display negative attitudes towards being overweight and young children who are overweight soon begin to internalize these messages. By age 4, children associate more positive personality traits with pictures of people who are attractive, of normal weight and without a visible disability/differences. Children perceive their own body image with a similar degree of accuracy to adults.

Social comparison and teasing are key factors in primary school. Teasing and peer comments act as the beginning of objectification of the body, beginning comparisons with cultural ideal and peers' bodies, leading to body dissatisfaction and poor self esteem. By the age of 6, girls have internalized a body image ideal which is significantly thinner than that aspired to by 5 year olds. 40% of primary school girls and 25% of primary school boys are dissatisfied with their weight and shape. One quarter of children between the ages of 7 and 10 have dieted to lose weight.

In terms of sexual development, interest in self exploration continues, or may wane somewhat. Children may start to ask direct questions about sexual matters. They are often fascinated to discover that the bodies of opposite-gender parent or siblings are different and will often stare, touch, comment and/or ask questions. Children are highly affectionate and enjoy hugging other children and adults.

Socially, the child will begin move from side-by-side play to playing with peers. They begin to test themselves in the social environment and learn necessary lessons about acceptable behaviour. Ideas about gender and gender roles are consolidated. They may imitate adult social and sexual behaviours, such as holding hands and kissing.

Reactions of rejecting the opposite gender or showing an interest in the opposite gender are both normal during early school years as both boys and girls learn about themselves as boys/girls. Friendships, playmates, games and activities are important during this period as a sense of self in society is developed. Gender identity is developed. Sexuality is often expressed by interest in sexual jokes, stories and songs. Sexual play with siblings and peers ("playing doctor"), mostly motivated by curiosity, and not an indication of attraction/pleasure, is therefore also not an indication of sexual orientation. Most children talk about marrying or living with a person they love when they are older. May role-play being married.

They exhibit interest in sexual content in the media and develop interest in "how babies are made". They are likely to hear accounts of human reproduction from peers and be aware of sexual content in media – and it's common for children in this age group to hold many misconceptions.

Young children of this age develop awareness of issues around sexual orientation, knowing that not all people are heterosexual. Their interest is mostly focused on relational aspects of gay or lesbian relationships although sexuality component may also become object of curiosity. Early sex education is appropriate at this stage, including preparing girls for menstruation.

Pre-Adolescence (approx. 8-12 years)

There is often a rapid transition from childhood to adolescence, which is the beginning of puberty for most children. Children become more self-conscious about their bodies and often feel more uncomfortable undressing in front of others, even a same sex parent.

A heightened preoccupation with physical appearance, can lead to feelings of inadequacy. Body image is closely related to pubertal status – especially in boys. Following puberty, boys may experience a plateau or even an improvement in body esteem, with younger boys often wishing to be bigger.

Towards the end of primary school, girls display similar levels of body dissatisfaction to that displayed by adolescent and adult women (50%+). Masturbation increases during these years and becomes more focused on pleasure and orgasm. Usually there is not much partnered sexual experience, but many questions. The idea of actually having sexual intercourse is unpleasant to most pre adolescent boys and girls. Same-gender sexual behaviour, including looking at and touching each others genitals and masturbating together is common, exploratory, and often unrelated to sexual orientation.

There may be increased interaction with opposite sex. The “crush” of younger children evolves into more adult-like attractions that may include feelings of sexual attraction. More pronouced steps into adult gender roles. Group dating and parties with dancing and kissing games common towards the end of this period, some may begin dating and “making out”. Kissing and hugging is common, breast and genital touching less frequent but not uncommon.
Although basis of sexual orientation likely to have been formed before puberty, lesbian, gay and bisexual youth are likely to become more concretely aware of sexual orientation as they begin to experience more direct sexual attraction and fantasy. The process of sexual identity formation is complex and often drawn out. Unlike members of other minority groups, most LGB individuals are not raised in a community of similar others from whom they learn about their identity and who reinforce and support this identity. In fact, their communities are likely to be either unaware or openly hostile. Most young people therefore enter the process of sexual identity formation on a presumtion of heterosexuality, with heterosexual young people spending little or no time considering their sexual identity. Gay, lesbian or bisexual teenagers are likely to experience a period of confusion and exploration starting with awakening awareness of same gender attraction (sexual orientation). Painful issues surrounding the potential consequences of LGB identification can lead some adolescents to avoid these issues altogether through identity foreclosure (heterosexual identity is taken on without consideration of alternatives, and despite same sex attraction and occasionally same sex behaviour) or through identity diffusion (where the person neither explores nor makes any commitment to any sexual identity).

Adolescence

At puberty the identity as boy or girl, formed in childhood, begins to develop towads male or female identity. During this development, the adolescent gradually integrates his or her physically mature sexual body into the central representation of him- or herself. Sexual development is not a separate phenomenon but is part of the psychological, social and somatic development. Early adolescence is a period of accelerated physical growth and pubertal development, and in middle and late adolescence, acceleration of cognitive and psychosocial development predominates. The physical, social and cognitive changes and emergence of abstract thinking allows adolescents to think about the future and experiment with different identities. Self descriptions begins to include personality traits and attitudes.

Early adolescence (10 – 14 years)

Many young adolescents do not have accurate information about sexual development and the consequences of early and unprotected sexual activity. Thinking is still concrete, with an appreciation of the immediate consequences of behaviour but little sense of later consequences. Rejection of parental guidelines may begin with the transition from obedient to rebellious behaviour. There is still an underlying need to please adults with an ambivalence between the wish for dependence and independence. There is a focus on making friends and having a same-sex "best friend" There are likely to be, "am I normal?" concerns, and giggling boy-girl fantasies.

Early adolescence is characterized by feelings of confusion about rapid physical changes, self-exploration and a need for comparison with peers of same gender due to concerns about normality. They may acquire social skills by interacting with individuals of their own gender. Adolescents' own interests come first, and concerns for others are secondary.

Body image is a very important part of psychological and interpersonal development and teenagers and especially girls become interested in their body and appearance and that of others. Being aware of body image and wanting to fit in is a normal concern for young people as they work out where they belong, driven by strong need for conformity and acceptance. Body image refers to shape and weight but also to skin apperance, hair colour and style, other physical attributes, disability, visible difference, and clothing.

Males may have more body image issues in early adolescence. While boys and men are also discontent with their body shape and weight, at least half of discontented males wish to gain weight, mostly by developing bigger arms, chests and shoulders, whereas females tend to focus on wanting to lose weight often in specific areas of their body. Boys' maturing bodies actually move them closer to the broad shouldered, tall and muscular ideal. Boys who go through puberty early have several advantages in terms of athletic skills, chance of leadership roles, and popularity amongst peers and adults. The timing of puberty has less of an obvious effect on girls, although the very early or very late developers may suffer from feeling different.

Unlike boys, the changes in a girl's physical body throughout puberty, which include an up to 50 pound weight gain, including 20-30 pounds of fat which is deposited in hips, buttocks, thighs and waist, moves girls further away from the current cultural ideal, culminating in increasing rates of body dissatisfaction. Compared to boys, girls have been found to evaluate more different individual parts of their body and to hold more negative feelings about each.

Middle Adolescence (15-17).

At this stage, most youngsters develop early abstract thinking, and the ability to connect separate events and understand later consequences. They tend to be self-absorbed & introspective, daydreaming and enoy rich fantasies. They may insist on independence and privacy. Overt rebellion or sulky withdrawal is common. They may need to please significant peers.

Sexual experimentation and risk-taking begins for many, and they may have unrealistic concepts of a partner's role. There may be confusion about self-image, and they may seek group identity. They may acquire diverse sexual and relationship experiences, often short and intensive. Relationships may be mainly narcissistic and generated from self-interest. Early interest in opposite gender moves onto group dating, individual dating and eventually sexual

intimacy. There may be sexual peer group pressure. Health information targeting sexual experimentation, its risks and prevention of unwanted results very is very important.

The gay, lesbian or bisexual adolescent may deepen sexual questioning and experimentation and experience increasing amounts of conflict between emerging feelings, peer group norms and internalized homophobia. They may begin to discuss same sex sexuality with another person or seek out social LGB events. In some cases, bisexual identitiy is tried on as a transitory identity which later gives way to a gay or lesbian identity.

Late Adolescence (18-25)

At this stage most develop the ability for adult abstract thinking and become philosophic. They may hold onto intense idealism about love, religion, social problems, and partner selection, but then develop a more realistic concept of partner roles. There's a possibility of re-establishment of family ties, characterized by building relationships that are more adult-like.

The ability to integrate emotional and physical intimacy in a love relationship emerges. Discussions around sexual maturity and sexual feelings would be helpful. True intimacy can only be possible after their own identity has been established.

The lesbian, gay or bisexual adolescent may have more time to take part in LBG social events, to show sexual behaviour, and to reflect, exchange views and develop new attitudes towards LGB themes. LGB identity may now be formed or further developed and the individual may choose who to share information about this aspect of identity with ("Coming Out"). The acceptance, commitment to, and integration of an LGB identity extends through adolescence and beyond. Despite an overwhelming drive towards seeking congruence between feelings, behaviour and attitudes in other aspects of life experience, many adults continue to show significant incongruence between the different aspects of sexuality (sexual identity, sexual orientation (attraction & fantasies) and sexual behaviour).

Health benefits of sexual expression

Many health benefits of sexual expression have been discovered in recent years. These include:

- improved self esteem
- body image and feelings of masculinity/femininity
- physical and mental relaxation
- distraction from pain, and pain relief
- feeling comforted and being able to give comfort
- ability to face another day and a strong link to overall relationship satisfaction

(see Whipple, B., Koch, P. B., Moglia, R. F., Owens, A. F. & Samuels, H. (2007) The Health Benefits of Sexual Expression. Planned Parenthood Federation of America. http://www.hawaii.edu/hivandaids/Health%20of%20Sexual%20Expression.pdf).

Sexuality and body image

If an individual has a poor body image, this is linked to low self esteem and can have significant impact of a person's engagement in life. They may choose not to engage in activities, or let opportunities pass them by, preventing them from taking up challenges in life. A healthy body image is related to people's successful and fulfilling engagement with life with and through the body.

Sexuality and identity

Achievement of different aspects of identity, including sexual identity, is a core developmental task of adolescence. Without achievement of sexual identity, adolescent cannot move onto the ability to experience true intimacy.

Each developmental task not accomplished is likely to make it harder for a person to experience a relative sense of fulfilment and satisfaction with life, as well as their ability to let go at the end of life.
See http://www.hawaii.edu/hivandaids/Health%20of%20Sexual%20Expression.pdf

The effect of diability/ chronic illness on sexuality, body image and development of sexual identity

"*I want information and help, not sympathy. I am a loving human being, and it is a strong dream, a strong wish of mine to be with a woman. My ability to love hasn't changed...It is within me... Am I a man? Deep down inside me, I am the same (as others), but on the surface I am not. But still, I am a man*." (David in Weiner, 1986)

"*One would think that on the brink of death, appearance, sexuality and the opposite sex would be far from one's mind. However, for a young person, establishing romantic relationships is one of the most important ways to determine one's identity. Although I had no idea whether I was to live or die, I knew I wanted to be in love. During treatment, I was fortunate to have a wonderfully supportive boyfriend. This relationship was my life force, and his support, love and encouragement is the reason I fought so hard. The promise of a future is a powerful thing and partners represent the prospect of a life beyond treatment. However, this kind of relationship can be both wonderful and so difficult during this period. Young people are making sense of their bodies and sexuality and this is especially complex when faced with challenges to self-esteem, a lowered libido and role changes within a relationship. Limitations of sexual function, whether actual or perceived, negativly affect a young person's sexual and romantic confidence. The question that plagued me was "How can I be a sexual being and a girlfriend that he's proud of when here I am, sick and bald*?" (Danielle Tindle, diagnosed with Hodgkin's Lymphoma, age 22)

As these quotes illustrate, many adolescents with chronic and life-threatening illness remain acutely aware of their emerging sexuality, their wish for an intimate connection with another, and their frustrations in not always feeling or not being treated like a sexual being in the same way as their peers. Both young children and adolescents with chronic illness have been found to identify themselves as sexual beings and most have the aspiration to one day live with a partner and possibly to have kids. Those whose medical condition is more serious have been found to have an even greater wish for a relationship than their less affected peers – a finding likely to be the result of an increased re-evaluation of priorities which are likely to include reaching key developmental milestones such as having a partner and losing one's virginity as well as a greater need for comfort, security, reassurance and the many other benefits of sexual expression.

Unfortunately, chronic illness during childhood and adolescence has also been found to negatively affect sexual development in a variety of ways. Delayed growth and puberty have been found to have a wide range of psychological and social effects, with patients often being

treated as younger than they are by parents, health care professionals and peers, resulting in lower self esteem and poor body image

Depending on the time of onset of illness, different developmental delays are likely. Milestones of development of increasing independence and rites of passage from childhood to adulthood are delayed or missed altogether. These can include

- increasing peer orientation
- academic and social or physical achievements
- parties and socialising
- early relationships
- moving out of the home
- passing a driving test, gaining license, and driving
- the first kiss
- early sexual experimentation
- loss of virginity, etc.

The likely effect of chronic illness in **early adolescence** are concerns of body image and body integrity, age-inappropriate relationships with parents

Middle Adolescence: peer relationships are more affected, and sexual development or experimentation may be delayed (lack opportunity or physical ability to masturbate, meet peers, and enjoy privacy). They may become sexually active, take more risks, often against their background with less information about sexual health and contraception. Risk taking, which is a general theme in this age group, may increase in defiance against the illness or condition, restrictive regimes, parental overprotection, out of a need to have fun or celebrate/challenge life, also a sense that taking risks matters little in the face of a possibly shortened life span.

Late adolescence: much of sexual development may already have been achieved, and the individual may be more confident, have a sexual identity, with concerns about establishing/maintaining a serious relationship, or a declaration of love. They may have a wish for children as legacy, to live on, or a partner may wish to have a child to preserve their memory. They may have to learn to adjust to new limitations, or learn new ways of expressing the self sexually if the old ways no longer work. Progressive illness requires constant re-adjustment to further limitations. If they have not already had sexual intercourse, loss of virginity may become a key concern.

"*I turn to the first page , which is not part of my journal, but a private goal sheet not meant to be seen by anybody. Of course, I have many more goals that are written here, but these are the two most important ones, the ones I must accomplish before dying in order for my life to have been worthwhile...*

1) Lose virginity

2) *Make a contribution – publication of journal*"

16 year old boy with a brain tumour in a novel by Schreiber (1983)

Some factors to consider:

Education

The individual may miss extended periods of school, opportunties to socialize with friends, also confidence from sharing common experience and feeling part of and on par with the group academically and otherwise. They may miss, or be excluded from sex education at

school, and miss out on informal sex education and interaction with their own and opposite gender peers.

Social Activities
There is less opportunity to develop social skills, less exploratory play such as “doctor” and “house”. Maintaining contact wth peers is difficult if you miss school for extended periods or can’t take part in hobbies on a regular basis. Relying on others for assistance for everyday activities can be felt as too embarrassing to be witnessed by peers. Symptoms, treatments and body appearance may be seen as unacceptable, and may lead patients to avoid contact with peers; thus early sexual experiences may be delayed or the opportunity may never arise.

Privacy
The individual will experience a lack of privacy. They may have difficulties in exploring and learning about the body and masturbation. There may be limited access to social activties or private meetings, and parents may accompany them to events which might otherwise have opened up into intimate or sexual experiences.

Social Skills
Individuals are prevented from developing age-appropriate communication and life skills consistent with their peer group. They may have poor contact ability with peers, due to environmental obstacles, their own insecurity, or being unsure how to go about negotiating relationships.

Others’ Reactions
There are tendencies to avoid the unknown and different, with uncertainty how to react and what to say or do. Others may fear that their illness is contageous, and the the disabled youngster may fear that contact may reduce social standing amongst peers. Other children's reactions can be cruel and rejecting, especially during phases of ongoing egocentricity and concern for fitting in and being desirable.

Confidence & Maturity

There may be conflicts including parental overprotection and young person’s ambivalence between wish for independence and dependence / reassurance of being looked after and protected in reducing confidence and slowing down development of maturity.

The young person may fear being dismissed or rejected by peers, if they fall short of the beauty ideal. As a result, they may avoid making contact with the opposite gender, or fail to notice, or be afraid to respond to, offers of friendship or potential romance, out of fear of rejection. Other common assumptions preventing teenagers from being open to opportunites for peer contact are an inability to explain their illness or the history of their impairments, and assuming nobody would want to be with them, especially if their condition is likely to progress.

Teenagers may remain embarrassed about discussing sexual themes not congruent with age, and generally show less mature sexual development and social skills. On the other hand, they may be more mature in other ways by having spent more time in the company of adults and having had to confront more serious issues at a young age. This often leads to feelings of being somehow out of synch with their peers and not sharing much common ground easily.

Body Image

The aspects of body experience found to be most relevant to body image in individuals with impairments or illness are

- body comfort
- body competence
- body appearance and
- body predictability.

However, it is important to note that the impact of objective physical impairment as it might be assessed by an observer is less related to a person's sense of body image satisfaction than their own perception and interpretation of their appearance and body integrity. Body image, therefore, is primarly determined by subjective processes of self evaluation and investment.

Perhaps counter-intuitively, several studies have found that the body image of young cancer patients is not reliably worse than that of healthy controls. In fact, some studies have reported that the body image of 16 year old females with chronic illness may be better than that of their healthy peers. This finding might be partially explained by the pervasive "normative discontentment" which exists in healthy young females of this age group. Other factors of relevance may be gradually changing and adjusting expectations of older adolescents who may have had a chronic illness for some time, possibly beginning to compare themselves more to peers in similar cicumstances than to the unreachable body ideal culturally presented, in line with response shift theory. It is also possible that these young women simply reach a more mature, accepting concept of body image, such as appreciating body function over outside appearance, sooner than their peers.

In line with the timing of body image development in healthy peers, children with chronic illness also begin to report greater body image concerns between the age of 5-9, compared to younger peers. The body image concerns of 10-14 year olds with chronic illness predict greater use of social withdrawal as a coping skill.

That body image concerns in chronic illness and after appearance changes can feel particularly devastating to a young person, and even outweigh concern over the illness itself, is illustrated by the following quote:

"*As a nurse carefully peeled back the dressing, I watched as an ugly bruised line appeared. I was devastated. How could I ever get a job in the performing arts now? What man would find a woman attractive when she looked like she had been sawn in half? It wasn't until a further week had elapsed that I was told the surgeon had in fact removed not a blood clot but a large tumour from my abdomen. As crazy as this might sound, at this point I was still more concerned about the scar. I hated the way cancer had disfigured my body, hated the way it had left such a big mark on me, both physically and mentally. I felt like a Raggy Doll. As a young woman I was still discovering who I was. The way I looked mattered greatly to me. I didn't want to stand out from the crowd because I looked freakishly different, I wanted to be like my peers. I was convinced that now I had a massive scar, men would run a mile before getting involved with me, not only because of my body but because getting to know me might be a short-term thing. Would they take the risk that I might not be around this time next year? I assumed because I was appalled by my ugly scars, everyone else would feel the same way.*"

(Faye Lilley, diagnosed with Ganglioneuroblastoma, age 21)

In general terms, variables such as changes in appearance as well as new knowledge of inner, less visible changes and loss of body function and control can all lead to a significant worsening in body image. Frequency and length of hospitalization , number of relapses, treatment side effects and response to treatment have all been found to be predictors of body image.

It is important to realize that the consequences of poor body image go far beyond a young person simply not feeling happy about the way they look and impacts on quality of life in a number of different ways. Body image has a direct impact on global confidence, self esteem and adjustment. Conversly, poor body image is related to depression and social anxiety and avoidance. Those who feel less attractive experience more social anxiety and feelings of loneliness.They have more difficulty initiating and maintaining peer relationships and may fail to recognize or respond to the approaches of potential new friends or partners. Any form of sexual contact may be avoided out of a fear of rejection..

It is therefore crucial to try to intervene and support the development of an adaptive body image and confidence. Social support, positive reinforcement, modelling, and the opportunity to talk to peers with similar challenges who have successfully negotiated a more positive body image have all been found to be helpful interventions.

Sexual Identity

Earlier sections of this module have referred to the complex challenges involved in the development of an LGB sexual identity in healthy children and adolescents. The challenges faced by young people with chronic or life-threatening conditions, when trying to develop a secure body image and sexual function in the context of a heterosexual sexual identity, have also been examined. Relatively little is known about the double challenge youth may be facing in coming to terms with chronic illness and an emerging LGB sexual identity.

It is perhaps worth noting that both identities carry many negative connotations, and that the combination of LGB sexual identity and disability may be seen as almost contradictory, and at least unexpected, by many members of the public. Stereotypically, members of the LGB community are still often seen as determined primarily by their sexuality, often with a negative connotation of being somehow "oversexed" or "abnormal". Individuals suffering from chronic illness and disability on the other hand are often thought to be asexual, and primarily defined by impairment, possibly with a connotation of being "pitiful" or "in need of care".

The following three quotes describe three very different accounts of individual experiences in negotiating this double-identity and others' reactions.

- "*Being disabled obviously to some people is physical, i.e. the fact that I am in a wheelchair: they don't see me; they see my wheelchair, so really that is the state of mind of how people perceive me, and a lot of people haven't got the foggiest idea that I am gay*."

- "*As far as disability is concerned, there is an acceptance about disability, a political understanding – even if it is crap and patronizing, it is acceptable to be disabled; it is basically about caring. You can influence disability; you can make an impression on*

how people see it and you. Whereas being lesbian or bisexual is about perversions and it is not acceptabe. So one is an acceptable difference and the other is a disgrace!"

- *"I had never been 'normal' as a child, so coming out as gay was just another not-normal thing to do, and didn't present me with any problem as such. If you are not expected to have a normal sexuality or to be a regular guy, being gay is no great shakes.*"

(in Shakespeare et al, 1996)

All the accounts refer in a striking manner to the experience of being chronically ill or disabled as a primary and heavy burden — one that leads to social invisibility, and a sense of being "not normal", "irregular", and someone who needs to work hard at presenting an acceptable face of disability, only to be patronized by others' displays of caring. The emerging sexual identity becomes a new challenge, to be managed in the context of the individual's lived experience of being identified as "disabled". In one account, this burden of a new and socially even more unacceptable and disgraceful identity seems almost too much to bear. The other two acounts, though superficially more positive, ultimately speak not of a whole-hearted, happy embracing of an LGB identity, but rather of a resigned conclusion that if nobody notices me as a person anyhow, or regards me as the "not normal" guy, a different sexual identity matters little.

All factors previously mentioned as impinging on the normative sexual development of young people with a life threatening condition clearly apply in similar ways to sexual development in the context of an LGB identity. Additional key factors seem to lie in the fact that the establishment of an LBT identity tends to take longer, be more conflicted and benefit greatly from the availabily of sources of support from sympathetic others, sources of information and access to the LBT community or social events. Where a heterosexual young person with a chronic illness or condition may encounter some difficulties in maintaining peer support and having the opportunitiy for sexual experimentation, the LGB young person may have significantly less opportunities to speak to another, to access relevant information, or to attend social events to explore their feelings and help consolidate a sexual identity. It has been pointed out that teens with a chronic illness or condition may feel even less comfortable than their healthy and non-disabled peers to involve parents or other remaining social contacts in their need to explore feelings around homosexuality, if they feel they have already burdened them with the hardship involved in the illness diagnosis and ongoing care.

The role of the health care team in supporting young people in exploring their feelings about sexual orientation and identity should therefore not be underestimated.

http://www.gayyouth.org.uk

What to look out for, what might be the issues, and what practical steps could be taken

4 year old

The **i**ssues:-

- Touching for self comfort, how to handle
- what knowledge they are missing out on at school
- concrete self concept in terms of physical characteristics

- competencies to be boosted
- getting to know the body as something positive
- missing important start to school where peers are taking leap ahead

Practical ideas:-
a) Specific:-
Discussion with parents may be helpful, checking out their attitude towards masturbation and normalising this behaviour and emphasising that from a medical perspective such behaviour is normal and probably helpful in developmental terms and that this is also an important source of comfort and self soothing in what may be particularly difficult circumstances. In most cases it will be most appropriate not to draw specific attention to the behaviour and to cope with its occurrence in inappropriate situations by distracting the child's attention away from their self soothing activity. If masturbation beomces problematic, try to explore senstively what the child feels (s)he is doing and discuss in a positive or neutral way — one could say something like: touching our bodies in this way (use the child's language, their own explanation) can feel nice but it is something we do in private. That means you should do it only when you are on your own. When you feel like doing this, you can, for example: "go to your own room, perhaps wait till night-time and do it after you've gone to bed". Find an agreed local solution and be prepared to repeatedly gently re-direct and remind them.

b) General ideas for the age group:-
Ensure continuation of the social support provided by family, friends and HCPs to boost self esteem, body image, etc., treating the child as the same person they were before they were disabled / ill / hospitalized etc. Find opportunities to help the young person to feel competent and to experience their body in a positive way. Have picture books available, and provide opportuntities for exposure to, and discussion of, age appropriate topics normally covered in Personal, Social, Health & Economic Education (PSHE) in school (see below). Encourage on-going interaction with siblings and peers, and encourage continued involvement in social activities.

9 years old

The issues:-
- peer group
- body image
- beginning need for privacy
- sex education about puberty, menstruation, with preparation for physical changes

Practical Ideas:-
Offer suggestions for how to maintain friendships. Help them to develop coping skills, to practice body presentation (e.g. clothing, wigs) & help them with body image concerns by providing social support. Help the young person check out reactions of others, facilitating cognitive restructuring and adjustment. Talking to others who have overcome body image and similar concerns may be helpful. Ensure age approriate PSHE topics are covered including physical changes in puberty.

Leave the door open for discussing any other questions they might have about how their body is changing and how they are beginning to feel different, or about relationships with others. Make age-appropriate reading available. Respect their need for privacy; offer opportunities to learn, to be creative, to feel competent and to experience their body in positive way.

16 year old

The issues:-

- struggles to keep up with peer group
- often seem to be out of active dating scene
- eager to continue sexual experimentation, but how?
- Questionning how they can now be attractive/fit in?
- worries about losing a partner if they have one
- worries of sexual identity confusion

Practical Ideas:-
They may need suggestions/encouragement to maintain friendships, so it's crucial for support to be there for them. Parents can offer lenient visiting arrangements, encourage friends to invite them/come round with a movie, for example, go out for a walk, enable social outings whenever possible.

It might be useful to rehearse anxiety-provoking social interactions, to develop coping skills, and to offer opportunities to experiment with body presentation, e.g. the use of make-up, nail polish, wigs, and baggy clothes to cover up unwanted changes. You can also suggest to them the decision to go against social norms and confront visitors with “the real me”. You can facilitate discussions about body image.

Offer the young person the opportunity to speak to their peers facing similar issues, and consider becoming “mentor” for younger people.

Include sexuality in routine screening and assessments; discuss sexual needs, desires and questions; provide age-appropriate sex and relationship information, including information about contraception, STIs and sexual functioning, emotions & relationships. Ensure that age-appropriate reading material is available.

Offer opportunities to talk about possibilities and losses, do grief work, connect to peer support groups, websites, e.g.
jimmyteens.tv for young cancer patients http://www.jimmyteens.tv
http://www.jimmyteens.tv/?s=sex
and Gay Youth UK http://www.gayyouth.org.uk

Ensure that they have access to the phone and the internet.

Addressing Sexuality

Sexuality remains a very private and sensitive topic in most cultures today. As individuals, we all vary in the degree to which we feel comfortable to openly discuss sexual themes with important others in our own lives. In a very similar way, we can find it difficult to find a way of raising the topic of sexuality with our patients. In fact, health care professinals consistently rate sexuality as one of the most difficult areas to speak about with their patients alongside spirituality and death & dying. Some of the common factors contributing to this difficulty experienced by professionals are:

- Lack of clarity about whether it is their role
- Lack of kowledge & confidence, feeling deskilled (HCPs often erroneously feel they need to know all the answers before being able to raise a topic)
- Uncertaintly whether anything can be done

- Fear of offending the patient, or making them feel worse by naming the topic
- Lack of time
- Lack of clarity about legal contexts surrounding young people and sexuality
- Assumptions (e.g. patient too young/too ill/ doesn't have partner, already knows everything/etc.)

Unfortunately, many young patients find it just as difficult to raise the subject for a variety of reasons, such as:

- Generally being reluctant to talk to adults about stuff
- Not knowing what words to use or how to start conversation
- Feeling embarrassed
- Not wanting to be seen as inexperienced
- Not knowing if this is the "right" professional to talk to about something like this
- Not knowing that what they are going through is "normal"
- Not wanting to be judged
- Not knowing that anything could be be done to help
- Being worried about confidentiality

It therefore clearly has to be the professional's responsibility to raise sexual concerns in the same way that developmental issues, symptoms and consequences of disability, and side effects of treatments are discussed.

PLISSIT Model (Anon, 1976)

This is a useful Conceptual Model emphasizing that in order to create the circumstances in which patients can feel comfortable to discuss concerns of a sexual nature, services and individual practitioners need to communicate clearly that

- Having conversations about sexual concerns is part of the remit of the service
- Sexuality is seen as important, and patients will not be judged for having sexual concerns
- The service is offered confidentially (be clear about limitations of confidentiality & where to get confidential help if not in the current setting)
- Help is available

These messages can be communicated in a variety of ways such as through clues in the environment, e.g. posters, display of books or video material, written information, use of screening tools which include sexual and relationship topics as well as in personal communication and formal assessment with a HCP. This so-called "**permission-giving**" is best seen as an on-going process rather than a once-only event.

Having received such permission to be a sexual human being, and to have sexual concerns without being judged, patients are more likely to feel able to raise any sexual concerns on their mind, or to answer questions of a sexual nature more openly and confidently.

The remainder of the PLISSIT model proposes a series of interventions to help patients address sexual concerns, ranging from the giving of limited information over the provision of specific suggestions and towards the option of intensive therapy or other intervention to overcome the most complex problems. Whilst originally proposed specifically to conceptualize only how concerns around sexual function and sex therapy can be addressed, a

similar framework is equally useful for conceptualizing the provision of sexual health & contraception services, where the giving of permission and limited information are again important cornerstones, followed by specific assessment/investigation and provision of simple suggestions or methods of contraception, with a few cases requiring more complex intervention.

Key messages of the model are:

- Every HCP has a role to play in addressing sexual concerns.
- Both the environment and every HCP contribute to the permission-giving aspect.
- No HCP should be expected to work above their personal comfort or skill level in this field — if permission-giving is all that an individual feels comfortable with, this is OK, as long as they have a clear sense of where to direct the patient to receive at least limited information.
- The system as a whole has a role in ensuring that all levels of input are provided when appropriate. Each HCP therefore needs to know who to hand over to, or refer on to, for the next level of intervention.
- Permission-giving can prevent some difficulties from arising, and can mobilize patients' inner coping resources to overcome some concerns by themselves.
- Most sexual concerns are addressed successfully by the giving of limited information or specific suggestions.

Sexual Communication Skills

The communication skills required to discuss sexual concerns are not fundamentally different from the advanced communication skills practiced during professional training, and rely primarily on expert use of basic listening and counselling skills. The key difference when trying to facilitate conversation around sexual topics lies in the particularly personal and private nature of the topic, and the previously mentioned barriers to open discussion frequently felt by both the health professional and the patient.

There is therefore a need for professionals not only to get an academic understanding of the importance of the subject, but also to have enough opportunity to practice discussing sexual topics, in order to gain confidence and find their own preferred way of including the topic in conversations, finding comfortable words to use, getting used to using them, etc. The feedback from generic advanced communication skills programmes has often been that there hasn't been enough time to specifically focus on the discussion of sexual problems. Also, application of generic communication skills sometimes falls short of giving patients the permission they need to raise a sexual concern.

In addition to clues in the environment, it can be helpful to find respectful and appropriate ways of enquiring about sexual themes in a more direct manner than usually practiced, thereby making in clear that such material is appropriate for discussion, without leaving a patient feeling forced to disclose information they do not wish to share.

Wherever possible, it is suggested that specific sexual communication skills workshops are accessed. These may be available from adult cancer or palliative care services, adult or young people's sexual health services, the PSHE & Citizenship Advisors at the local health education service, or as part of relevant conference programmes.

Modelling by other members in a team can be an excellent way to learn. Self monitoring is also an effective strategy. Topics to monitor:

- Current level of comfort in raising sexual themes with younger patient group
- How often we actually manage to raise a sexual topic
- Reflection on how it went
- Reflection on why we did not raise sexuality as a topic with others cases

Try to avail yourself of discussions as part of reflective practice or clinical supervision groups where possible.

The following are some examples of how sexual topics may be introduced into a conversation:

- "Do you have a partner at the moment/are you going out with/seeing anybody/ is there anybody special in your life at the moment?" ….."How are they coping with the illness?"...."Has your relationship been affected in any way by the illness?"... "Has it affected the ways in which you are intimate together? Has it lead to any problems sexually?" Or "I'm not sure how far you have already taken things intimately as a couple, but many people who have an illness like you find that it can really get in the way. Have you found any difficulties like that?"

- "Often, after many treatments or disease progression, a young person's thoughts about him or herself and relationships, including sexual relationships, may be affected by treatment or its side effects. Sometimes an illness can affect relationships, especially when you don't have enough time to hang out with your friends. How has your illness affected your thoughts about your relationships, sexual or non-sexual, between you, your friends and/or your partner?"

- "Many young men/women experience fatigue, feel unhappy about the way they look, or experience other side effects, some of which affect sexual functioning, that can have an impact on their relationships. There are a variety of things we can suggest in these circumstances. Would you like to talk about any concerns like that, and what you can do to manage issues related to sex or relationships?"

- "Many people your age (and in fact adults of all ages) have questions about sexuality or relationships. It can be even more difficult when you have a condition like this/ are stuck in a place like this and you don't get to spend as much time with your friends as you would like, and you might not get as much of an opportunity to find out about this kind of thing. We often talk to young people about their worries about relationships or sex, and we can also advise on things like safe sex and contraception."

- "Other teenagers I work with often wonder about…"

General comments:

- Ideally, develop collaborative relationship with parents.
- Depending on age and level of independence & understanding, discuss how confidential information will be handled.
- Know the law around privacy and sex education and provision of sexual health services for minors (see below).

- Build supportive relationship with the patient, treat them as independent and self-responsible.
- Naming of sexuality as a legitimate topic can be helpful in early/induction meetings where young person and parents are present.
- Consider offering a sexual resource list, naming one professional as the "sexual health expert" but making it clear that everybody else on the team can also be approached for support.
- Offer opportunities to speak to the patient on their own as well as with parents or partner, depending on context.
- Use proper terminology for sexual parts, actions and problems, possibly also offering some alternative, more colloquial words. Check the patient's understanding and knowledge.
- Clarify the meaning of terminology used by the young person; for example, they may say they are not having sex but regularly engage in oral sex.
- Consider adjusting to the language used by the young person — some will find this helpful and informal, whereas others may dislike an adult using "their words"; ask!
- Do not make assumptions about sexual orientation – use neutral language, e.g. "partner" "the person you're with" , "are you dating/seeing anyone?" instead of making reference to "boyfriend/girlfriend".
- Check their knowledge of reproduction and sexual activity. Check their desire for sexual information. Check their self-image, current relationships.
- Understand how sexuality was expressed and pleasure was achieved before, if there are any problems/changes, and what the wish for the future is.
- It can be helpful to assess the age and stage of development and if there is deviation from expected norms.

Useful Resources

Examples of useful textbooks are

- Bukatko, D. (2007). Child and Adolescent Development: A Chronological Approach
- Bekaert, S. (2004) Adolescents and Sex: The Handbook for Professionals Working with Young People
- Coleman, J. & Roker, D. (1998) Teenage Sexuality: Health, Risk and Education
- British Association for Sexual Health & HIV (BASHH) (2006) National Guidelines for consultations requiring a sexual history-taking http://www.bashh.org/documents/84/84.pdf
- WHO (2001). Counselling Skills Training in Adolescent Sexuality and Reproductive Health – A Facilitator's Guide http://whqlibdoc.who.int/hq/1993/who_adh_93.3.pdf

Sex Education

- There is strong evidence that health care professionals generally dismiss or undervalue non-life threatening aspects of any condition
- HCPs also feel ambivalent about discussing sexuality with young people with life-limiting conditions as it implies a focus on the future and fear upsetting the parent or the child.

- Parents often are equally reluctant to discuss sexuality with their child for fear of upsetting them, giving them false hopes, or encouraging early sexual experimentation. They can have a tendency to keep their child overprotected and immature.
- There may be a need to help anxious parents to let go and promote independence.
- Many teenagers with chronic illness and disabilities are sexually active and if not, they usually have the same social and sexual aspirations as their peers.
- They may have missed opportunities for formal and informal sex education.
- They have human rights of access to family planning education and services (see also sexual health rights earlier).
- Effective sex education does not encourage early sexual experimentation.

Sex Education in British Schools

The Education Act 1996 requires that sex education should inform pupils "about STIs and HIV and encourage pupils to have due regard to moral considerations and family life". It is therefore compulsory for schools to teach the biological aspects of puberty, reproduction and the spread of viruses. These topics are mandatory as part of the National Curriculum for Science which is taught to all pupils of primary and secondary school age.

The broader subject of sex and relationship education (SRE) is currently not compulsory in schools even though schools are recommended to offer it (SRE Guidance DfEE 0116/2000) as part of PSHE and Citizenship. In practice, the majority of schools do provide at least a certain amount of SRI as part of their Curriculum for Personal, Social and Health Education (PSHE). What is included in SRI is variable from school to school. Both primary and secondary schools must have an up-to-date policy that describes the content and organization of SRE taught outside the Science Curriculum. If the decision is taken not to teach non-compulsory SRE components, this also needs to be documented by the school. Each school's governing body is responsible for developing their school's policy and making sure it is made available to parents. Different sources of support exist to guide schools in the process of developing their policy and curriculum, for example from the local PSHE advisors based in local government and the Sex Education Forum (see Resources). Parents have the right to withdraw their children from SRE taught outside the Science Curriculum. Recent surveys show that 90% of parents and 93% of school governors support the teaching of SRE in schools.(2010 Report: SRE — Views from teachers, parents and governors). http://www.nga.org.uk/uploadfiles/SRE%20Education%20Views%20from%20teachers%20parents%20and%20governors.pdf)

In general terms, Sex and Relationship Education (SRE) helps students to learn about the emotional, social and physical aspects of growing up, relationships, sex, human sexuality, and sexual health. It seeks to equip children and young people with the information, skills, and positive values to have safe, fulfilling relationships, to enjoy their sexuality, and to take responsibility for their sexual health and well-being.

The Sex Education Forum stipulates that good quality SRE should:

- Start early in childhood and continue throughout life
- Be accurate and factual covering a comprehensive range of information about sex, relationships and sexual health
- Be positively inclusive in terms of gender, sexual orientation, disability, ethnicity, culture, age, faith, belief, HIV status, pregnancy and other life experiences
- Include the development of skills that enable personal responsibility, support healthy relationships and ensure good communication about sex and relationships
- Promote critical awareness of different social and peer norms and values
- Nurture the development of clear values based on mutual respect and care

- Ensure that children and young people are clearly informed where they can get confidential advice and support

Although SRE supports young people to delay early sexual activity, secondary schools also have a duty to promote the well-being of those pupils who, for whatever reason, experience early and often unprotected sex.

Confidentiality

Teachers in schools are not in a position to guarantee absolute confidentiality. They must have a good working knowledge of their school's confidentiality and safeguarding policy, and ensure that pupils understand what might happen to any personal information they might disclose in the classroom.

All schools have a legal duty to safeguard the welfare of children and young people. This means that if it is suspected or established that sexual activity there involves abuse or exploitation, this activity needs to be reported in line with the child protection policy.

Some schools have developed additional contractual obligations that require staff to report all disclosures of sexual activity, regardless of circumstance. Information about alternative sources of confidential support should be provided to students.

In terms of legal background around young people's capacity to consent to sexual activity, the legal age for consent is 16 and sexual activity of young people aged 16 or above is generally deemed unproblematic. The law also does not wish to criminalize younger people who are in a mutual sexual relationship. While it may be appropriate to consider whether the welfare of a young person aged 13-15 may be at risk through early mutual sexual activity, there is not a legal requirement to report it. A child aged 12 or under is never deemed capable of consenting to sexual activity and any such activity needs to be reported.

See: Sex Education Forum. Confidentiality in Schools Factsheet http://www.ncb.org.uk/PDF/sef_ff_38.pdf for more detailed information

Further Information

Main Reports & SRE Overviews

- Department for Education and Employment (2000) Sex and Relationship Education Guidance (http://www.education.gov.uk/publications//eOrderingDownload/DfES-0116-2000%20SRE.pdf)

- Ofsted (2002) Report on Sex and Relationship Education http://www.ofsted.gov.uk/Ofsted-home/Publications-and-research/Browse-all-by/Education/Curriculum/Personal-social-health-and-economic-education/Primary/Sex-and-relationships-education-in-schools

- What is taught in schools? Summary of learning outcomes Ofsted Report of Sex and Relationships (2002). http://www.swish.org.uk/?q=parents/school

- Family Planning Association (2010) Factsheet Sex and Relationships Educationhttp://www.fpa.org.uk/media/uploads/professionals/pdf_sex_relationships_and_education_factsheet__jan_2011.pdf

- Sex Education Forum (2008).Young People's Survey on SRE – Key Findings http://www.ncb.org.uk/dotpdf/open_access_2/sef_youngpeoplessresurvey_briefing.pdf

- Sex and Relationship Education – Views form teachers, parents and governors (2010) http://www.nga.org.uk/uploadfiles/SRE%20Education%20Views%20from%20teachers%20parents%20and%20governors.pdf

Age-appropriate curriculum & resources

Primary

- Sex Education Forum (2001) Sex and Relationship Education for Primary Age Children, http://www.ncb.org.uk/dotpdf/open%20access%20-%20phase%201%20only/ff28_sef_2001.pdf
- Sexual Education Forum. SRE Curriculum Content Age 3-6 http://www.ncb.org.uk/sef/resources/curriculum_design/questions_to_explore/ages_3-6.aspx
- Sexual Education Forum SRE Curriculum Content Age 7-8. http://www.ncb.org.uk/sef/resources/curriculum_design/questions_to_explore/ages_7-8.aspx
- Sexual Education Forum SRE Curriculum Content Age 9-10 http://www.ncb.org.uk/sef/resources/curriculum_design/questions_to_explore/ages_9-10.aspx

- Sexual Education Forum SRE Resource List for Primary Schools http://www.ncb.org.uk/PDF/Resource%20List%20-%20Primary.pdf

- Sexual Education Forum. Samples of Lesson Outlines for Primary Schools by year http://www.ncb.org.uk/sef/resources/curriculum_design/sow-_primary.aspx

Secondary

- Sexual Education Forum SRE Resource List for Secondary Schools http://www.ncb.org.uk/PDF/Resource%20List-%20Secondary.pdf
- Sexual Education Forum SRE Curriculum Content Age 11-13 http://www.ncb.org.uk/sef/resources/curriculum_design/questions_to_explore/ages_11-13.aspx
- Sexual Education Forum SRE Curriculum Content Age 14-16 http://www.ncb.org.uk/sef/resources/curriculum_design/questions_to_explore/ages_14-16.aspx
- Sexual Education Forum SRE Curriculum Content Age 16+ http://www.ncb.org.uk/sef/resources/curriculum_design/questions_to_explore/ages_16.aspx
- Sexual Education Forum. Samples of Lesson Outlines for Secondary Schools and 16 + http://www.ncb.org.uk/sef/resources/curriculum_design/sow-_secondary.aspx

Disability & Special Needs

Sex Education Forum Factsheet on SRE for Children and Young People with Learning Disabilities (2004) http://www.ncb.org.uk/dotpdf/open%20access%20-%20phase%201%20only/ff32_sef_2004.pdf

Sexual Education Forum SRE Resources Special Needs and Disability
http://www.ncb.org.uk/PDF/Resource_List_Special_needs_Disability.pdf

Sexuality Education for Youth with Disability and Chronic Illness. A Resource List.
http://www.med.umich.edu/yourchild/topics/disabsex.htm

Canadian Council on Learning (2010). Best practice on sexuality education for children and young people with physical disabilities. http://www.ccl-cca.ca/pdfs/FundedResearch/EsmailFullReport.pdf

NICHCY (1992) Sexuality Education for Children and Youth with Disabilities.
http://www.nichcy.org/InformationResources/Documents/NICHCY%20PUBS/nd17.pdf

Parents

- Sex Education Forum (2001). Talk to your children about sex and relationships, Support for parents http://www.ncb.org.uk/dotpdf/open%20access%20-%20phase%201%20only/ff31_sef_2001.pdf
- Sexual Education Forum Resource List Parents and Carers http://www.ncb.org.uk/PDF/Resource_List_Parents_carers.pdf

Other

Personal, Social, Health & Economic Education (PSHE) Association. http://www.pshe-association.org.uk/ for list of resources and local advisors

Birmingham Health Education Service ("Centre of Excellence" with national reputation in the planning and delivery of PSHE (Personal, Social and Health Education) and Citizenship education initiatives
http://www.bgfl.org/bgfl/71.cfm

- Sex Education Forum Factsheet on Faith, Values and Sex and Relationship Education (SRE) (2004)http://www.ncb.org.uk/dotpdf/open%20access%20-%20phase%201%20only/ff_faith02_sef_2005.pdf

Sexual Health (Preventing Sexual Ill-Health) – Helping Teenagers and young people minimize some of the risks associated with sex

Most young people in the UK become sexually active aged 16 or over. However, 25-33% of young people will have heterosexual intercourse before the age of 16. Approximately 10% of 16-19 year olds report having used no contraception at first intercourse. Contraceptive use is significantly lower in those under 16. Knowledge about different kinds of contraception and where to go for help amongst young people is poor, with only 49% stating they know where their local sexual health clinic is. The UK continues to have the highest teenage pregnancy rate in Europe, with most pregnancies under 18 occurring to girls of 16 or 17. Approximately 50% of pregnancies under 18 end in abortion. This figure increases to 61.5% of pregnancies in girls under 16. Infant mortality for babies born to teenage mothers is 60% higher than for babies born to older mothers (DfES, 2006). Teenage mothers are more likely not to finish education and to bring up their child alone and in poverty.

Sexually Transmitted Infections (STIs) are more common amongst young people than any other group. 16-24 year olds represent 12% of the population but account for more than half of all newly diagnosed STIs. In 2008, the 16-24 age group accounted for

65% of new chlamydia diagnoses

55% of new genital warts diagnoses

47% new gonorrhea

44% genital herpes (HPA, 2009)

> (taken from Sexual Education Forum. Data and Statistics about sexual health in young people. http://www.ncb.org.uk/sef/evidence/data_and_statistics.aspx)

Young people with chronic illness have been found to be as likely or more likely to be sexually active than those with no such medical history. For some the forming of relationships may also be delayed or prevented altogether through the physical and psychosocial side effects of being chronically ill. As previously outlined, young people with chronic illness or disability often miss out on some of the formal and informal routes to sex education. They may be more likely to engage in risky sexual behaviours stemming from a combination of lack of knowledge and a potentially increased willingness to take risks to challenge life/live life to the full. Those who have not been able to engage in sexual experimentation or experience intercourse may become increasingly more focused on this as part of crystallizing priorities.

Clearly, sex education is a cornerstone of equipping young people with the information they need to make responsible decisions about the sexual behaviours they engage in and what precautions they take. Access to confidential information, support, and treatment services is equally important. It is the duty of all health and social care providers, including in children's and palliative care settings, to work in partnership to ensure all young people have equal access to such information and services, treat all young people, irrespective of disability or health status as full, and therefore sexual, human beings. They should ensure that young people with disabilities and chronic illness receive age-appropriate information and opportunities to develop the psychosocial skills to form healthy relationships. They need the ability to critically appraise the physical or mental desire to engage in sexual behaviour and the consequences of doing so in a variety of contexts. It is also crucially important that young people with chronic illness have a full understanding of how to protect themselves and their partners from sexually transmitted infections or unwanted pregnancy. It may be helpful to allow the opportunity to openly explore their thoughts around the priority safe sex has in their lives at the moment without fear of repercussions. Opportunities should be given to discuss sexual health related themes in the paediatric or palliative care setting. Access to contraception, including emergency contraception and wider sexual health services should be facilitated by displaying posters and written information, including sexual health information and information about local services and how to access them. Help with access should be provided where appropriate.

Resources:

Statistics, Sexual Health Guidance & Professional Bodies

- Sexual Education Forum. Data and Statistics about sexual health in young people. http://www.ncb.org.uk/sef/evidence/data_and_statistics.aspx
- Health Protection Agency (2008). Sexually Transmitted Infections and Young People in the UK. http://www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb_C/1216022460726
- BASHH (2002) guidelines for development of comprehensive sexual health services for young people under 25 years. http://www.bashh.org/documents/24/24.pdf
- BASHH (2010).Guidelines for Management of STIs and Related Conditions in Children and Young People. http://www.bashh.org/documents/2674
- Faculty of Sexual and Reproductive Healthcare (FSRH) (2010) Contraceptive Choices for Young People. http://www.ffprhc.org.uk/admin/uploads/ceuGuidanceYoungPeople2010.pdf

http://www.chlamydiascreening.nhs.uk/

http://www.nhs.uk/worthtalkingabout/Pages/sex-worth-talking-about.aspx

Health Protection Agency Sexual Health Information
http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/SexualHealth/SexualHealthPromotion/

http://www.sexualhealthpromotionbirmingham.info/assets/pdfs/sti_files.pdf

http://www.sexualhealthpromotionbirmingham.info/resources/res.html

http://www.healthysex.bham.nhs.uk/Sex_Directory_07.pdf

Department of Education Teenage Pregnancy guidance
http://www.education.gov.uk/childrenandyoungpeople/healthandwellbeing/a0066808/teenage-pregnancy-guidance

Manual of the Society of Sexual Health Advisers (2004)
http://www.ssha.info/resources/manual-for-sexual-health-advisers/

Faculty of Sexual and Reproductive Health. http://www.ffprhc.org.uk/

British Association for Sexual Health and HIV http://www.bashh.org/

Society of Sexual Health Advisers www.ssha.info

Health Protection Agency www.hpa.org.uk

Sexual Health Information for Young people

- Like it is – www.likeitis.org.uk
- NSPCC – www.there4me.com
- Family Planning Association – www.fpa.org.uk

- Brook Centers http://www.brook.org.uk/
- Gay Youth UK http://www.gayyouth.org.uk
- BPAS "You think you may be pregnant?" information sheet for young people http://www.bpas.org/js/filemanager/files/young_persons_low_resfinal_issue_3.pdf

Where to find Sexual Health services

- NHS Choices for listing of Sexual Health Clinics for Young People http://www.nhs.uk/ServiceDirectories/Pages/ServiceResults.aspx?Name=young%20people&ServiceType=SexualHealthService&JScript=1&Filter=13090&PageNumber=1

Brook Centres http://www.brook.org.uk/find-a-centre

BPAS – leading private provider of abortion services, www.bpas.org

Genetic Testing

Young people diagnosed with conditions with a known genetic component should be offered access to genetic counselling and testing to help them in their decision-making around

- sexual risk-taking and contraception (i.e. accidental pregnancy)
- their or their partner's wish to have a baby (planned pregnancy)

Since "genetic counselling" is primarily focused on information-giving about the genetic risks involved, processing of such information cannot be achieved in a single meeting. Additional support and opportunity to digest information and make decisions should be given in the young people's or palliative care setting as appropriate.

Resources:

UK Network for Genetic Testing http://www.ukgtn.nhs.uk/gtn/Home

Database of Genetic Testing Services http://www.ukgtn.nhs.uk/gtn/Search+for+a+Test

Association for Genetic Nurses and Counsellors http://www.agnc.org.uk/index.htm

Confidentiality in Health Care & Sexual Health Settings

In principle, the duty of confidentiality owed to a person under 16 is the same as that owed to any other person. Specific regulations are found in individual professional codes of conduct.

Unlike teachers in schools, doctors or health professionals in health care settings are 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:

- he / she understands the advice provided and its implications

- his or her physical or mental health would otherwise be likely to suffer and so the provision of advice or treatment is in their best interest

These criteria are enshrined in the Fraser Guidelines (see resources). Even if a decision is taken not to provide treatment, the duty of confidentiality still applies. The duty of confidentiality is not, however, absolute. In cases where the health care professional believes there may be a risk to the health, safety or welfare of the young person, agreed child protection protocols should be followed. This applies particularly to any sexual activity involving children under 13, or where information is obtained about abusive or seriously harmful sexual activity.

Confidentiality Resources:

General Medical Council. 0-18. Guidance for all doctors. http://www.gmc-uk.org/static/documents/content/0-18_0510.pdf

Feming, (2006), C. Risk Management and the Fraser Guidelines. Confidentiality and Consent. http://onlinetog.org/cgi/reprint/8/4/235.pdf

Department of Health (2004) 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. http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4086914.pdf

Sexual Health (Promoting Sexual Well-Being)

— Helping Teenagers and Young People Express Themselves Sexually

Since the AIDS epidemic in the 1980s, health professions dealing with human sexuality in all its forms have almost exclusively focused on themes of risk containment, such as the prevention and treatment of STIs and prevention and support around teenage and unwanted pregnancy. Most professionals never encounter any positive teaching on sexuality throughout their entire training and later development, unless they specifically seek it out. This is despite the fact that both being in an intimate relationship and enjoying regular sexual expression (as part of an intimate relationship, in more casual encounters or through masturbation) are associated with a wide variety of health benefits. See http://www.theoncologynurse.com/article/why-intimacy-and-sexuality-matter-and-what-you-can-do-help-your-patients for a brief overview and selection of further references, and http://www.hawaii.edu/hivandaids/Health%20Benefits%20of%20Sexual%20Expression.pdf for a White Paper on the Health Benefits of Sexual Expression, leading the World Association of Sexology to conclude that “Sexual pleasure, including autoeroticism, is a source of physical, psychological, intellectual and spiritual well-being”.

As has been amply discussed, sexuality and its development are of particular relevance to teenagers and young people, and this applies to those with disabilities and chronic illness in the same way as it does to their healthy peers.

It is also known that the importance placed on sexuality by an adult person does not change significantly as they encounter chronic illness, or approach the end of life. How sexuality is

expressed may change in line with physical limitations posed by fatigue, pain, impaired mobility etc. For some, intimacy and sexual expression become more important: they help the patient to cope with anxiety and to feel normal; they release stress, induce relaxation, improve sleep, and help reduce pain; they help the patient feel closer to their partner, to feel loved and accepted, to feel wanted, and to express love and care; they improve the patient's body image, their self esteem, their view of self as a man or woman; they help them to hold onto life, indeed to celebrate life, and are also an important way of saying goodbye at the end of life.

Young people facing life-threatening illness are likely to be able to experience the same benefits, although less research has been conducted to confirm this. In addition, sexual expression, and in particular concrete, significant events such as "the first time holding hands" "the first kiss" "the first heavy petting" "the first time" (i.e. intercourse) may also signify the reaching of an important developmental milestone. For some, the wish to reach these milestones and, for example, to experience sexual intercourse before dying, is very strong.

Human sexual functioning is determined by complex interactions between a variety of physical and psychological factors as well as our relationships. When trying to understand patients' difficulties, and helping them to find a way forward, it is important to consider the role played by each of these elements, to be able to give the most appropriate advice. For a "patient-friendly" explanation of this model see chapter 2 of http://www.sexualadviceassociation.co.uk/downloads/sexuality-intimacy-for-cancer-patients.pdf

Frequently, when exploring these different elements, discussions take place about parental values, peers' influences, sex education or lack thereof, access to information and contraception, body image, sexual confidence and communication skills and (lack of) opportunities to be sexual (e.g. privacy, potential partner, ability to self-stimulate).

Apart from paying attention to these important broad psychosocial contextual variables, it is obviously also important to get a good understanding about what exactly happens physically and behaviourally when the young person tries to be intimate with a partner or engage in masturbation. If we are not practiced at doing this, it can feel awkward to ask very explicit questions about sexual behaviours. Usually such a discussion does not come out of the blue but rather develops in the context of having already spoken more generally about problems related to sexual expression or function (see also earlier section on Addressing Sexuality). To find out where exactly the patient is experiencing difficulties, it can be helpful to ask explicitly about the different stages of the human sexual response. Before changing the discussion to a somewhat more clinical and explicit range of questions, it can be helpful to give a "warning shot" and ask the young person's permission to continue.

For example, "*In order to understand your difficulties better and to try to help you, I would like to ask you some more direct questions about what happens in the bedroom and where any difficulties appear. Is that OK? (Please tell me if you prefer not to answer any question.)"*

An example of helpful questions:

- Do you ever spontaneously get any sexy thoughts or daydreams or do you respond to seeing an attractive person? (desire)

- When you masturbate or are in a sexual situation with someone, do you become sexually excited? (lubricate, erections = arousal)

- Do you experience orgasms?

To determine if there are problems in any stage of sexual response cycle and get an early impression of whether a sexual dysfunction is present.

It is also helpful to ask:

- What kinds of things do you do with your partner?
- Do you ever have any problems with pain or mobility when trying to be intimate?
- What ways have you tried for overcoming these?
- Have you ever tried to have intercourse? How did it go?
- When was the last time you were intimate? What happened?
- How often do you make love at the moment?
- How does that compare to before?
- What would you like to be different?
- What effect is this situation/problem having on your life?

It's important to remember the PLISSIT model previously discussed. Not everybody needs to be comfortable in asking this level of detailed questions, but at least one person per setting should.

Many HCPs hesitate in enquiring about sexual problems as they fear not having all the answers. It is important to know that finding solutions to many sexual concerns is not “rocket science” but rather based an ability to form relationships with patients, develop trust, confidence, and skill to ask the right number of questions sensitively (and non-judgementally) until we truly understand where the patient is at. We need the humility to understand that we do not need to be experts, that it is often enough to accompany patients on this journey, to apply common sense, and to offer what may seem to be “basic” suggestions.

Although little has been written specifically to help young people with chronic or life-limiting illness overcome or work around sexual difficulties, different resources have been created for adults facing a variety of health conditions (see resources below). These are likely to contain a variety of relevant tips, ideas and access to resources which will be equally helpful to a younger person. While it can be helpful to have an understanding of the patient’s specific medical condition and to consider how this impacts on sexual function in a biomedical sense, in most cases, most useful interventions are made at the “Information & Specific Suggestions” level. Only a few cases require the opinion of a specialist. At the level of specific suggestions, most helpful ideas are often of a very practical nature (e.g. how to talk to a partner, how to extend foreplay until fully aroused, how to challenge traditional ideas of sexuality if these are not helpful, how to get out of a mindset of performance pressure, how to try different positions, etc). These suggestions are often generic in nature and therefore suitable for helping patients with a variety of conditions overcome difficulties they share in common. It may therefore be worthwhile scanning the literature available across different conditions to find the most helpful ideas in a given case.

Resources

Books

Sexual Function in People with Disability and Chronic Illness - Marca L. Sipski and Craig J. Alexander 1997 Aspen Publishers Inc
The Ultimate Guide to Sex and Disability – by Miriam Kaufman, M.D., Cory Silverberg and Fran Odette 2003 Cleis Press
The New Joy of Sex by Susan Quilliam 2009
The Sex Book by Suzi Godson with Mel Agace, 2002 Cassell

Disability-Specific information

Multiple Scelerosis
http://www.mstrust.org.uk/downloads/sexuality_and_ms.pdf

Cystic Fybrosis
http://www.cysticfibrosis.ca/assets/files/pdf/Sexuality_and_CF_adolescentsE.pd

Muscular Dystrophy
http://www.muscular-dystrophy.org/about_muscular_dystrophy/yourstories/interviews/3018_sex_and_disability
http://www.muscular-dystrophy.org/assets/0000/6390/Final_proof_signed_off_14-8-08.pdf
Article
http://www.muscular-dystrophy.org/how_we_help_you/publications/1928_personal_relationships_and_sexuality

Sexperts Sex Info Online
http://www.soc.ucsb.edu/sexinfo/question/muscular-dystrophy-is-affecting-my-sex-life

Outsiders
http://www.outsiders.org.uk/leaflets

Leaflets to download on the following topics

- Disability and Body Image
- Physical Disability and Sexual Intercourse
- Personal Relationships and People with Physical Disabilities
- Continence and Sex
- Sex with a Heart Condition
- Sex and Multiple Sclerosis
- Practical Sex Tips for Disabled People
- Sex Toys and Disability
- Sex and Your Child with a Disability
- Sex and your Partner with a Disability
- Contraception for People with Disabilities
- Sex and the Person with an Ostomy
- Disabled and Homosexual
- Disabled People and Paid Sex
- Sex after Hip Replacement

- Sex and Learning Disabilities
- Fatigue

Cancer
http://www.cancervic.org.au/downloads/brochures/cancer_types/Sexuality_cancer_08.pdf
http://www.sexualadviceassociation.co.uk/downloads/sexuality-intimacy-for-cancer-patients.pdf
Teen Info on Cancer and Sexuality http://www.click4tic.org.uk/Search/SearchResults?SearchableText=sex
http://be.macmillan.org.uk/be/p-298-relationships-sex-and-fertility-for-young-people-affected-by-cancer.aspx
http://www.jimmyteens.tv/?s=sex

General Information on Disability & Sex

Sexual Health & Disability Alliance (SHADA) http://www.shada.org.uk/
Self Help Group affiliated to SHADA http://www.outsiders.org.uk/home
Contact a Family: Sex and Relationship Education for Young People with Physical Disabilities, also available in audio format http://www.cafamily.org.uk/publications.html?scat=39
http://www.cafamily.org.uk/pdfs/GrowingUpYoungPeople.pdf
http://www.cafamily.org.uk/pdfs/GrowingUpParents.pdf fs/GrowingUpTeachers.pdf
British Association for Sexual Educators http://www.baseuk.org/ please
http://www.thesite.org/sexandrelationships/havingsex/sexanddisability
http://www.sexualhealth.com/channel/view/disability-illness/
http://www.sexsupport.org/DisabilityLinks.htmlhttp://www.scisexualhealth.com/About.html
http://www.healthyplace.com/sex/menu-id-66/
http://www.disaboom.com/search/results?query=sex
Lovers' Guide Online http://www.loversguide.com/sex_and_disability.html
Leonard Cheshire Disability http://www.lcdisability.org/?query=sex&lid=7

Disability friendly reputable sex shops who offer information & support

www.goodvibes.com
http://www.goodvibes.com/content.jhtml?id=1272 for disability articles
http://www.goodvibes.com/search/super_search.jhtml?query=disability&searchType=Toys for disability friendly sex toys

- http://www.mypleasure.com/education/sexed/disabilitylist.asp
- http://www.comeasyouare.com/default/index.cfm/sex-tips/sex-and-disability/ tips on adapting
- **Spokz** website selling sex toys for disabled people http://www.spokz.co.uk/sections/sex-aid-products-_-be-advised_-adult-content.asp
- www.beecourse.com
- Shiri Zinn offers to hand-make quality sex aids for people with disabilities shirizinn@btinternet.com

Professional Help

http://www.fpa.org.uk/media/uploads/professionals/pdf_sexual_behaviour_factsheet__apr_2009.pdf
http://www.fpa.org.uk/media/uploads/professionals/pdf_sex_relationships_and_education_factsheet__jan_2011.pdf i
Couldrick L, Sadlo G, Cross V (2010) Proposing a new sexual health model of practice for use by physical disability teams: The Recognition Model. International Journal of Therapy and Rehabilitation 17 (6) 290-299 (abstract under http://www.ijtr.co.uk/cgi-bin/go.pl/library/abstract.html?uid=48152

Tricky Problems

Some of the most difficult situations around dealing with sexual questions in a paediatric palliative care setting arise when patients' requests go beyond those of listening or provision of straight-forward information. It is not uncommon for a young person to build up enough trust in a member of staff to ask for more specific help in achieving sexual fulfillment.

Examples may be :

- a request for help in obtaining a suitable sex aid
- a request for some day-time privacy or that a partner may spend the night
- a request to explore options enabling the young person to have a sexual encounter of some kind or experience sexual intercourse when they have not been successful in meeting a partner

Case Studies

Several case studies of young disabled men who were helped to access sex workers have been reported in the media and literature.

Nick (22 years, Duchenne's muscular dystrophy):

"*I had always hoped I would experience sex as part of a close relationship but began to accept this might not happen for me.*" He shared with his health care team the wish to, if nothing else, experience a sexual experience before he died. He had decided that the only way forward was to pay for a sexual experience, with or without the support of his health care team. The team decided that it was their duty of care to support him. Nick met the sex worker in his own home but with a nurse and another adult in the next room in case he needed them.

Nick's own evaluation of the encounter was as follows: "*She turned out to be intelligent and pleasant woman, attractive, in her late 20s. I guess that she was used to relating to nervous people as she put me at ease. The two hours passed quickly and it was, you may say, satisfactory. I am pleased I had the tenacity and commitment to see it through. The experience, while not emotionally fulfilling, gave me confidence and a sense that I was not missing out. I do not think I will necessarily choose to repeat it, although I have not ruled it out*."

http://www.telegraph.co.uk/news/uknews/1540753/Hospice-helped-dying-man-lose-his-virginity.html

Another positive account of an encounter between a sex worker and a young disabled man can be found in Women of the Light: New Sacred Prostitute by Kenneth Ray Stubbs (1994), this time told through the eyes of the sex worker.

Unsurprisingly, sexual encounters between disabled young men and a person previously unknown to them are not always unproblematic or necessarily a positive experience as demonstrated by the following quote:

Eddie:

"*I lost my virginity when I was 14. I tried to do it, probably couldn't manage to do it , although it made me think I did, because I haven't got feeling in my penis or anything, therefore, although I could get semi-erections, I couldn't tell if I was in properly. She was older. It was like an organized thing. I thought she was a prostitute but I didn't pay her. Whether my friends did or not, I don't know. It was a very unpleasant experience. I don't know whether my friends thought they were helping me out, or whether they were mocking me, because that's what it sounds like, because sex was supposed to be a really wonderful thing and this wasn't at all… And it meant nothing to her and that hurt me.*"

Comparing the two encounters may help in drawing out some basic guidelines. First and foremost, in these as in all other cases are a consideration of age and consent.

What other factors may need to be taken into account when considering the case of a young single person with disability or life-limiting illness contemplating ways to have a sexual encounter? (maybe this could be an exercise for people to complete before having answers revealed?)\

Key factors to be considered:

- Reasons for request and specific circumstances
- Age and capacity
- Legal situation
- Local policy
- Professional guidelines
- Informed consent

How to make the decision

- It has to be the patient's request.
- Take into account THE patient's circumstances and reasons for their request.
- Take into account the key factors above.
- Involve the full MDT in discussion including, where possible, psychology, social work, occupational health, spiritual support .
- Ensure both sides of the arguments are given equal attention.
- Let at least one person function as advocate of patient & their request.
- Each member has to be aware of their own personal values and attitudes in this field which may sway the group to rule out certain options without fair consideration.
- Try to keep an open mind in this highly emotive, value-laden area: medical and legal facts should be the main guide. The patient's rather than the health care team's values are of primary importance.
- Approach a legal expert for advice in specific case (see resources below).

What to explore with young person & how to support them

- If you find that supporting the young person is this area is difficult due to your personal values, lack of experience, or discomfort discussing the topic, try to find another member of the team who may be able to do this more comfortably.
- Ensure that as HCP, you have a good understanding of the reasons for this wish by having several meetings with the patient over period of time, at which you listen out for emotional content.
- Ensure the patient's full understanding, and therefore make sure that their consent to any sexual activity is indeed informed (i.e. informed consent). This could involve detailed conversations about what the limitations of any encounter might be, for example:
  - They can't provide a relationship.
  - They can't provide an emotional connection.
  - It might feel like a real disappointment even if "successful" (first times often feel like a bit of a let-down even as part of an uncomplicated, "normal" relationship).
  - They might end up feeling "cheap" , "dirty" , "desperate" or "guilty".
  - Even having achieved exactly what they wanted, they may not feel it has the positive long term effect hoped for (maybe having had sex one time is not enough but leads to acute awareness that under normal circumstances a first time is likely to lead to more opportunities for intercourse often in the context of a personal relationship).
  - Despite having achieved their goal of losing their virginity, it does not make them feel more accepting of their condition or their nearing death, but only more full up with grief or anger.
  - The encounter itself may be disappointing. The wished-for sexual experience may not happen (perhaps due to physical limitations, pain or erectile difficulties often caused by performance pressure inherent in the situation).
  - Equally, give room to acknowledge what some of the hoped-for positive outcomes may be: achieving a milestone — "must do's before I die"; knowing what it's like, what it's all about; "becoming a man/woman"; release of sexual tension, etc.
  - Look at all available alternatives.
  - Keep an open mind-set.
  - Where is it not possible for the young person's request (or newly arrived-at alternative) to take place, be mindful of how difficult this may be for the young person and offer ongoing emotional support.
  - Equally, where the desired encounter does take place, ensure a "debriefing" and ongoing support.
  - Detailed and sensitive attention should be paid to decision-making for help with finding a partner or having help with masturbation.

What do Local Authorities think?

In 2009, Outsiders and the TLC Trust carried out a Survey to find out about views and policies regarding the physical and emotional well-being of disabled men and women. Selected results can be seen at http://www.outsiders.org.uk/foi-policy-survey-2009**.**

Key findings relating to sexual relationships and the use of sex workers

- **72% support the rights of disabled people to develop and maintain sexual relationships**
- **78.5% don't condone hiring of sex workers by disabled people within their care - 86.7% do not condone payment of sex workers by money originating form social services**
- **Only 3% have a policy on the use of sex workers by disabled men and women**

Overall, the responses given by many local authorities revealed a lack of understanding of the law relating to such questions. How sensitive and controversial a topic this is was demonstrated by this article and subsequent debates and comments from readers http://www.dailymail.co.uk/femail/article-1303993/Offering-mentally-disabled-sex-prostitutes-taxpayers-expense-madness.html

The level of uncertainty and misinformation exposed surrounding this topic has led SHADA to urge health care organization s to develop their own policies on sex and relationships for disabled people as well as policies on using sex workers and enablers for disabled people. The have produced a range of guidance documents:

Policy on implementing a sex and relationships policy for disabled adults in residential homes http://www.shada.org.uk/sites/default/files/Residential_Policy.pdf

Policy on Implementing a sex and relationship policy for Consultants in Secondary and Tertiary Care
http://www.shada.org.uk/sites/default/files/Consultants_policy.pdf

Policy on implementing a policy on Using Sex Workers and Enablers
http://www.shada.org.uk/sites/default/files/SexWork_Policy.pdf

Policies for other professional groups are available.

Variety of options for single individuals wishing to experience a sexual encounter

It is not uncommon that a friend's or sibling's sexually open-minded friend hears of the problem and volunteers to offer the required experience. Such a situation should not be presumed to be unhealthy or worrying. Where the situation becomes known to HCW, it might be appropriate to counsel both partners as above. Also, consider the legal situation, which is no different from other consenting sexual relationships as long as there is no exchange of money.

In many cases, it may be necessary, and in some instances more appropriate, to involve a professional sex worker, experienced and comfortable working with clients with disabilities. The TLC is a helpful website for finding a local and responsible sex worker.

Where the TLC lists no sex worker locally, the site gives advice on finding one: by typing "escort"and your home town into a search engine such as Google, and searching one of the many websites with excellent listings: Punternet, or McCoys Guide, for example.

When speaking to a sex worker about a potential client, it is important to find out a little bit about each other and discuss the sex worker's comfort in working with a disabled person. It is also important to make the escort aware of the desired outcome (e.g. to have a positive and respectful experience of losing virginity, to feel good afterwards, to provide rich fantasy for masturbation, to have good memories of how their body felt, improved body image, improved confidence and improved sexual knowledge on masturbation and sexual engagement).

The Legal Situation

Sex Aids:

- Providing information about sex aids is legal & young person has human rights argument in its favour
- It is not an offence to buy or use sex aids at any age
- It is not an offence to buy sex aids on behalf of a young person. There is a remote possibility under the Obscene Publications Act where currently prosecution is rare and usually fails. Future criminalization cannot be ruled out. It may be safest (but not necessarily most clinical helpful) to supply products with ambiguous uses to a young person
- Sex shops are not permitted to let under 18s on their premises
- Many online shops and high street chains such as Ann Summers are unlicensed.

Sexual Contact between Minors:

- Age for ability to give sexual consent is 16. If both partners are over 16, no criminal offence is taking place, as long as there are no other significant factors such as coercion or inability to consent for other reasons
- If one or both partners in a consenting couple are under 16 that could be a legal issue. The Sexual Offences Act is very prescriptive and whilst its avowed aim is to “protect” children, not criminalize them, it could have that effect as any sexual activity between persons hetero/homosexual where either or both are under 16 is an offence. Thus two 15 years old who have consensual sexual activity are technically committing an offence. Their prosecution or not is left to the prosecutor’s discretion.
- Between 13 and 15 they are generally not prosecuted. It was not Parliament’s intention to punish children unnecessarily or for the criminal law to intervene where it is wholly inappropriate. It is generally not deemed in the public interest to prosecute children who are of the same or similar age, who have the understanding that they are engaging in sexual activity, where the activity is truly consensual for both parties and there are no aggravating features such as coercion or corruption.
- When one partner is under 13, however, any sexual activity is always deemed illegal.

Health Care Workers permitting sexual activity to take place:

See Sexual Offences Act Section 14 Arranging or facilitating commission of a child sex offence

- It is an offence for a person to facilitate something that he intends or believes would happen that would result in the commission of a child sex offence.
- It is a defence if the person arranges or facilitates something that although he believes it might happen, he does not intend to happen, as long as he acts for the protection of the child.
- Under this clause, it is (for example) legal to provide a condom to a young person in circumstances where the young person says they are already having sex.
- The defence does, however, not apply if the person acts for the purpose of causing or encouraging the activity – it would therefore be an offence to give a condom to a child under 16 whilst arranging for him or her to have sex with a friend.
- It would be a defence for the HCW to have acted for the well-being of the child and not to have intended any sexual activity to take place.
- There is no case law in this area relating to care home/hospice settings allowing partners to stay the night and "turning a blind eye".
- Prosecution seems unlikely especially if there was no express encouragement of sex and two beds were in the room.

Prostitution

- Prostitution is not an offence in the UK (although there is more complicated fine detail surrounding the regulation of prostitution — brothels and soliciting on the streets/kerb crawling are all offences, see links for further details).
- If patients or clients wish to use sex workers, that is perfectly legal, provided that they are over 16 and do not suffer from any condition that might prevent them from giving "informed consent." The sex worker needs to be 18 years or older.
- Young people under the age of 16 are not legally allowed to use the services of a prostitute.
- There are instances where care workers have supported this for teenagers, but it is a criminal offence to do so. To date nobody has been prosecuted.
- It is not a criminal offence for a Health Care Workers to arrange a sex worker on behalf of a client who is over 16 provided there is no element of coercion or exploitation.
- If a sex worker visits a client in a hospice or hospital, that is not illegal under criminal law and does not convert the premises to a brothel.

When contemplating the specifics of an actual case, it is obviously helpful to get the advice of an experienced legal expert (see links).

Legal Background and where to get help

Family Planning Association: The Law on Sex
http://www.fpa.org.uk/media/uploads/professionals/pdf_the_law_on_sex_factsheet_january_2011.pdf

SW5 Sex worker's advice site http://sw5.info/law/
http://sw5.info/morelaw.htm

Claire de Than human rights lawyer specializing in sex and disability clairedethan@mac.com

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

Summary

- Sexuality is an integral part of normal life for most people and an important aspect of quality of life
- Issues relating to sexuality are amongst the most poorly addressed in palliative care
- Gold Standards Framework in Palliative Care: "We only get one chance to get it right"

Complete List of References

Sexuality
Development of sexuality & sexual identity

1. Whipple, B., Koch, P. B., Moglia, R. F., Owens, A. F. & Samuels, H. (2007). The Health Benefits of Sexual Expression. Planned Parenthood Federation of America. http://www.hawaii.edu/hivandaids/Health%20of%20Sexual%20Expression.pdf
2. Bukatko, D. (2007). Child and Adolescent Development: A Chronological Approach
3. Bekaert, S. (2004) Adolescents and Sex: The Handbook for Professionals Working with Young People.
4. Coleman, J. & Roker, D. (1998) Teenage Sexuality: Health, Risk and Education.
5. British Association for Sexual Health & HIV (BASHH) (2006) National Guidelines for consultations requiring a sexual history taking. http://www.bashh.org/documents/84/84.pdf
6. WHO (2001). Counselling Skills Training in Adolescent Sexuality and Reproductive Health – A Facilitator's Guide. http://whqlibdoc.who.int/hq/1993/who_adh_93.3.pdf

Sex Education in British Schools

7. SRE Guidance DfEE 0116/2000.
8. 2010 Report: SRE- Views from teachers, parents and governors. http://www.nga.org.uk/uploadfiles/SRE%20Education%20Views%20from%20teachers%20parents%20and%20governors.pdf
9. See: Sex Education Forum. Confidentiality in Schools Factsheet http://www.ncb.org.uk/PDF/sef_ff_38.pdf for more detailed information.
10. http://www.fpa.org.uk/media/uploads/professionals/pdf_sex_relationships_and_education_factsheet__jan_2011.pdf

Main Reports & SRE Overviews

11. Department for Education and Employment (2000) Sex and Relationship Education Guidance. http://www.education.gov.uk/publications//eOrderingDownload/DfES-0116-2000%20SRE.pdf
12. Ofsted (2002) Report on Sex and Relationship Education. http://www.ofsted.gov.uk/Ofsted-home/Publications-and-research/Browse-all-by/Education/Curriculum/Personal-social-health-and-economic-education/Primary/Sex-and-relationships-education-in-schools
13. What is taught in schools? Summary of learning outcomes Ofsted Report of Sex and Relationships (2002). http://www.swish.org.uk/?q=parents/school
14. Family Planning Association (2010) Factsheet Sex and Relationships. Education http://www.fpa.org.uk/media/uploads/professionals/pdf_sex_relationships_and_education_factsheet__jan_2011.pdf
15. Sex Education Forum (2008).Young People's Survey on SRE – Key Findings. http://www.ncb.org.uk/dotpdf/open_access_2/sef_youngpeoplessresurvey_briefing.pdf
16. Sex and Relationship Education – Views form teachers, parents and governors (2010). http://www.nga.org.uk/uploadfiles/SRE%20Education%20Views%20from%20teachers%20parents%20and%20governors.pdf

Age appropriate curriculum & Resources
Primary

17. Sex Education Forum (2001) Sex and Relationship Education for Primary Age Children.

http://www.ncb.org.uk/dotpdf/open%20access%20-%20phase%201%20only/ff28_sef_2001.pdf
18. Sexual Education Forum. SRE Curriculum Content Age 3-6. http://www.ncb.org.uk/sef/resources/curriculum_design/questions_to_explore/ages_3-6.aspx
19. Sexual Education Forum SRE Curriculum Content Age 7-8. http://www.ncb.org.uk/sef/resources/curriculum_design/questions_to_explore/ages_7-8.aspx
20. Sexual Education Forum SRE Curriculum Content Age 9-10. http://www.ncb.org.uk/sef/resources/curriculum_design/questions_to_explore/ages_9-10.aspx
21. Sexual Education Forum SRE Resource List for Primary Schools. http://www.ncb.org.uk/PDF/Resource%20List%20-%20Primary.pdf
22. Sexual Education Forum. Samples of Lesson Outlines for Primary Schools, by year http://www.ncb.org.uk/sef/resources/curriculum_design/sow-_primary.aspx

Secondary

23. Sexual Education Forum SRE Resource List for Secondary Schools. http://www.ncb.org.uk/PDF/Resource%20List-%20Secondary.pdf
24. Sexual Education Forum SRE Curriculum Content Age 11-13. http://www.ncb.org.uk/sef/resources/curriculum_design/questions_to_explore/ages_11-13.aspx
25. Sexual Education Forum SRE Curriculum Content Age 14-16. http://www.ncb.org.uk/sef/resources/curriculum_design/questions_to_explore/ages_14-16.aspx
26. Sexual Education Forum SRE Curriculum Content Age 16+. http://www.ncb.org.uk/sef/resources/curriculum_design/questions_to_explore/ages_16.aspx
27. Sexual Education Forum. Samples of Lesson Outlines for Secondary Schools and 16+. http://www.ncb.org.uk/sef/resources/curriculum_design/sow-_secondary.aspx

Disability & Special Needs

28. Sex Education Forum Factsheet on SRE for Children and Young People with Learning Disabilities (2004) http://www.ncb.org.uk/dotpdf/open%20access%20-%20phase%201%20only/ff32_sef_2004.pdf
29. Sexual Education Forum SRE Resources Special Needs and Disability http://www.ncb.org.uk/PDF/Resource_List_Special_needs_Disability.pdf\
30. Sexuality Education for Youth with Disability and Chronic Illness. A Resource List. http://www.med.umich.edu/yourchild/topics/disabsex.htm

Parents

31. Sex Education Forum (2001). Talk to your children about sex and relationships, Support for parents. http://www.ncb.org.uk/dotpdf/open%20access%20-%20phase%201%20only/ff31_sef_2001.pdf
32. Sexual Education Forum Resource List Parents and Carers. http://www.ncb.org.uk/PDF/Resource_List_Parents_carers.pdf

Other

33. Personal, Social, Health & Economic Education (PSHE) Association. http://www.pshe-association.org.uk/ for list of resources and local advisors
34. Birmingham Health Education Service ("Centre of Excellence" with national reputation in the planning and delivery of PSHE (Personal, Social and Health Education) and Citizenship education initiatives. http://www.bgfl.org/bgfl/71.cfm

35. Sex Education Forum Factsheet on Faith, Values and Sex and Relationship Education(SRE)(2004)
36. http://www.ncb.org.uk/dotpdf/open%20access%20-%20phase%201%20only/ff_faith02_sef_2005.pdf

Other

Statistics, Sexual Health Guidance & Professional Bodies

37. Sexual Education Forum. Data and Statistics about sexual health in young people. http://www.ncb.org.uk/sef/evidence/data_and_statistics.aspx
38. Health Protection Agency (2008). Sexually Transmitted Infections and Young People in the UK. http://www.hpa.org.uk/web/HPAweb&HPAwebStandard/HPAweb_C/1216022460726
39. BASHH (2002) guidelines for development of comprehensive sexual health services for young people under 25 years. http://www.bashh.org/documents/24/24.pdf
40. BASHH (2010).Guidelines for Management of STIs and Related Conditions in Children and Young People. http://www.bashh.org/documents/2674
41. Faculty of Sexual and Reproductive Healthcare (FSRH) (2010) Contraceptive Choices for Young People. http://www.ffprhc.org.uk/admin/uploads/ceuGuidanceYoungPeople2010.pdf
42. Department of Education. Teenage Pregnancy guidance. http://www.education.gov.uk/childrenandyoungpeople/healthandwellbeing/a0066808/teenage-pregnancy-guidance
43. Manual of the Society of Sexual Health Advisers (2004) http://www.ssha.info/resources/manual-for-sexual-health-advisers/
44. Faculty of Sexual and Reproductive Health. http://www.ffprhc.org.uk/
45. British Association for Sexual Health and HIV. http://www.bashh.org/
46. Society of Sexual Health Advisers. www.ssha.info
47. http://www.fpa.org.uk/media/uploads/professionals/pdf_sexual_behaviour_factsheet__apr_2009.pdf

Sexual Health Information for Young people

48. Like it is – www.likeitis.org.uk
49. NSPCC – www.there4me.com
50. Family Planning Association – www.fpa.org.uk
51. Brook Centres - http://www.brook.org.uk/
52. Gay Youth UK - http://www.gayyouth.org.uk
53. BPAS “You think you may be pregnant?” information sheet for young people http://www.bpas.org/js/filemanager/files/young_persons_low_resfinal_issue_3.pdf
54. NHS Choices for listing of Sexual Health Clinics for Young People. http://www.nhs.uk/ServiceDirectories/Pages/ServiceResults.aspx?Name=young%20people&ServiceType=SexualHealthService&JScript=1&Filter=13090&PageNumber=1
55. Brook Centres - http://www.brook.org.uk/find-a-centre
56. BPAS – leading private provider of abortion services, www.bpas.org

Genetic testing

57. UK Network for Genetic Testing http://www.ukgtn.nhs.uk/gtn/Home
58. Database of Genetic Testing Services http://www.ukgtn.nhs.uk/gtn/Search+for+a+Test
59. Association for Genetic Nurses and Counsellors http://www.agnc.org.uk/index.htm

Confidentiality Resources

60. General Medical Council. 0-18. Guidance for all doctors. http://www.gmc-uk.org/static/documents/content/0-18_0510.pdf
61. Feming, (2006), C. Risk Management and the Fraser Guidelines. Confidentiality and Consent. http://onlinetog.org/cgi/reprint/8/4/235.pdf
62. Department of Health (2004) 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. http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4086914.pdf
Tool
63. Couldrick L, Sadlo G, Cross V (2010) Proposing a new sexual health model of practice for use by physical disability teams: The Recognition Model. International Journal of Therapy and Rehabilitation 17 (6) 290-299 (abstract under http://www.ijtr.co.uk/cgi-bin/go.pl/library/abstract.html?uid=48152)
Helping teenagers and young people express themselves sexually
Books
64. Sexual Function in People with Disability and Chronic Illness - Marca L. Sipski and Craig J. Alexander 1997 Aspen Publishers Inc
65. The Ultimate Guide to Sex and Disability – by Miriam Kaufman, M.D., Cory Silverberg and Fran Odette 2003 Cleis Press
66. The New Joy of Sex by Susan Quilliam 2009
67. The Sex Book by Suzi Godson with Mel Agace, 2002 Cassell
68. Joannides, P. (2009) The Guide to Getting It On.
Disability-specific information
Multiple Sclerosis
69. http://www.mstrust.org.uk/downloads/sexuality_and_ms.pdf
Cystic Fibrosis
70. http://www.cysticfibrosis.ca/assets/files/pdf/Sexuality_and_CF_adolescentsE.pdf
Muscular Dystrophy
71. http://www.muscular-dystrophy.org/about_muscular_dystrophy/yourstories/interviews/3018_sex_and_disability Interview
72. http://www.muscular-dystrophy.org/assets/0000/6390/Final_proof_signed_off_14-8-08.pdf Article
73. http://www.muscular-dystrophy.org/how_we_help_you/publications/1928_personal_relationships_and_sexuality factsheet
74. Sexperts Sex Info Online http://www.soc.ucsb.edu/sexinfo/question/muscular-dystrophy-is-affecting-my-sex-life
Outsiders
75. http://www.outsiders.org.uk/leaflets and other resources elsewhere on site
Cancer
76. http://www.cancervic.org.au/downloads/brochures/cancer_types/Sexuality_cancer_08.pdf
77. http://www.sexualadviceassociation.co.uk/downloads/sexuality-intimacy-for-cancer-patients.pdf
Teen Info on Cancer and Sexuality
78. http://www.click4tic.org.uk/Search/SearchResults?SearchableText=sex
79. http://be.macmillan.org.uk/be/p-298-relationships-sex-and-fertility-for-young-people-affected-by-cancer.aspx
80. http://www.jimmyteens.tv/?s=sex
81. Sexual Health & Disability Alliance http://www.shada.org.uk

82. Physical and Social disability Self Help Group which runs SHADA http://www.outsiders.org.uk/home
83. Contact a Family: Sex and Relationship Education for Young People with Physical Disabilities also available in audio format: http://www.cafamily.org.uk/publications.html?scat=39
84. http://www.cafamily.org.uk/pdfs/GrowingUpYoungPeople.pdfhttp://www.cafamily.org.uk/pdfs/GrowingUpParents.pdf also add in parents section
85. http://www.cafamily.org.uk/pdfs/GrowingUpTeachers.pdf
86. British Association for Sexual Educators http://www.baseuk.org/
87. http://www.thesite.org/sexandrelationships/havingsex/sexanddisability
88. http://www.sexualhealth.com/channel/view/disability-illness/
89. http://www.sexsupport.org/DisabilityLinks.htm
90. http://www.scisexualhealth.com/About.html
91. http://www.disaboom.com/search/results?query=sex
92. Lovers' Guide Online http://www.loversguide.com/sex_and_disability.html
93. Leonard Cheshire Disability http://www.lcdisability.org/?query=sex&lid=7
94. www.goodvibes.com http://www.goodvibes.com/content.jhtml?id=1272 for disability articles
    **Disability friendly sex toys **
95. http://www.goodvibes.com/search/super_search.jhtml?query=disability&searchType=Toys
96. http://www.mypleasure.com/education/sexed/disabilitylist.asp
97. http://www.comeasyouare.com/default/index.cfm/sex-tips/sex-and-disability/ tips on adapting sex toys
98. Spokz website selling sex toys for disabled people http://www.spokz.co.uk/sections/sex-aid-products-_-be-advised_-adult-content.asp
99. www.beecourse.com
100. Shiri Zinn makes beautiful sex toys and offer to hand-make sex aids for people with disabilities http://www.coco-de-mer.com/