

Sexual Health (Promoting Sexual Well-Being):

Helping Teenagers and Young People Express Themselves Sexually

This document offers extended content to the Sexuality E-Learning Module in Core Competencies for Paediatric Palliative Care. It may be useful reading for all professionals working with children and young people, with or without chronic or life-threatening illness, as well as those working with adults.

Introduction

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 (be it 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 (WAS) 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 as a way of having many fundamental human needs met at a critical time. The benefits of sexual expression can include

- improved coping with or release of stress & anxiety

- feeling “normal”
- relaxation & improved sleep
- distraction from and reduction of pain
- feeling closer to partner
- feeling loved, accepted & wanted
- being able to express and receive love and care
- improved body image, self esteem & view of self as man/woman
- way of holding onto or celebrating life.

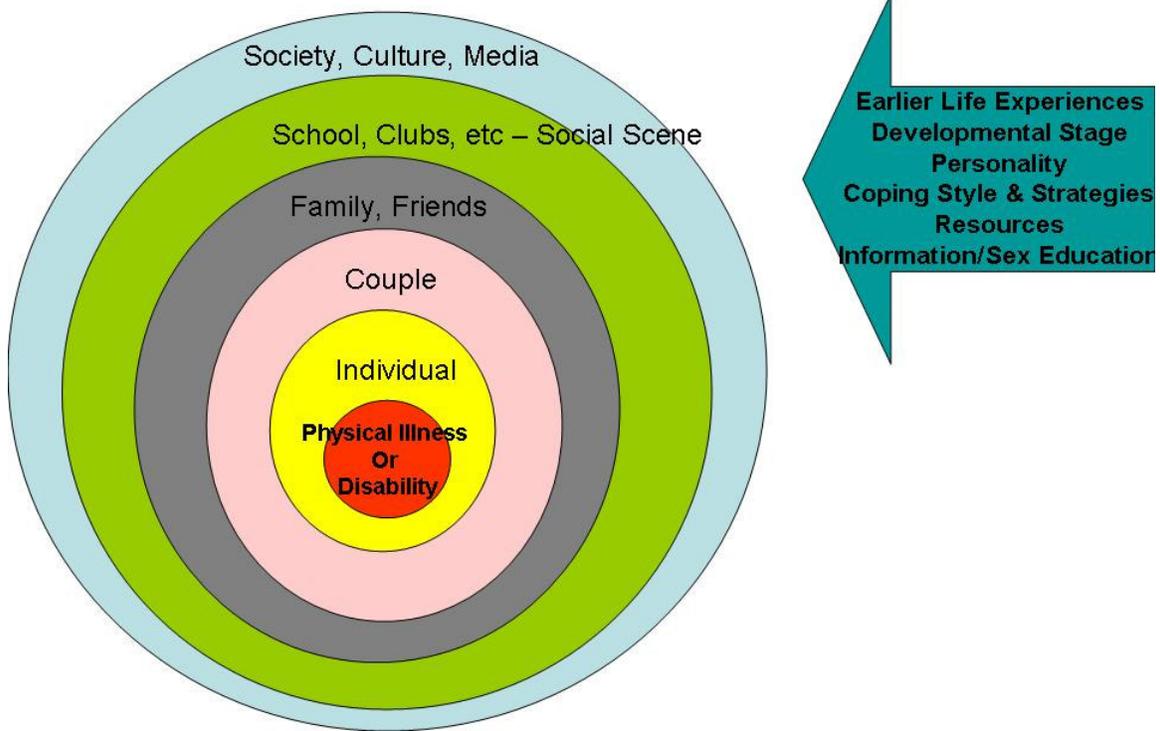
Very importantly and often overlooked, sexual expression can also be important way of saying goodbye at the end of life.

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 (Please refer to the later section on Tricky Problems for guidance on how to deal with some practical issues which may arise & an overview of the legal situation).

Further Assessment of Sexual Concerns

Human sexual functioning is determined by complex interactions between a variety of physical and psychological factors as well as our relationships:

Biopsychosocial Determinants of Sexual Functioning



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 <http://www.sexualadviceassociation.co.uk/downloads/sexuality-intimacy-for-cancer-patients.pdf>, chapter 2).

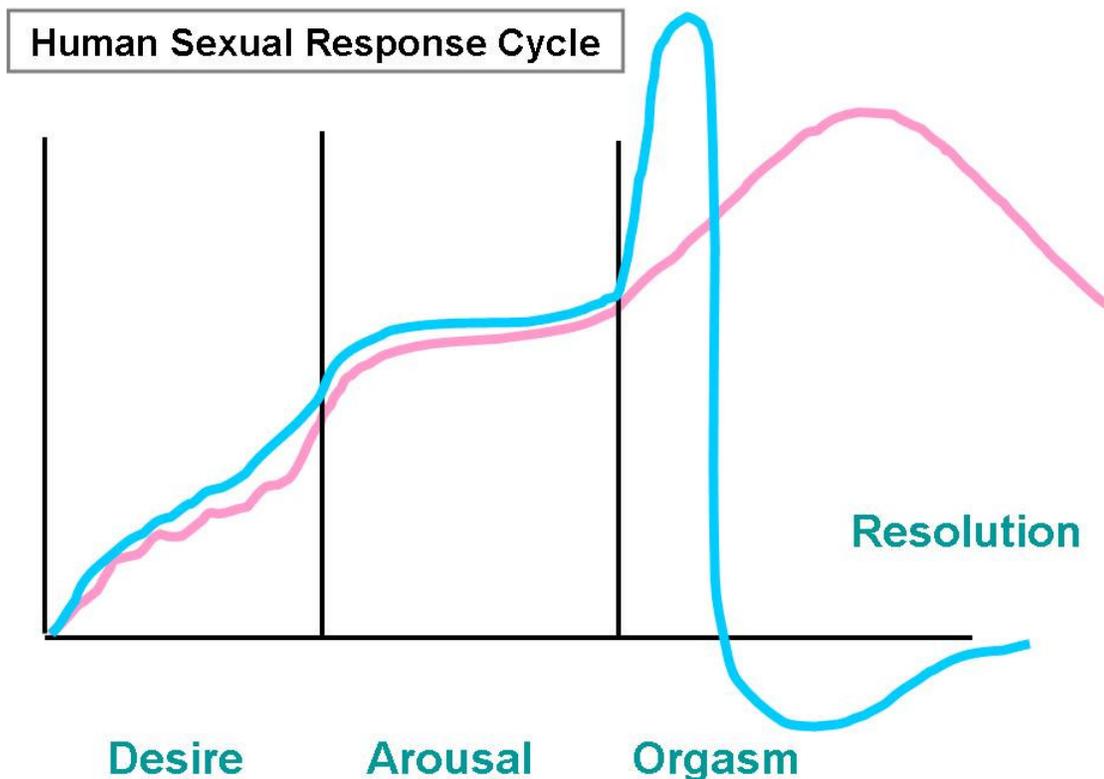
It can therefore be helpful to keep the above model of contextual factors in mind whilst assessing sexual concerns. Frequently, when exploring these different elements, discussions can take place about important topics such as

- parental values
- peer group influences
- sex education or lack thereof
- access to information and contraception
- body image
- sexual confidence

- confidence and language in discussing sexual matters
- (lack of) opportunities to be sexual (e.g. privacy, available of potential partner, ability to self stimulate).

In addition to obtaining relevant information on which to base later advice, the exploration of psychosocial variables can also help to consolidate the relationship between the HCP and patient and break the ice, making it easier to approach a discussion of more explicit sexual behaviours and physical problems encountered whilst being intimate with a partner or in masturbation.

Without practice, it can initially feel awkward to ask very explicit questions about sexual behaviours. Concerns about offending the patient or not having enough expertise to start the conversation are usually unfounded. It is helpful to ensure that a more detailed clinical discussion does not appear 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 above and also earlier section on Discussing Sexuality). To find out where exactly the patient is experiencing difficulties, it can be helpful to ask direct questions relating to 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.

Eg) *“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 at any stage you would prefer not to answer any question I ask.”)*

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?” (“Does this differ from before?”)*

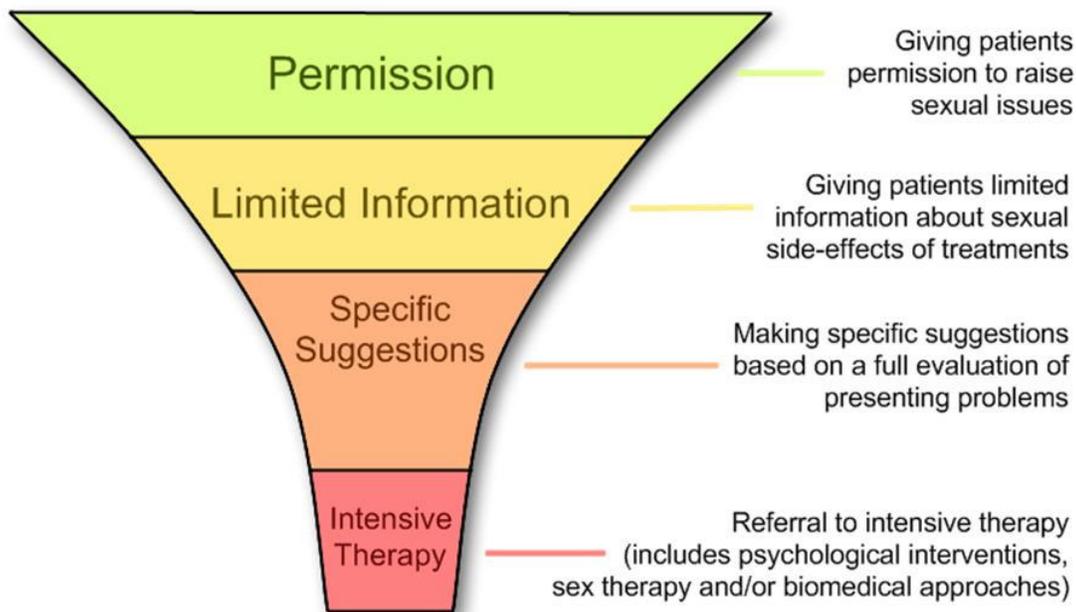
To determine if there are problems in any stage of sexual response cycle and get an early impression of whether a sexual dysfunction is present.

It can also be helpful to ask the following questions:

- ✓ *“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 can be helpful to remember the PLISSIT model previously discussed:

PLISSIT Model of Addressing Sexual Functioning (Annon, 1974)



- The majority of patients can be helped by simple interventions involving having the permission to discuss sexual issues and receiving some limited information.
- Not everybody needs to be comfortable in asking the level of detailed questions discussed here. You may be happy to stick to the basic permission-giving level of care in this area and know who to refer onto if problems are identified.
- At least one person per setting should take on the further role of providing limited information and maybe moving onto making an assessment detailed enough to provide specific suggestions to the patient. Examples of information and specific suggestions are given later in this section.
- Each professional in the system has the responsibility to ensure that patients' needs are addressed by being able to refer onto the next level of intervention if required.

Many Health Care Professionals hesitate before enquiring about sexual problems as they fear not having all the answers. It is important to know that finding solutions to many sexual concerns does not require a highly complex and totally different skills set to the one we already possess. Rather, it is based on:

- Our ability to form a trusting relationship with patients

- The confidence and skill to ask the right number of questions sensitively until we truly understand the difficulties the patient is encountering
- 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

Resources:

Although little has been written specifically to help young people with chronic or life-limiting illness overcome or find ways around sexual difficulties, a wide variety of relevant resources have been created for adults facing a variety of health conditions. Their content is generally as applicable to a younger person facing sexual difficulties as it is to the intended adult audience, even if specific wording or design might not be overtly youth-focused. Given the generic nature of sexual problems, it may be worthwhile scanning the literature available across different conditions to find the most helpful ideas for a given case.

The resources listed below are an addition to those listed in <http://www.sexualadviceassociation.co.uk/downloads/sexuality-intimacy-for-cancer-patients.pdf>. Please refer to both documents.

Alternative to PLISSIT:

- 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>)

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

- **The Guide to Getting It On.** Joannides, P. (2009)

Disease-specific information:

Multiple Sclerosis

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

Cystic Fibrosis

http://www.cysticfibrosis.ca/assets/files/pdf/Sexuality_and_CF_adolescentsE.pdf

Muscular Dystrophy

- http://www.muscular-dystrophy.org/about_muscular_dystrophy/yourstories/interviews/3018_sex_and_disability_Interview
- 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_factsheet
- <http://www.soc.ucsb.edu/sexinfo/question/muscular-dystrophy-is-affecting-my-sex-life>
Sexperts info online

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>

Outsiders (Information Leaflets)

<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

General Information on Disability & Sex:

- Sexual Health & Disability Alliance <http://www.shada.org.uk/>

- Outsiders <http://www.outsiders.org.uk/home>, online community of people with social and physical disabilities

- Contact a FamilySex and Relationship Education for Young People with Physical Disabilities, also available in audio format (other titles also available)

- <http://www.cafamily.org.uk/publications.html?scat=39>

- <http://www.cafamily.org.uk/pdfs/GrowingUpYoungPeople.pdf>

- <http://www.thesite.org/sexandrelationships/havingsex/sexanddisability>
- <http://www.sexualhealth.com/channel/view/disability-illness/>
- <http://www.sexsupport.org/DisabilityLinks.html>
- <http://www.scisexualhealth.com/About.html>
- <http://www.healthyplace.com/sex/menu-id-66>
- <http://www.disaboom.com/search/results?query=sex>
- http://www.loversguide.com/sex_and_disability.html
- <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.ihtml?id=1272> for disability articles
 - http://www.goodvibes.com/search/super_search.ihtml?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>
- Spokz website selling sex toys for disabled people
[http://www.spokz.co.uk/sections/sex-aid-products- -be-advised -adult-content.asp](http://www.spokz.co.uk/sections/sex-aid-products--be-advised--adult-content.asp)
- www.beecourse.com