

MND Podcast number seven:
Sexuality, MND and Palliative Care



Hello my name is Robyn Reid. Welcome. I am the MND Shared Care Worker in the Southern Region of Melbourne. This podcast is about Sexuality, MND and Palliative care. Palliative care strives to assist people to maintain their quality of life and to address any issues in a holistic way. Love and affection and sexuality are a vital part of people's lives. Diagnosis with a life limiting illness impacts on partnerships and relationships. Health professionals need to be able to listen to these concerns and to have conversations and explore these issues. This podcast will explore some simple techniques to allow health professionals to explore issues of intimacy and sexuality without needing to be an expert in sex therapy. It will also discuss the specific issues as they relate to people with MND.

Sexuality is an important part of relationships and means more than just having sex. This includes how patients view their body image, tactile expressions and their need for intimacy and closeness. Just because a patient has a life-threatening diagnosis, it does not automatically mean that they no longer wish to express their sexual feelings, or to convey expressions of their sexuality.

Health professionals may make assumptions about sexuality based on age, partner or status. While health professionals are not expected to go beyond their comfort level, they are expected to be able to listen to concerns about sexuality with empathy and non-judgement. Health professionals must be able to give permission to people to grieve any loss and discuss concerns related to sexuality and sexual health. They must take into consideration the persons

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preferred gender and sexual orientation in a way that allows the person to feel comfortable and accepted. It is important to be non-judgemental and open to sexuality and different practices and beliefs in order to be available for people's concerns.

Sexuality is a subjective, internal experience. It involves complex physical, psychological and biological components. Sexuality is not static but rather is part of the individual's on-going life changes. Each person has her or his own individual concept or agenda of sexuality. Sexuality is closely linked to intense emotions, self-image, and self-consciousness.

The helpful Health professional is able to listen carefully and actively and is open to and interested in the patient's concept of love and sexuality. They are able to respond to complex emotions such as shame, with skill and compassion, and are able to respect and not be judgemental of the person's sexual practices.

Sexuality is comprised of a number of processes. Physical processes involve the physiology of the human sexual response. Psychological processes include desire, arousal, body experience, self-perception and gender identity. Social processes occur within a social context such as interaction with the partner and social norms, laws and conventions. Disturbances on one level will also affect the others, so these processes cannot be dealt with in isolation.

There are many factors impinging on sexuality in palliative care. There are various treatments such as drugs, chemotherapy, radiotherapy which may

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affect tissues or may damage function or cause impotence. Symptoms such as muscle spasm, pain, paralysis, difficulty communicating, fatigue, nausea, respiratory function, wounds and secretions may affect sexuality. As well there are mental health issues such as dementia, depression and grief which will alter sexual responses, desire and activity.

Palliative care work is an intimate arena-more so than many other types of work as it deals with dying which affects people deeply and intensely and is intimate by its very nature. How do we create intimacy and trust to help people tell us their concerns? Sex and death the two taboos. How do health professionals communicate and allow people to share their vulnerabilities and most personal experiences with them? They need to demonstrate non-judgement, trustworthiness, active listening, rapport building and respect for the individual and their culture and provide knowledgeable and skilled care.

There are many things that change when there is a diagnosis of life limiting disease. Suddenly the spouse or partner becomes a carer and there is a change in roles. Medical appointments take up time and visitors and health professionals visiting the home can reduce both time to be alone, and privacy. There is often emotional distress, anger or resentment, grief, fear and many other emotions that can be expressed or impact on the relationship. There may be changes to the physical body resulting in diminished strength, and altered appearance leading to body image issues. Some wounds may be disfiguring or produce unpleasant smells. The environment may be filled with

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equipment such as tubes, Non- invasive ventilation, hospital beds or wheelchairs. All of these things will affect sexual activity and desire.

Health professionals need to create opportunities for people to describe or talk about the impact of illness on their relationships and their sense of intimacy with their partner. This means not just normalising sexuality but being specific in terms of drilling down to the issue for that particular person or providing the option for Intensive therapy at any stage. They may need to speak to someone with expertise. There may be side effects of treatment such as for example dealing with impotence as a result of drug therapy. As the level of intervention increases the level of knowledge, training and skills required are greater.

One model for enabling discussions about sexuality and intimacy is the extended PLISSIT model. Plissit stands for:

- **Permission-giving (not just normalising)**
- **Limited Information**
- **Specific Suggestions**
- **Intensive Therapy**
- **Reflect**
- **Review**

1. Permission giving:

People may not bring up concerns about their sexuality. Most people experiencing sexual problems can resolve them if given permission to be

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sexual, to desire sexual activity and to discuss sexuality. Talking can be therapeutic. Validate concerns and allow them to be 'heard'. Empathy and capacity to listen is important even when health professionals might not know the answers. Ask questions about changes in intimacy when changes occur that may impact upon it.

Questions such as - How is your relationship with your partner? How has this affected you as a couple? Some people find that it impacts upon their sexual relationship. Is there anything you would like to ask me about? These let people know that the health professional sees this as something to talk about. It is useful to highlight significant changes to initiate discussion. For example, when the move is made to an electric bed or wheelchair, or where there is loss of movement in arms or legs, or specific symptoms that could impact intimacy. You might ask: How do you think this will affect your relationship? How will you manage this? How do you feel about that? By talking about "some or many" people when discussing these issues, it enables people to identify as normal and feel comfortable.

2. Limited information can be given. For example;

- Some people with muscle spasms find some sexual positions more comfortable than others
- Many people experience impotence as a side effect of this drug. Is this something you have experienced?



- Having an electric adjustable bed has many advantages but it may also impact on your relationship as a couple.

3. Specific suggestions

Where pain is present suggest that analgesia is taken before sexual activity and that it's easier to initiate sex at a time of day when they are least tired. Suggest alternative sexual activities or positions to deal with changes in health or function. Suggest alternative ways of communicating love and affection. Warm baths can reduce muscle spasm and help with sexual activity. Sign language for I love you when there is no speech.

Ensure the couple are getting sufficient sleep and respite. Treat underlying conditions such as depression. Help them with strategies to feel connected and foster intimacy in other ways. Ensure carers are having time out from their caring role to have time alone or have fun to reassert their relationship connection other than as carer.

- 4. Intensive therapy** can be offered at any stage. It is important to recognise your own strengths and limitations and refer on to a peer who is comfortable with the topic of sexuality or refer to an expert on psychosexual therapy and relationship counselling. Certain specialists such as urologists or gynaecologists may need to be involved to address functional issues or specific treatments.



5. Reflect. In addition to reflecting and reviewing interventions with individuals, Health professionals need to reflect on their own attitudes and the impact that these might have had on the consultation. Supervision can be an important tool in this process.

6. Review

Once the topic has been discussed don't assume that sexuality has been fully addressed. Seek the person's perspective and provide further permission-giving to discuss how things are going since the last conversation. For example:

"When we last spoke you didn't have any concerns or questions about your sexual relationship. I wonder whether this is something that you've thought about since and if there is anything you would like to talk about today..?"

There is a level of sensitivity required to allow people to discuss their issues with sexuality. The context for the discussion must arise out of changes that could impact on their sexual activity or relationship rather than "out of the blue" questions about their sex life. For example: this new bed in your home is a big change, some people find it decreases the feeling of closeness they get from sleeping with their partner.. what impact do you think it might have for you? By always introducing the topic health professionals give permission for people to talk about the impact of the changes on their sexuality and its

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expression, and that it is ok to talk about that with them. Be purposeful but provide a context. Don't make assumptions and don't stereotype. Ask questions. Avoid value judgements. Address relationships and possible changes. Ask when a term or language used by people that is not known or understood. Ensure confidentiality and privacy at all times.

People living with MND and their partners may experience barriers to sexuality and intimacy. The person with MND can suffer exhaustion, physical pain, and loss of spontaneity, difficulty breathing, muscle weakness and cramps as well as having to manoeuvre a range of equipment from Non- invasive ventilation and Peg tubes to wheelchairs and aids. Partners may experience obstacles such as environmental issues due to separate beds, equipment and lack of privacy. They may be worried about hurting their partner if they engage in sexual activity. There may be inappropriate laughter and crying from their loved one due to cognitive changes, fatigue, changes in sexual roles and concerns about breathing. There may be discord in the relationship due to the impact of the role of carer.

Women with MND may still be menstruating and this may be an issue for their carer so they may need advice about contraception and menstruation management. Riluzole used in the treatment of MND has not been cleared for safety in pregnancy. If a person with MND was to be pregnant then there would be increased risks due to low mobility such as the development of deep vein thrombosis and the ability to carry out normal labour and sustain the

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pregnancy to term. Carers may be pregnant and there may be issues around lifting and their carer role.

For many people, it can be reassuring to know that MND does not directly affect fertility or sexual function. It has no direct effect on libido, sexual arousal, or the ability to have an erection or orgasm. Even if the person has limited movement, the sensation of touch is not affected by MND. Both the person and their partner can still enjoy the comfort and pleasure of touch.

If the person has restricted movement, it might be necessary for their partner to take a more active role to enable them to be comfortable. Some people are concerned that a PEG or RIG tube will be pulled or become dislodged during sex (these are tubes inserted directly into the abdominal wall to assist with the intake of food). As the PEG tube is normally well secured by a button on the inside of the stomach, it is rarely dislodged. Some people with MND worry that they will have difficulty breathing whilst having sex. If they use a ventilator, it is not harmful for them to have sex. If the person finds that they can't tolerate any pressure on the chest or abdomen, it might be necessary to consider a position where they are supported in an upright or semi-upright position, to allow for good expansion of the chest and diaphragm.

Physical symptoms should act as triggers to questions to facilitate the discussion of changes to intimacy. Consider the following examples:

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If there are changes to speech the health professional might say “many people feel that as their speech changes they no longer have conversations with their partner like they used to. Is this something that you have experienced?” Some people find excessive salivation and drooling affects their desire to kiss their partner. Has this affected your relationship? The impact of MND may change the couples socialising habits. Going out to restaurants like they used to may be difficult, due to dietary restrictions and difficulty swallowing.

Feeding a partner may change the way people see themselves as a wife, husband or partner. Asking questions about how these changes feel, validates and gives permission to express any sense of loss or discomfort. Physical weakness may mean the carer is dressing and toileting their partner and that they become increasingly dependent. Acknowledging that these changes affect all aspects of the relationship is helpful.

In summary, sexuality and intimacy are important issues that are affected by life-limiting illnesses. Health professionals must be able to discuss these issues in a way that encourages conversation and exploration. I would like to take this opportunity to give my thanks to staff at Bethlehem Calvary Health care and MND Victoria and VRSS for the support and training received in my role as MND SCW in the Southern Region. I also wish to thank Bridget Taylor, senior lecturer, Oxford Brookes University, for her research, encouragement and support on this topic. Please feel free to contact me should you wish to have an education session on MND for your agency or to receive a secondary

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