BoneCast

Special Edition

Quality of life in patients with osteoporosis – Impact of sexuality and touch

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Osteoporosis and Sexuality

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Osteoporosis and Sexuality

1. What patients are dealing with
2. Impact of osteoporosis on the patient’s sex life and love relationship
3. Consequences for health care
4. How we can help our patients

1. What patients are dealing with

Understanding the patient’s pain

What patients are dealing with

As a human being you are also a sexual being.

This is also true when you have a chronic disease.

Our sexuality is a fundamental part of our humanity.

What patients are dealing with

- As a human being you are also a sexual being. This is also true when you have a chronic disease. Our sexuality is a fundamental part of our humanity.

- Sexuality needs to be integrated into our lives, otherwise we lose this fundamental part of our humanity.

- A loss of sexuality is painful and unbearable for most people, regardless of whether they are healthy or sick.

What patients are dealing with

- Chronic diseases disrupt our experience as a sexual being and the way we have lived our sexuality so far.
- Chronic diseases remove us from what society regards as sexual.

Society

Reality

Osteoporosis

- Bones and joints become weaker
- Dissonance between your body-image and the way your body changes
- Your body changes in ways that make you feel sexually unattractive (like rounding of the back)
- Sexual movements become painful and dangerous (fractures)
- Some sexual positions become impossible (maybe your favourite)
- You can’t fulfill your own and your partner’s sexual desires anymore in the way you used to

Osteoporosis

For osteoporosis patients, it can feel like they are losing their sexuality.

This creates great emotional hardship in their lives.

Loss of sexuality

Important: *Loss of sexuality* does not mean that you actually lose your sexuality. That's impossible. It's about the *feeling* that you lose your sexuality.

This includes:

- Not feeling like a sexual being anymore
- Not feeling sexually attractive anymore
- Feeling sexually incapable
- Feeling sexually discarded by your partner and society
- Becoming sexually inactive

Loss of sexuality

Important: *Loss of sexuality* does not mean that you actually lose your sexuality. That's impossible. It's about the *feeling* that you lose your sexuality.

José Al (therapist for sexual trauma and MS-patient):

"You're at the sidelines of life. Not being of essential value. And when your self-worth and self-image collapse like a house of cards, little remains of the feeling of being attractive and desirable."

Patient stories

What are patients telling us?

Patient stories

- Patients experiencing: pain, lack of energy, lack of interest, decreased feeling of self worth and (fear of) fractures
- Wonder whether to live with the consequences or search for solutions
- Want to know how to avoid pain, risk and fear
- Have said that healthcare providers do not initiate a discussion about the topic

and also research has shown that the majority of healthcare professionals do not proactively discuss sexuality issues with service users

Burden of the disease

The hardship that patients suffer due to the disruption of their sexual experience aggravates the burden of the disease.

This includes:

- Decrease in self-worth: from partner/lover to patient
- Relational stress: loss of intimacy, touch, connection, love
- Loneliness and the consequences thereof
- Intensified experience of pain
- Osteoporosis-depression cycle
- More physical and mental/emotional health problems
- Patient needs even more health care

Necessity of addressing sexual problems

“In this large study of U.S. adults’ ratings of the importance of sexual health and satisfaction with sex life, sexual health was a highly important aspect of quality of life for many participants, including participants in poor health.

Moreover, participants in poorer health reported lower sexual satisfaction. Accordingly, sexual health should be a routine part of clinicians’ assessments of their patients.

Health care systems that state a commitment to improving patients’ overall health must have resources in place to address sexual concerns. These resources should be available for all patients across the lifespan.”

Flynn, Kathryn E. et al. 2016. Sexual Satisfaction and the importance of Sexual Health to the quality of Life Throughout the Life Course of U.S. Adults. In: Journal of Sexual Medicine. Vol. 13. Issue 11. P. 1642 - 1650.

2. Impact of osteoporosis on the patient’s sex life and love relationship

- The psychological and physical stress that arises from painful sex
- The relational stress that arises from trying to have a sex life when partners become caretaker and patient
- The psychological and physical stress that arises from a lack of touch

The psychological and physical stress that arises from painful sex.

Sex

Sex can be an immensly beautiful, deeply fulfilling, all-encompassing, sensual and emotional experience for humans.

But this is only possible when the sex is wanted and pleasurable.

Unwanted and unpleasurable sex

When the sex is either unwanted, unpleasurable or both, it has the opposite effect:

It becomes traumatizing.

Unwanted/unpleasurable sex is traumatizing

- This is also true when the sex happens within a love relationship and out of love for your partner.
- E.g. when one partner does not enjoy the sex but does it anyway for the pleasure of the other partner.
- The body then develops gradual sexual trauma over time.
- This development is marked by a loss of sexual desire and eventually the shutting down of the body.

Sex and Osteoporosis

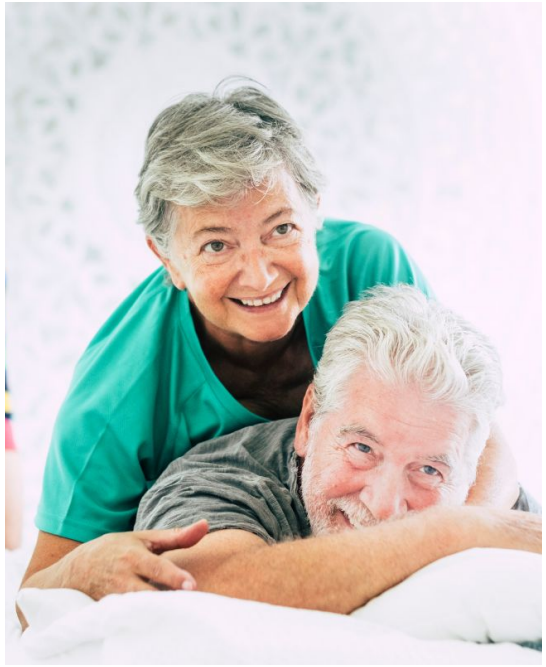
When you have osteoporosis, sex can become dangerous. It can be painful and cause fractures in your body.

Problem for osteoporosis patients:

You might *want* to have sex with your partner but it's too dangerous, too painful, and/or causes actual injury (e.g. from forceful movements or holding each other tight)

Sex and Osteoporosis

What the patient needs:



- Guidance in making sexual positions safe and pain-free.
- Guidance in developing other ways of intimacy and sexual pleasure than conventinal penis-in-vagina sex (most important).
- Help patients not to see this as a loss but as an opportunity for a richer sex life.
- Developing new ways of intimacy and sexual pleasure means an increase in sexual activity and a broading of your sexual repertoire.

The relational stress that arises from trying to have a sex life when partners become caretaker and patient

Relational stress

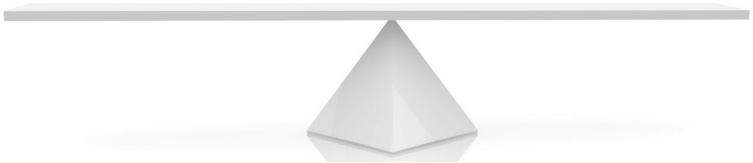
Chronic diseases have a fundamental impact on love relationships because they change the roles that partners have in the relationship.

Relational Stress

- Partners in love relationships fulfill several roles with respect to each other: e.g. lovers, companions, confidants, advisers. Some partners are also business partners together.

Relational Stress

Roles of equality



Roles of dependency

Relational Stress

- Important: Love relationships flourish when partners are in roles of equality with respect to each other (all above mentioned roles are roles of equality)

- When partners enter roles of dependency, it creates stress, strain, and/or suffocation in the relationship (e.g. role of parent, therapist, or problem-solver)

Relational Stress: chronic diseases

Equal roles

Patient and Caretaker

Relational Stress

- When one partner in a love relationship develops a chronic disease, it introduces the roles of patient and caretaker into the relationship.
- These are roles of dependency where the patient-partner becomes dependent on the caretaking partner.
- Even if these roles are taken in with great love, care, and dedication, they put stress and strain on the relationship.

Relational Stress

This happens in two ways:

- **In order to take care of someone, you have to set your own needs aside.** Even if you do that with great love, there is a limit. At some stage, your needs need to be addressed as well. It's common for the caretaking partner to develop resentment towards the patient-partner.

- **Disruption of the lovers-relationship, i.e. the role of the lovers**

Please note:
This is a very simplified description. Chronic diseases disrupt all aspects your life including your social life. For this presentation, we are only focusing on the disruption of the lovers-relationship.

Disruption of the lovers-relationship

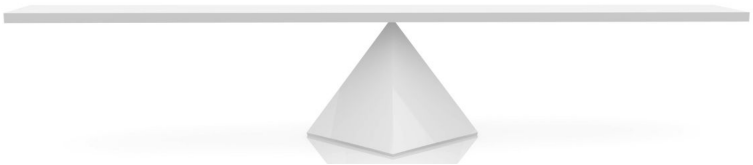
Example: monogamous couple

Monogamy can be a relationship of equality or dependency, depending on how it’s practiced.

Being aware of that is beneficial when you want to give advice and guidance to patients with osteoporosis.

Monogamous couple

Equal monogamy



Dependent monogamy

Disruption of the lovers-relationship

Example: monogamous couple

- Monogamy can be a relationship of equality or dependency, depending on how it's practiced.
- The relationship is equal when both partners have approximately equal sexual desire and *enjoyment* in sex. Partners then feel connected, sexually free, and fulfilled together.
- When one partner has more sexual desire and/or more enjoyment than the other. The relationship becomes unequal. The partner with more desire/enjoyment becomes sexually dependent on the partner with less desire/enjoyment.

Disruption of the lovers-relationship

Dependent monogamy

- The partner with more desire keeps initiating sex and asking for sex while the partner with less desire keeps rejecting and avoiding.

- Creates huge personal pain on both sides. The partner with more desire feels frustrated, rejected, and hopeless. The partner with less desire feels guilty and overwhelmed. Both partners can feel resentful towards each other.

Disruption of the lovers-relationship

Chronic disease and monogamy

Caretaking partner becomes sexually dependent on patient partner.

Disruption of the lovers-relationship

Chronic disease and monogamy

- Caretaking partner becomes sexually dependent on patient partner.
- Patient partner is already suffering from a felt loss of sexuality, feeling unattractive, low sexual self-worth, and feeling sexually incapable.
- Creates great inner conflict on both sides:
  - Caretaking partner: guilt, desperation, resentment, not knowing what to do, not knowing where to go.
  - Patient partner: guilt, overwhelm, low self-worth, fear, desperation, hopelessness

Disruption of the lovers-relationship

Chronic disease and monogamy

What now? Live with it? Open relationship? Affair?

Or:

Help partners to find new ways of sex and intimacy within the bounds of the disease.

Disruption of the lovers-relationship

Chronic disease and monogamy

- Advice: try to help partners to find ways of being intimate and sexual together before trying something else.
- Because living with the problem, trying an open relationship or having an affair creates a whole other dimension of emotional complexity and potential emotional pain.

The psychological and physical stress that arises from a lack of touch

Lack of touch

What happens when partners physically withdraw from each other?

Lack of touch

What happens when partners physically withdraw from each other?

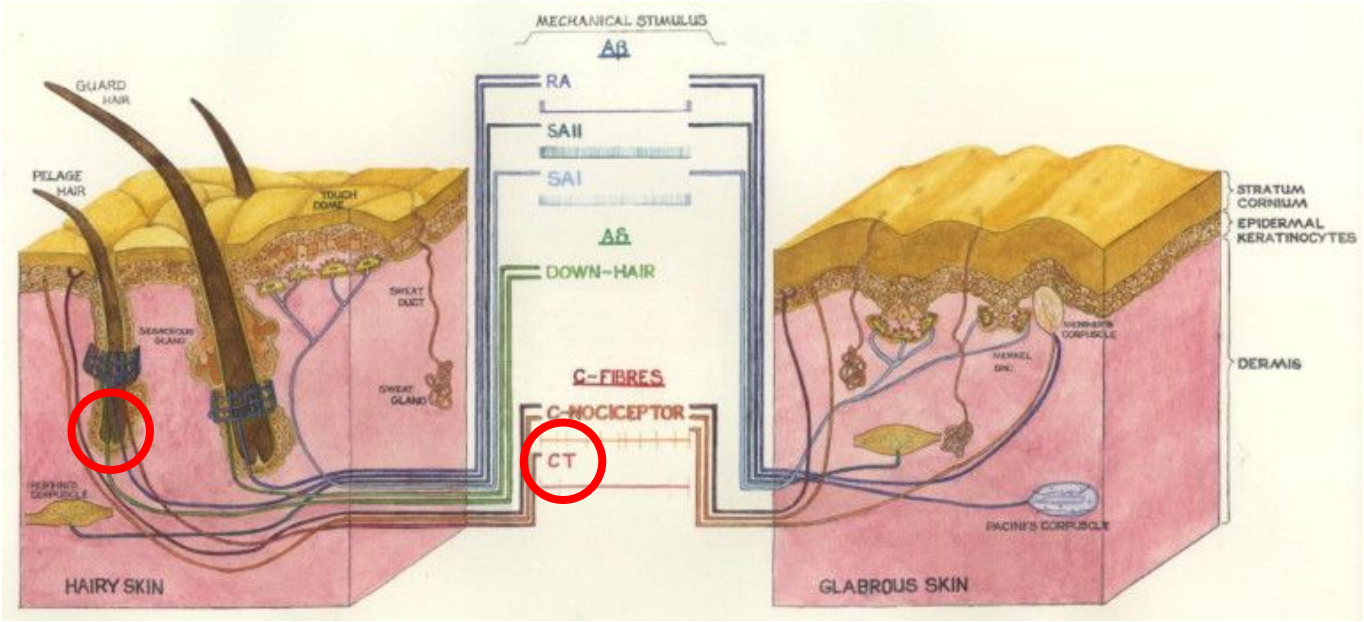
- Loss of touch

- Our skin is our most important social organ. We need to be in physical touch with other human beings to feel connected and to be physically, mentally, and emotionally healthy.

- Large body of research shows that affectionate touch plays a fundamental role in all aspects of our lives: infant development, cognitive and social development, mental health, self-perception, social behavior, and so on (see references).

Lack of touch - CT-Fibers

For today: A little insight into the magnitude of this problem



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CT-fibers:

C-tactile afferent fibers

CT-fibers

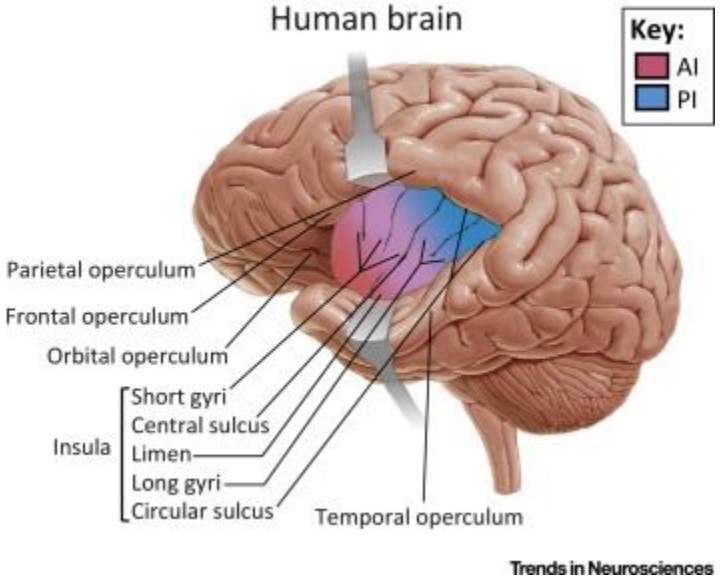
- CT-fiber stands for: C-tactile afferent nerve fiber. Afferent meaning that the nerve sends impulses to the brain, which are then received and interpreted by the brain.

- Special: CT-fibers only react to affectionate touch and are allowed to signal directly to the brain without any further evaluation from the nervous system.

- CT-fibers are connected to the insular cortex of our brain. The insular cortex is involved in: (see next slide)

Lack of touch - CT-Fibers

For today: A little insight into the magnitude of this problem



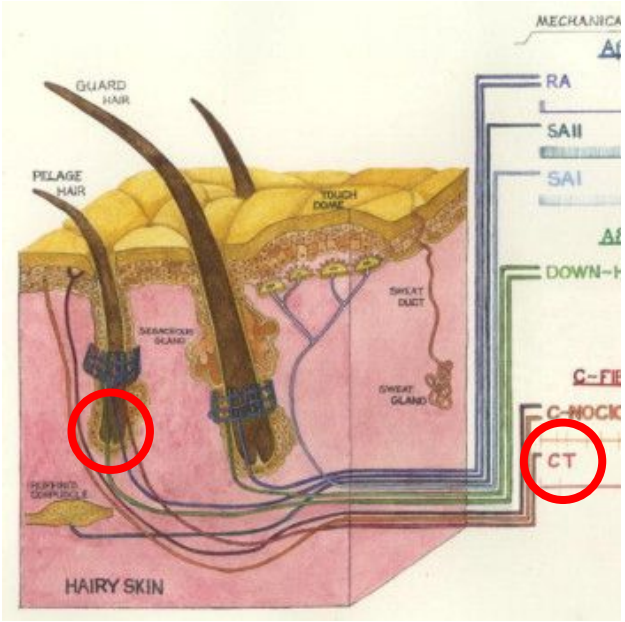
Source:
https://www.cell.com/trends/neurosciences/fulltext/S0166-2236%2818%2930132-2

Insular cortex

- Self-perception / self-awareness
- Interoception (perception of inner bodily sensations)
- Emotional regulation
- Emotional guidance of social
- And much more (see references)

Lack of touch - CT-Fibers

Consequences of CT-stimulation through affectionate touch



Source: Unknown

Presence

- Feeling of belonging
- Feeling of being loved
- Increasing/positive self-image
- Increased self-worth
- Calmness
- Pain reduction (indirect consequence, oxytocin and others)

Absence:

- Feeling of exclusion/loneliness
- Feeling of not being loved
- Decreasing/negative self-image
- Decreasing self-worth
- Anxiety
- Pain increase (indirect consequence, anxiety-pain-cycle)

Lack of touch

- Lack/loss of affectionate physical touch is one of the worst things that can happen to human beings.

- Osteoporosis patients are especially in danger because a tight loving hug alone can lead to injury, causing the patient to withdraw.

- Finding ways for patients to stay in loving touch with their partners can offset some of the negative consequences of the disease.
  - Decrease the loss of self-worth
  - Decrease feelings of loneliness and exclusion
  - Decrease feelings of anxiety and desperation
  - Help patients to deal with changes in their body and looks
  - Decrease in physical pain

3. Consequences for health care

Compliance decreases

Many osteoporosis patients stop medication within the first year.

The majority of these patients stops within the first 3 months.

Compliance decreases

- Current situation: Treatment with medication often takes years.
  - After 1 year, about 50% of the patients have stopped taking medication.
  - The majority has stopped medication after 3 months.
  - Adherence is increased by the quality of the interaction including the patient-provider relationship and patient satisfaction.

- Relationship with the health care provider is an important factor in patient compliance and success of treatment.

- The way people *feel* impacts the relationship with the healthcare provider.

Positive relationship with the patient

A positive relationship between patient and healthcare professional is crucial for compliance.

Positive relationship with the patient

- When patients have the idea that they cannot talk to their healthcare provider about their private problems, they feel disconnected and alone.

- Patient-centered communication is associated with positive therapeutic alliance.
  - Responding to the need of the patient

Health care consumption increases

Burden of the disease aggravates.

Problems of the patient multiply.

Increased healthcare needs.

Health care consumption increases

- Increase in healthcare needs. Because the burden of disease aggravates. Problems of the patients multiply.

- Healthcare professionals regularly acknowledge the importance of sexuality for their patients but have difficulties acting on their beliefs.

4. In practice

What can we do to help our patients?

Situation of the healthcare professional

It can be very difficult for a healthcare professional to talk about sex with their patients.

1. Sexuality is a taboo topic
2. Lack of confidence
3. Bias about people with chronic disease
4. Medical model of sexuality

When a patient opens up to a healthcare professional about their sexual challenges, it can feel uncomfortable and overwhelming.

McGrath et al 2020: Addressing Sexuality Among People Living With Chronic Disease and Disability: A Systematic Mixed Methods Review of Knowledge, Attitudes, and Practices of Health Care Professionals. In: Archives of Physical Medicine and Rehabilitation.

Reasons why healthcare professionals feel inhibited to talk about sex with their patients

1. Sexuality is a taboo topic

- Depending on your own relationship with sexuality, it can be an uncomfortable topic for you.
- Sexuality is highly personal and private. Afraid of violating the patients privacy.
- Afraid of judgment by colleagues.

Reasons why healthcare professionals feel inhibited to talk about sex with their patients

2. Lack of confidence

- Afraid that you don’t have the expertise to talk properly about sex with your patient.
- Idea that talking about sex should be handled by a qualified specialist.
- Afraid of acting outside your own discipline.

Reasons why healthcare professionals feel inhibited to talk about sex with their patients

3. Cultural bias

- Our culture has a strong bias that only young and able-bodied people are sexual, while older people, people with disability, and people with diseases are regarded non-sexual.
- Given that we are all part of that culture, we find the same biases in the medical community.
- Sexuality for people with chronic diseases and disabilities is often regarded as irrelevant or a luxury.

Reasons why healthcare professionals feel inhibited to talk about sex with their patients

4. Medical model of sex

- Medical model of sex is restricted to the mechanics of sexual functionality. This means: when the penis goes into the vagina the sex is working.
- Within that model, sexual problems only arise when those mechanics don’t work i.e. when the penis cannot go into the vagina (for whatever reason).
- The greater aspects of sexuality, such as intimacy, closeness, connection, and - most importantly - sexual pleasure are not recognized by the medical model, and therefore largely ignored.
- This is a problem because those aspects of sex have the greatest impact on a persons quality of life.
- Whether the penis goes into the vagina or not says nothing about the quality of someone’s/a couple’s sex life.

Situation of the healthcare professional

When a patient opens up to a healthcare professional about their sexual challenges, it can feel uncomfortable and overwhelming.

Yet, the need of the patient is very clear. Patients want to have this conversation (or at least the option to talk about it).

McGrath et al 2020: Addressing Sexuality Among People Living With Chronic Disease and Disability: A Systematic Mixed Methods Review of Knowledge, Attitudes, and Practices of Health Care Professionals. In: Archives of Physical Medicine and Rehabilitation.

Changing our mindset

Taboo

Gift

Changing our mindset: from taboo to gift

- Because sex is such a personal, private, and taboo topic, talking about sex is a fundamental expression of trust.
- Think about this trust as a gift.
- It means that you have done something or acted in some way that gave them the trust and confidence to open up to you.
- Take this as a compliment.

What to do with this gift?

Step 1: Awareness of the patient's situation

- The patient makes themselves extremely vulnerable by opening up to you.
- Never underestimate the shame, unworthiness, and insecurity the patient feels about their sexuality.
- Be aware of testing: the patient will test the waters before they open up. They will probably belittle the problem.

What to do with this gift?

Step 2: No solutions, just listening

Do:

- In the moment of opening up, people are not looking for solutions.
- They want to feel seen and heard.
- They feel terribly embarrassed and ashamed.
- They want to know that they are normal and not crazy.

Don't:

- Pathologizing and rejection
- "This is not my area of expertise but I can refer you to a specialist."

What to do with this gift?

Step 3: Empathy and confirmation

- “Don’t worry. No need to feel embarrassed. This is totally normal.”
- “This is totally normal. So many people are struggling with this”
- “We are more than happy to help you.”
- “Tell me more about your situation.”

What to do with this gift?

Step 4: Connecting with a specialist

Do:

- “If you would like help with that, I am more than happy to connect you with the right people.”
- “We know people who are specialized in exactly these problems, and they are more than happy to help you.”

Don’t:

- “I can refer you to a specialist/sexologist/therapist”

Useful tools for the healthcare professional

Better Model (Mick, Huhges & Cohen, 2003)

Bring up the topic

Explain you are concerned with quality of life issues, including sexuality

Tell patients you will find appropriate resources to address their concerns

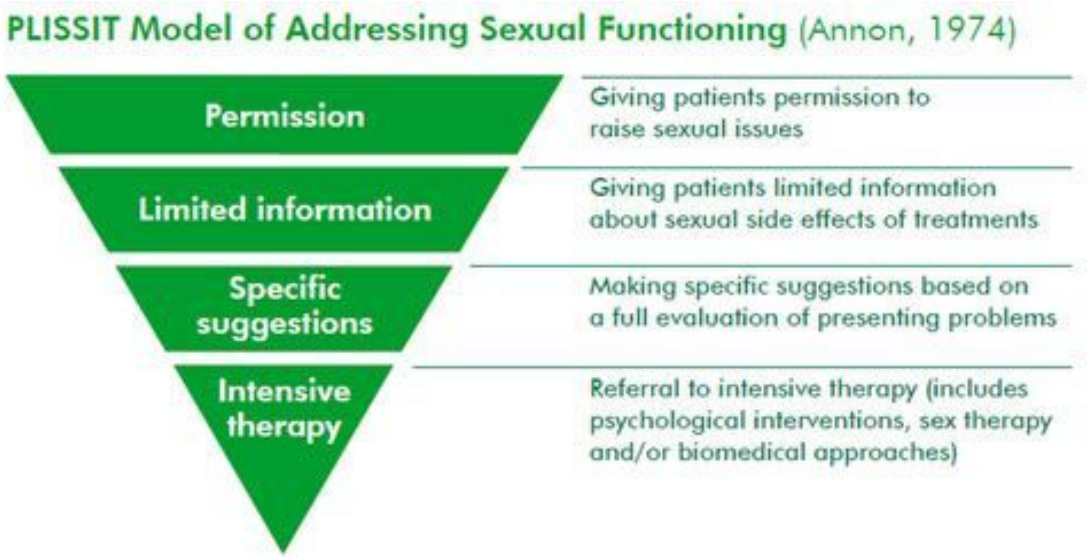
Timing may not seem appropriate now, but they can ask for information or help at any time

Educate patients about the side effects of their treatment

Record your assessment and intervention in the patient chart

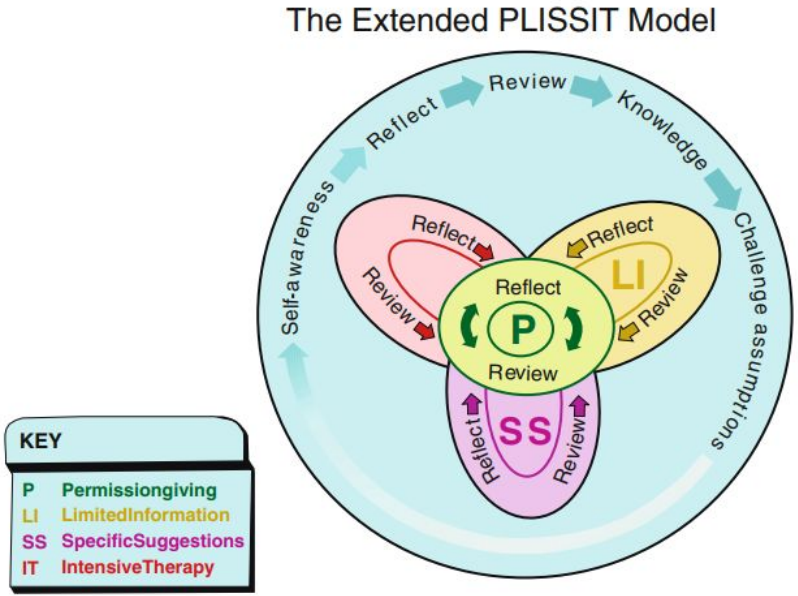
Mick, J. et al. 2003. Sexuality and cancer: How oncology nurses can address it BETTER. Oncology Nursing Forum, 30. p. 152 - 153.

Useful tools for the healthcare professional



Annon, Jack S. 1975. The Behavioral Treatment of Sexual Problems. Vol 1: Brief Therapy. New York. Harper & Row
Annon, Jack S. 1976. The Behavioral Treatment of Sexual Problems. Vol. 2: Intensive Therapy. New York: Harper & Row.

Useful tools for the healthcare professional



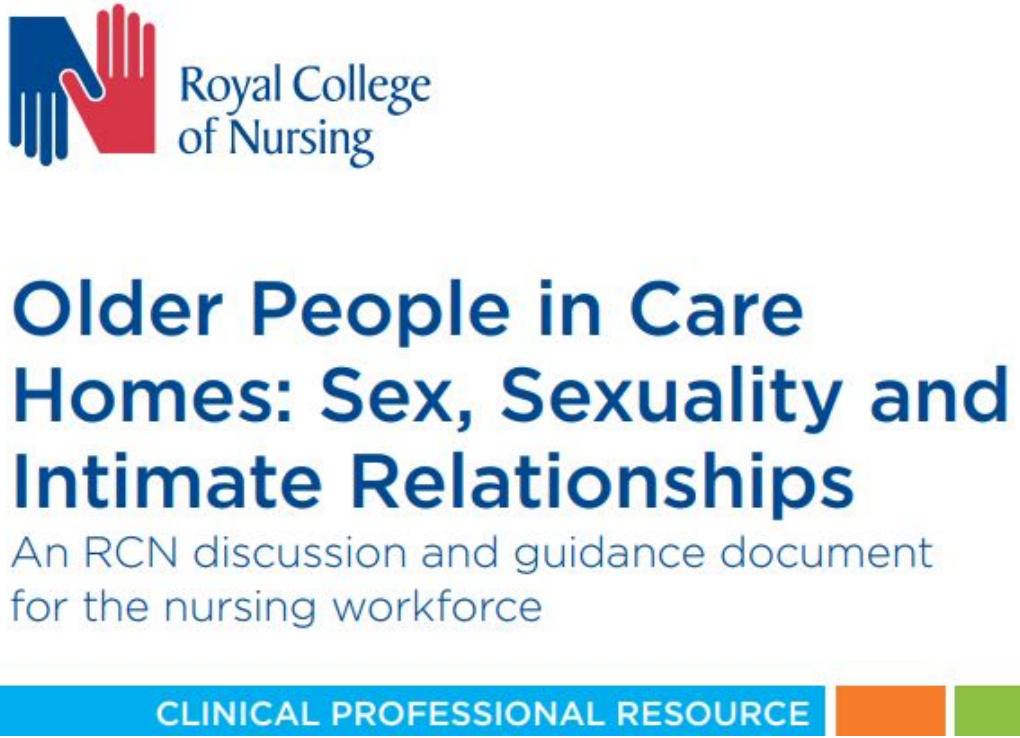
Important point of this model:

More focus on permission.

Healthcare professionals tend to skip this step and move immediately to sharing information.

Taylor, Bridget & Davis Sally. 2007.The Extended PLISSIT Model for Addressing the Sexual Wellbeing of Individuals with an Acquired Disability or Chronic Illness. In: Sexuality & Disability. Vol. 25. p.135–139.

Useful tools for the healthcare professional



This resource uses the Extended PLISSIT Model to communicate with patients.

Royal College of Nursing. 2018. Older People in Care Homes: Sex, Sexuality and Intimate Relationships. An RCN discussion and Guidance Document for the Nursing Workforce. Clinical Professional Resource.

Example of possible materials for the patient

Male	Position	Female	Position
Back pain during extension/ extension intolerance	Spooning Missionary position	Back pain during extension/ extension intolerance	Spooning Missionary position (perhaps with pillow to support) When pain in pelvis: stretch legs Bending over (doggy style) but lean on hands not elbows
Back pain while bending/ flexing intolerance	Doggy style (hinge from the hips) Female leaning on elbows Both: laying in their sides	Back pain while bending/ flexing intolerance	Doggy style while leaning on elbows Laying on your belly, perhaps with a pillow supporting your pelvis/hips

Thank you!

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What patients are dealing with

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Decrease in compliance and increase in health care consumption

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This is a Dutch resource pertaining to the Netherlands. We estimate that numbers are comparable across Western countries.
However, please do your own research for numbers on compliance and health care consumption in your country.

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Healthcare professionals: what can we do to help our patients?

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BETTER MODEL
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Q&A

Dr Mirjam Hachem

Ms Agnes Offenberg

THANK YOU

On behalf of IOF, we thank you for your participation in this webinar

IOF International Osteoporosis Foundation

BoneCast

Special Edition Webinar

IOF
International Osteoporosis Foundation

Our vision is a world without fragility fractures,
in which healthy mobility is a reality for all.

Join us