

# Sexuality in ALS – a conspiracy of silence

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**In this plea the following topics are addressed:**

- **Relevance**
- **Barriers**
- **Sexual problems experienced in MND**
- **Identify and discussing problems**
- **PLISSIT model**



## Why relevant? Illness and sexuality

- Acute/transient illness: Reduced desire for having sex is common and (usually) not problematic.
- A situation with a stable course: Often one time adjustment sufficient. (e.g. amputation)
- Chronic/progressive illness: Temporary or permanent negative consequences for sexual functioning



## Sexuality in patients with ALS and their partners (N=91)

“Sexual interest decreased 72% to 44% for patients and from 78% to 44% for partners

Sexual activity decreased from 94% to 76% for the patients and from 100% to 79% for the partners

Premorbid 19% of the patients and 20% of the partners reported sexual problems, this increased to 62% of the patients and 75% of the partners.

Less desire, passivity of patients or partner, physical weakness and body image change

**Sexuality is an important and problematic issue for a large portion of ALS patients and their partners. Topic rarely discussed in medical setting. Counseling and information should be made available in order to better address this important aspect of quality of life”**

Wasner et al., 2004



## Perceptions of sexuality in individuals with ALS and their treating clinicians

N= 21 patients with ALS, N= 81 Healthcare professionals (HCPs).

“90% of respondents stated that ALS impacts the sexuality of an individual with ALS and agreed that sexuality-related discussion is needed as a complementary therapy

Over 75% of HCPs reported they were not familiar with any strategies or interventions to help the patients”

Shabazi et al., 2017



## Scientific research on sexuality

Sexuality has important positive impact on Quality of Life



Sexual problems have a negative impact on QoL



S.de Moree





## ‘Conspiracy of silence’



Assumptions from both HCPs and patients:

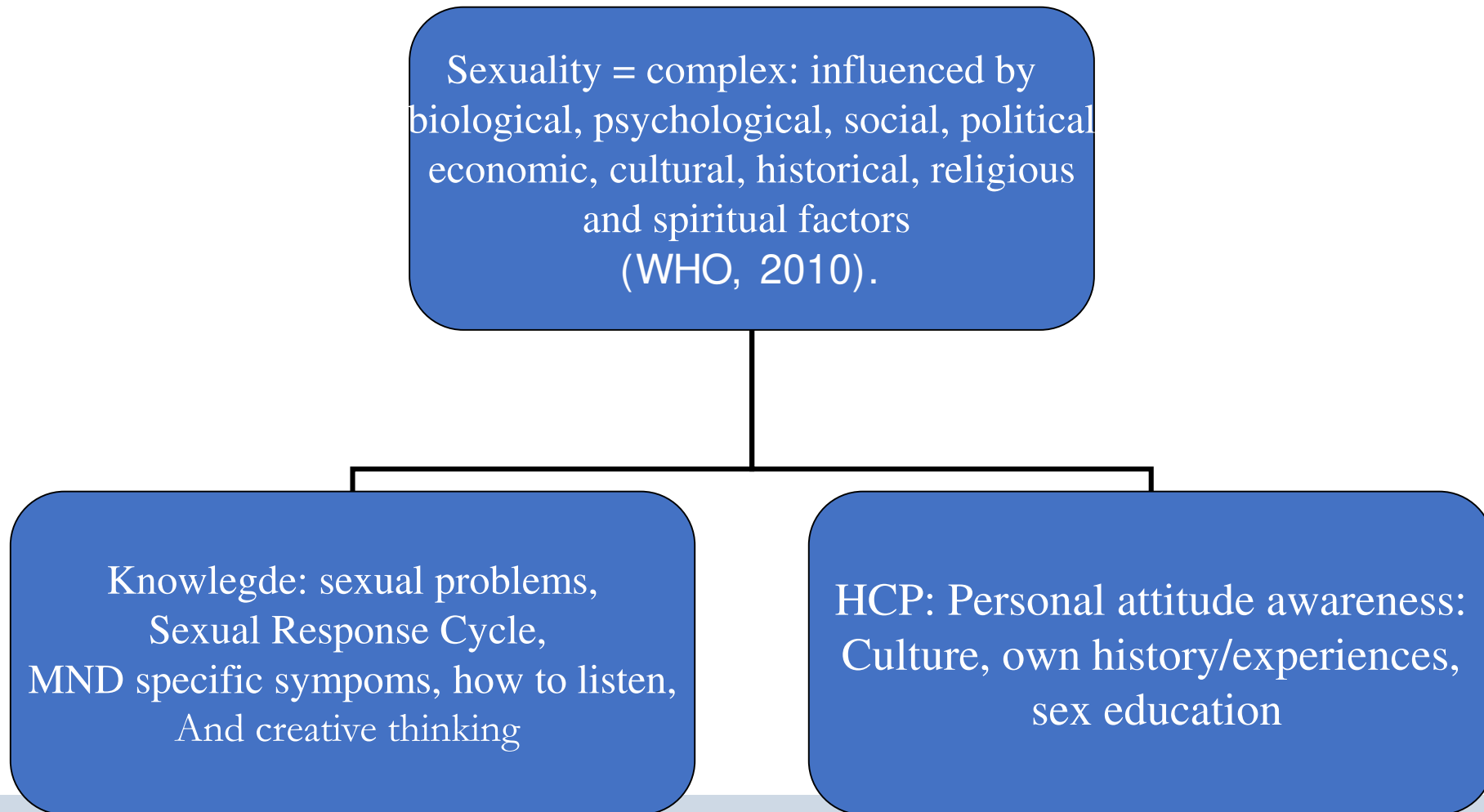
“They didn’t mention it, so they don’t want to talk about it”

or

“This is not the time and the place to talk about it“



## Barriers to talking about sexuality with patients (and their partners).







## **Personal attitude: ideas and opinions of HCP about sex are heavily influenced by**

- **Personal experiences**
- **Socially accepted myths** (o.a. Mercer, 2008) in both of patients/partners and HCPs
  - People who are ill do not have sex or are not interested in sex
  - Ill people should not have sex
  - If you are dying or if you know you will die then there is no need or desire for sex anymore.
- **Personal definition**



Sex: it is not all about intercourse!

It can mean so much for the individual involved:

*intimacy, showing affection, attraction, feeling, love, support, kissing, caressing, licking, biting, lie together, feeling each others warmth, making love, getting excited/sexually aroused, having orgasmes, as a 'medicine' or as comfort to feel better, to cherish one another, being relaxed, feeling connected, having fun etc.*

For most it is important and for some even more important when you know you are loosing your life



**ALS or PMA does not directly influence sexual functioning and sexual needs do not disappear -- but things do change!**

- **Relational changes**
- **Practical problems**
- **Adjustment problems**
- **Medication**

Do not rule out patients who are single: they are/can be sexually active on their own or with friends with benefits or otherwise



## As a HCP: Just check it !

Are they experiencing sexual problems because of ALS/PMA?

→ If not: continue and go to the next subject on the intake list →

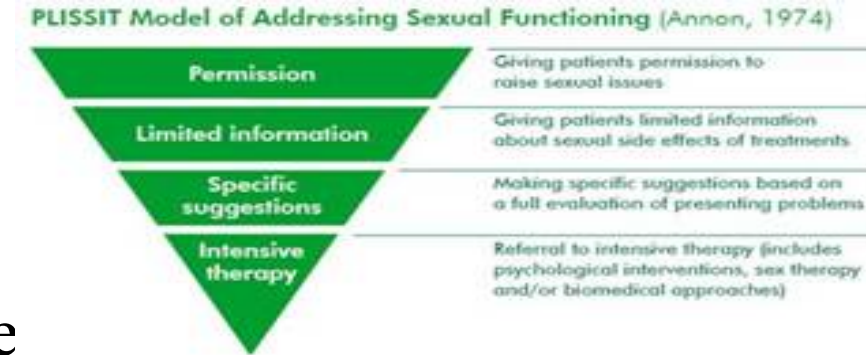
→ If so: do they want to discuss this?

→ If no: tell them they are welcome to talk about it some other time if they change their minds and do want to talk about it →

→ If so: explore further and invite to elaborate



## PLISSIT (Annon, 1974)



- **Permission:**  
asking patients permission to raise sexual issue
- **Limited Information:**  
giving patients limited information about sexual side effects of the illness
- **Specific Suggestions:**  
making specific suggestions on full evaluation of presenting problems
- **IT Intensive therapy :**  
referral to intensive therapy (medical, psychological or sex therapy)



## Formulating your questions: Permission and limited information Plissit

- *“In order to offer you the best care I don’t want to leave anything out so I want to ask a question about sexuality. People with illnesses often experience sexual problems such as loss of desire or problems with enjoyment because of fatigue or other physical problems due to the illness. Is it OK if I ask you some questions about this subject?”*
- *“In the intake/application questionnaire you indicated you encountered sexual problems. It is very common that illnesses affect sexuality. Do you want to talk about it?”*
- *“Many people with an illness are concerned with how the disease and impairments might affect their sexuality. Do you recognize that concern?”*
- *“Did MND affect your sexual relationship?”*
- *“Would you like to tell me more? We can talk about it and you are free of course to not answer my question if you are not comfortable with it.”*
- *“How has your health affected your sexuality?”*



What kind of problems can occur: **Specific suggestions Plissit**  
Creative thinking with the patient and partner

- **Saliva/ swallow problems**, can cause shame/ disgust/anxiety:

Medication/ change bodily positions

- **Bodily changes** caused by muscle atrophy: shame/(un) attractiveness

Clothing to cover-up, to feel more confident than being totally naked/ dim the lights

- **Role change** and dependency:

Communication/ more active role of the partner/other in sex play

- **Practical:** like less muscle power, fatigue

Time of day adjustment/ more comfortable bodily positions/less intense sexual activity

- **Need for new ‘recipes’:**

- Communication/ experiments/creativity/ sensate focus: touch stays intact



## Anxiety and depression

Psychological treatment and/or medication

- **After diagnosis** more or less desire for sex

Communication

- In case of **differences in desire** impact on the partner

Intimacy in other ways/ communication

- **Ventilation**

Comfortable body positions/ within reach/ with ventilation or without during sex

- **PEG/PRG**

Bodily positions/ taping, sticking/ tight clothing

- **Cognitive impairments/ less empathatic**

Inform partner: knowledge about cognitive impairment.





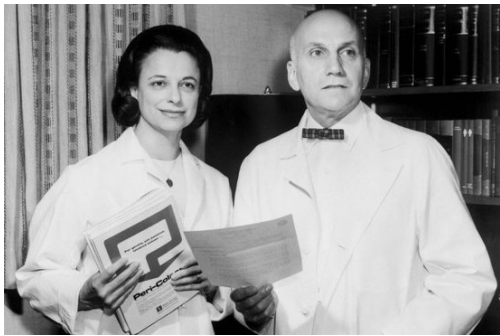
## Intensive therapy by a specialist Plissit

- Relational problems, sexual abuse or other severe physical problems that cause sexual problems:

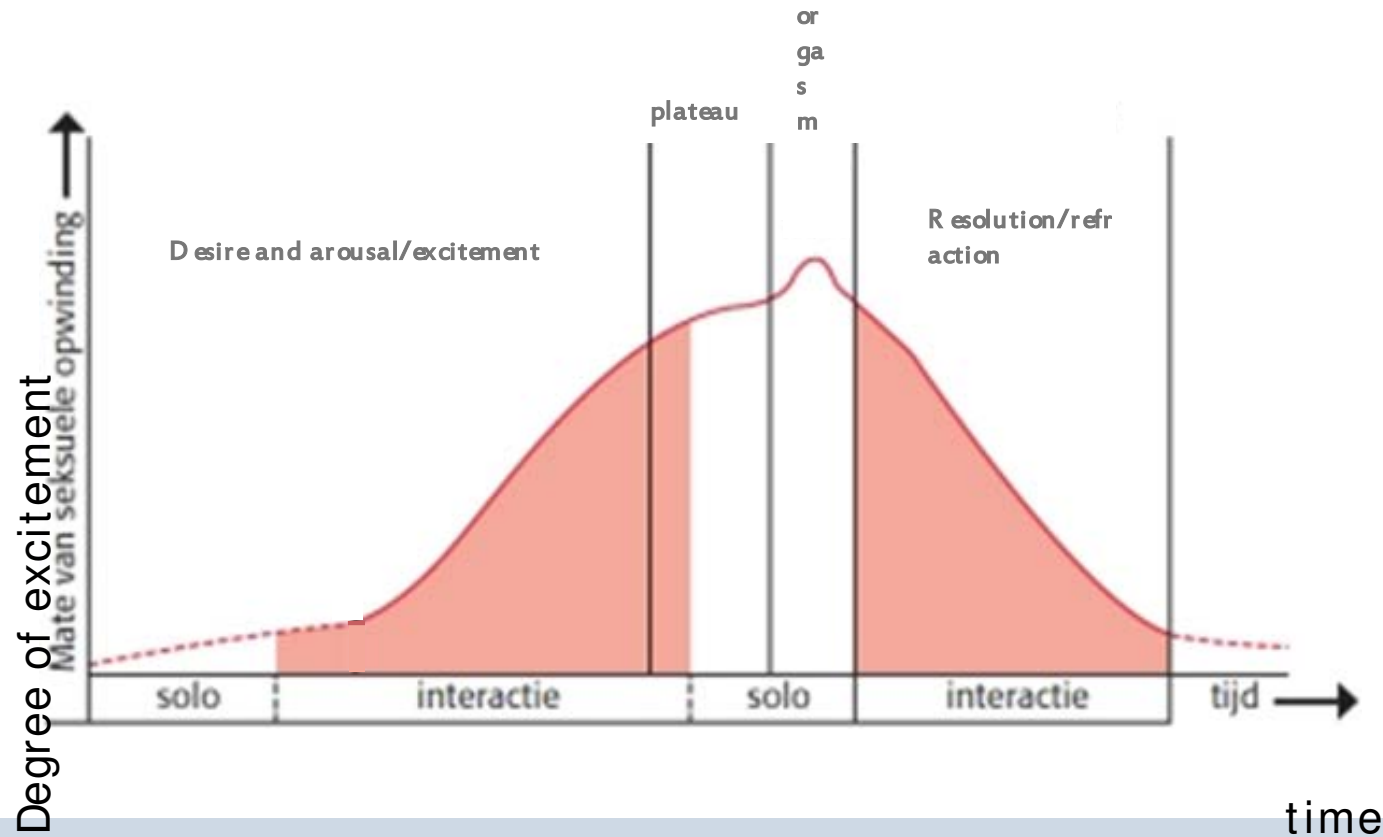
**REFERAL!!**



# Sexual response cycle



William Masters  
Virginia Johnson



# What to expect as a HCP?



## Check if people want to talk about this issue, if so:

- Start with open questions: what? how? who? when? where? explore
- Then: gradual elaboration, go into detail

Words are very important!

*“In order to know how I can help you it is necessary to know exactly what we are talking about “*

*“What do you mean by it?”*

*“What do you mean by sex?” “What exactly do you mean?”*

- Caregivers can also experience physical problems caused by caring
- People rarely spontaneously address masturbation, sexual abuse and sexual contacts outside the relationship.



## Do not be afraid!!

You are just addressing it, so people are not left alone with it. You just need more information to know how to inform them or refer them adequately.





Have faith and trust: Yes you can! Just try it : )

Thank you for your attention!



## Reading material

- Sexual functioning, satisfaction, and use of aids for sexual activity in middle aged adults with long term physical disability. By Amanda E Smith, Ivan Molton et al (brief report, Top spinalCord Inj Rehabil. 2015)
- The impact of assistive equipment on intimacy and sexual expression, by Bridget Taylor (British journal of occupational therapy, 2011).
- Sexuality in patients with ALS and their partners by Maria Wasner et al (J.Neurol, 2004)
- Why has so little progress been made in Practice of Occupational therapy in relation to sexuality by M. Mc Grath and D. Sakellarriou (Am J occup ther., 2016)
- Inappropriate sexual behaviour in case of ALS and FTD: succesful treatment with setraline by Anneser, Jox et al (Amyotrophic Lateral sclerosis,2007)
- Agressiveness, sexuality and obsessiveness in late stage of ALS patients and their effects on care givers by Marconi et al (Amytrophic lateral sclerosis, 2012)
- Experiences of sexuality and intimacy in terminal illness: a phenomenological study, Bridget Taylor, (Palliative Medicine, 2014).