
European Huntington Association Conference

Sexuality & Huntington's Disease *Alzbeta Mühlbäck*

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Sexuality & HD



- Introduction
- Why to talk About Sexuality
- How to Talk About Sexuality
- Case Study
- Common Problems
- Different Approaches

Sexuality



Sexuality

- is natural and belongs to us
- part of our life
- part of patient's life
- part of medical assessment



Sexual Dysfunction – Sexual Problems

..... we don't talk about it
..... we neglect sexuality

- Sexual dysfunction is common
- Sexual dysfunction is even more common in neuropsychological disorder (depression, anxiety, sleep disorders)
- Sexual dysfunction is common in many neurological diseases – Parkinson's Disease, Multiple Sclerosis and Huntington's Disease



Why We Should Talk About Sexuality?

Sexual problems affect BOTH patients and their partners

Patient – Doctor Relation create an excellent platform for discussing sexual issues

We can provide support

We can even find solutions



What Is Our Problem?

We are not asking about sex and if we are finally asking, we tend to ask:

Do you have some sexual problems?

Answer is NO

If we are asking about Headache, Stomachache, Nausea, Diarrhea, we are more creative:

How often do you have headache, what kind of headache, pressure, what intensity, when, how often, which part of the day, do you need to take medication? you suffer lot?



How To Talk About Sexuality?

During regular consultation (it refers to nonmotor symptoms of HD, urinary tract or gynecologic problems)

We need to make an invitation to the topic

This is my regular invitation to the topic:

.....people with HD (depression, anxiety, stress) have problems with sex , sexual problems are nowadays common. Are you experiencing any problems? Are there questions that you would like to discuss?



How To Talk About Sexuality?

Patient is not responding?

You feel that he or she feels uncomfortable?

You need **Plan B** ?

Plan B: *If you prefer, we can discuss this topic later /next time*



Reality – Case Study

The young woman at the age of 35 told me that she has no orgasm and it is a big problem, she is a person with HD risk, her father died of HD, she has a full time job as a project manager, she suffers from anxiety and panic and she takes antidepressants. Her family doctor advises her to stop taking the medication, but she is afraid that the panic attacks could worsen.

We need to ask the same question as we are asking about the headache?

When did you notice the first changes in your sexual life? What kind of problems? Is not having orgasm your only problem? How is your relationship? Do you have sex regularly? What do you consider to be sex?

Reality – Case Study



In a short conversation (10 Min), I discovered that she is always exhausted in the evening, then she tries to motivate herself to have sex, she is already afraid that it won't work out, that her partner will be disappointed, her head is busy, she is not relaxed. .

Continue talking:

I explained to her that she's jogging in the morning, so maybe this is the best time for sexual activity, weekend?

Could she be thinking about sex without orgasm (hugging, touching, feeling, kissing) to relieve pressure?

She decided to talk to her partner about her concerns.



Common Problems

Lack of Satisfaction, Frustration, Reduced Desire and Arousal, Lack of Orgasm

- Timing
- Tension, Unrest - Relaxation, Regular Exercise, Yoga
- Anxiety, Panic, Depression – Psychotherapy
- Changing the way of thinking - from “goal oriented ” intercourse to “pleasure oriented”.
- Couple Counseling
- Antidepressants/medication change – the last option - needs to be consult, doses reduction or medication change



Some Other Issues

- Examination (Urologist, Gynecologist)
- Exclude infections, problems in pelvic region, hormonal dysfunction, testosterone deficiency,
- Other endocrinological problems
- Cardiovascular or respiratory problems
- Orthopedic problems
-

Look in your region for other specialists - Sexual Therapists – inform the patients about this possibility



Reality – Case Study

47-year-old man in an early stage of Huntington's disease reported erectile dysfunction, he suffers from discrete hyperkinesia, otherwise rather lack of motivation, sleep problems , in recent months often concentration deficits in work

In the **further discussion** it turned out that he has clear concentration deficits, he could not work on 2 tasks at the same time, he felt lost in his thoughts.



Reality – Case Study

- Sex is multitasking and requires a certain concentration.
- Therefore, it is important to discuss and explain this fact.
- The sex can be divided into several small steps so that it is easier to concentrate on one step.
- Ask patient if they are taking some PDE5 inhibitors e.g. Sildenafil (Viagra, Revatio), Tadalafil (Cialis), Vardenafil (Levitra) und Avanafil (Spedra) – advice the patient to look for the specialist

Thank you!



Gila Bronner

Sheba Medical Center, Ramat Gan sheba, Israel
Health Psychology, Sex Therapist

B-Day Girl!



Thank you!

