
European Huntington Association

Sexuality & Huntington's Disease *Alzbeta Mühlbäck*

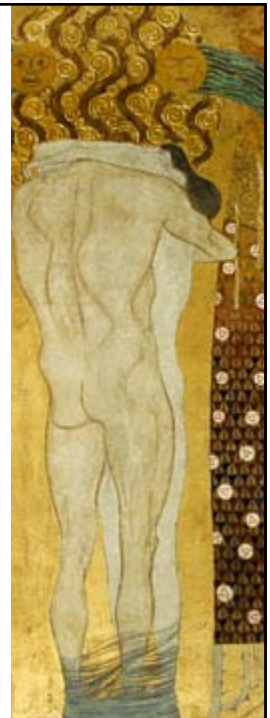
November 25th, 2020
Webinar



1

Sexuality & HD

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

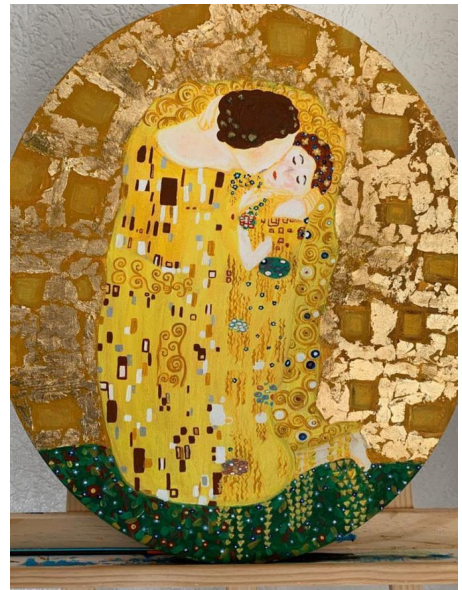


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2

Sexuality

- Sexuality
- is natural and belongs to us
- part of my life,
- part of your life,
- part of our life
- part of your patient's life
- part of a doctor conversation



3

Why We Should Talk About Sexuality?

Sexual problems affect **BOTH** our clients & patients and their partners



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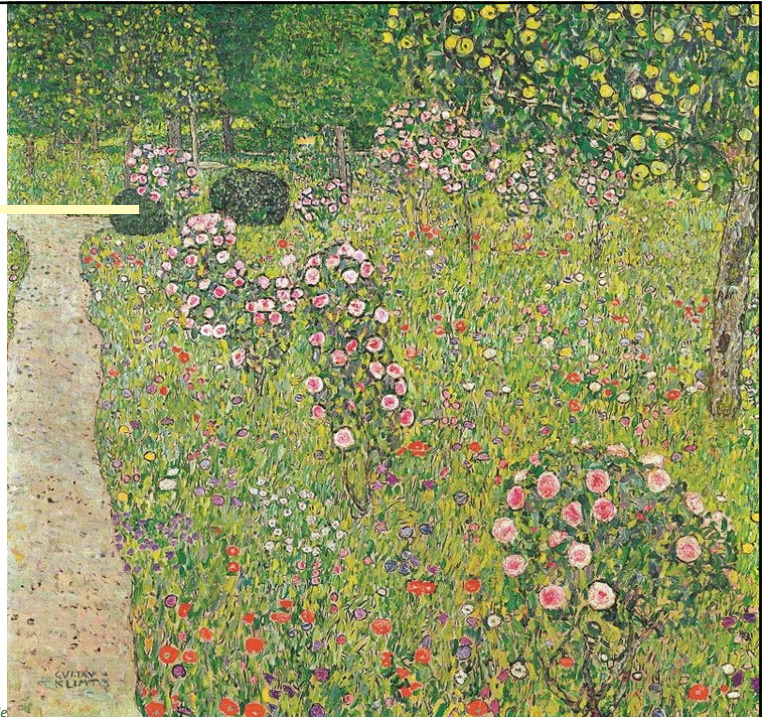
4

Why We Should Talk About Sexuality?

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

We can provide support.

We can find solutions.



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5

Sexual Dysfunction

.....we don't talk about it
..... we neglect sexuality
..... we pretend not to have a problem

- Sexual dysfunction is common
- Even more in psychological disorders (depression, anxiety, sleep disorders)
- Also in many neurological diseases – Parkinson's Disease, Multiple Sclerosis, Huntington's Disease, Stroke.



6

What are we not doing?

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***



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We need to invite our patients & clients to this conversation

Introducing the problems associated with depression, anxiety and stress, all of which can contribute to sexual dysfunction, are common nowadays.

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7

Keep Talking

Which questions/issues/topics about sex you would like to discuss?

How is your relationship?

How is life with your partner?

What is your partnership like?

How is your sex life?

How satisfied are you with your sex life?

What/how is your masturbation technique?

YES/NO Questions to be avoided → Open Questions!



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8

Time To Ask ?



If your doctor/therapist/psychologist does not ask you?
What do you do then?

- A. You start a conversation
- B. You take your partner with you and your partner starts a conversation
- C. You teach your doctor to talk about sex
- D. You are looking for an alternative doctor for consultation
- E. You ask your neighbour

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9

Let's practice talking about sex

You are thinking about one of your usual problems that you know:

headache, stomach ache, nausea, diarrhea, itching, allergy

❖ Guide for Patients

How do you describe your symptoms when it comes to physical problems?

I have diarrhea, it is really bad, I can't live with it, I am disturbed, my partner is suffering, my life is turned upside down, I need immediate help, we need to find a solution!

❖ Young Doctors' Guide

What questions do you ask about headache?

How often do you have headaches, what type of headache, pressure, intensity, when, how often, at what time of day, do you have to take medication? do you suffer a lot?

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10

Reality – Case Study

The **young woman at the age of 35** told me that **she does not have an orgasm** and that it is a big problem. She is a person **at risk of HD**, her father died of HD, she has a full-time job as a project manager, she **suffers from anxiety and panic** and she is on anti-depressants. Her GP advises her to stop taking the medication, but she is afraid that the panic attacks might get worse.

We need to ask more questions:

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



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11

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 will not work, that her partner will be disappointed, that they will not have sex again, her head is busy, she is not relaxed.



We keep talking:

I explained to her that she usually jogs in the morning, so maybe instead of jogging, she should try sex: the best time for sexual activity is in the morning, maybe on the weekend?
Could she think about having sex without orgasm (hugging, cuddling, touching, feeling, rubbing,, kissing) to relieve pressure?
She decided to talk to her partner about her concerns.

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12

Identifying Problems – Looking for Solutions

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 → need to be consulted with your doctor, doses reduction or medication change

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13

Getting Back in Sexual Live

Many strategies that can help get intimacy back in rhythm

1. **Switch off autopilot** – you need to be active
2. **Restart the romance** - sex life begins outside the bedroom. Do things together.
3. **Plan for romance/intimacy** - make sex happen to get back in the rhythm
4. **Find the best time** - energy levels vary throughout the day and night and per person
5. **Be patient – take your time** - arousal is not spontaneous
6. **Build from desires** - before and during sex ask your partner what feels good and what sparks interest. And then share what you like.

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14

Reality – Case Study

47-year-old man in the early stages of Huntington's disease reported erectile dysfunction, otherwise rather lack of motivation, sleep problems, in recent months often lack concentration at work. He feels stressed. His wife is very patient and supportive, but still he feels pressure that he cannot describe.

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, he is afraid that he is not able to have sex and achieve erection. He thinks that he is not able to satisfy his wife any more properly



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15

Case Study

We discuss further:

- 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
- We need to relieve the pressure from the patient



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16

Some Other Issues To Consider

- Examination (Urologist, Gynecologist)
- Exclude infections, problems in pelvic region, hormonal dysfunction, testosterone deficiency
- Other endocrinological problems
- Cardiovascular or respiratory problems
- Orthopedic problems
- Lifestyle Factor: Overweight, Smoking, Alcohol, Drugs

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

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17

Erectile Dysfunction (ED)

- Difficulty achieving or sustaining an erection
- caused by a combination of physical and emotional issues
- ED makes intercourse difficult, which can lower sex drive and desire
- ED can increase anxiety and depression and affect a man's relationship with his partner
- 1/3 ED caused by the physical problems (cardiovascular, urologists) → consult you physician

If you are taking or your consider to take PDE5 inhibitors e.g. Sildenafil (Viagra, Revatio), Tadalafil (Cialis), Vardenafil (Levitra) und Avanafil (Spedra) → consult you physician

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18

Coming Soon!

Let's Talk About Sex

....we want to continue to talk about sexuality
....we want to write about sexuality

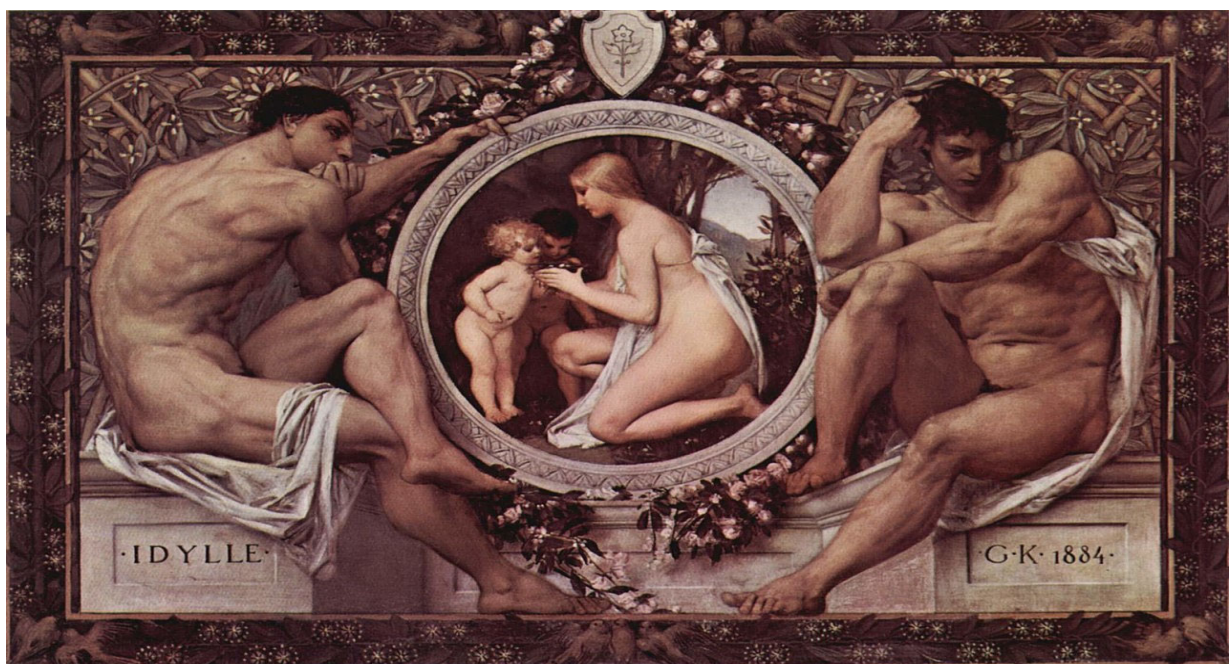
as a Christmas present, we will bring you a booklet about
sexuality A joint project that will be done with EHA & DHH



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19



20

#YOUR SEXUAL LIFE MATTERS#

Thank you!

