Sex, Relationships & Cancer: Finding Our Voice!

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Cured – But at What Cost?
Macmillan Cancer Support Report (2013)

- 1 in 4 people in the UK (approx. 500,000) living with cancer face poor health or disability after cancer treatment
- Around 240,000 are living with mental health sequelae
- Around 80,000 are living with menopausal / hormonal symptoms
- Around 90,000 are living with gastro-intestinal symptoms
- Around 150,000 are living with urinary problems
- **Around 350,000 are experiencing sexual difficulties**
- Treatment late effects usually emerge some months after treatment & can persist for > / = 10 years

Poll Question

- What is the most common reason HCPs give for **NOT** talking about sex after cancer?

A. Ageism

B. Embarrassment / Fear of Patient Embarrassment

C. Lack of HCP Training

D. Opposite gender consultations

E. Cultural & religious influences

F. Sexual stereotyping / harassment of nurses

G. Lack of privacy

H. Lack of Time

I. Lack of services / referral pathways

J. Not considered a care or role priority by HCPs

Barriers to Talking about Sex

Individual factors

- **Ageism** (Gott et al, 2004; White, 2009; Dyer & Nair 2013; Ben Charif, 2016; Flesia, 2023)
- **Opposite gender consultations** (Sarkadi & Rosenqvist, 2001; Gott et al, 2004; Burd et al, 2006; White, 2009; Dyer & Nair 2013; Ben Charif, 2016)
- **Cultural & religious background** (Lewis & Bor, 1994; Gott et al, 2004; White, 2009; Meston& Ahrold 2010)
- **Embarrassment / Fear of patient embarrassment** (Lawler, 1991; Wall-Haas, 1991; White, 1994; Guthrie, 1999; Meerabeau, 1999; Cort et al, 2001; Haboubi & Lincoln, 2003; Gott & Hinchliff, 2003; Gott et al, 2004; White, 2009; Dyer & Nair 2013)
- **Sexual stereotyping / harassment of nurses** (Lawler, 1991; Porter, 1992; Robbins et al, 1997; Guthrie, 1999)
- **Lack of training** (Cort et al, 2001; Haboubi & Lincoln, 2003; White, 2009; Dyer & Nair 2013)

Organisational factors

- **Lack of privacy** (Lewis & Bor, 1994; White, 1994; Guthrie, 1999)
- **Lack of time** (Guthrie, 1999; Stead et al, 2001; White, 2009 ; Dyer & Nair 2013)
- **Lack of services / Referral pathways** (White, 2009)
- **Not perceived as a care priority or role priority by professionals** (Kautz et al, 1990; Gamel et al, 1993; White, 1994; Guthrie, 1999; White, 2009)

Communication Practices in Healthcare Conversations About Sexual Health

(Kelder et al, 2022, Pt. Educ. & Couns, 105: 858-68)

Findings

- **Avoid using "delicate terms"** - use of vague / neutral terms e.g. "it / that" to refer to intercourse
- **Delay using "delicate" terms**- introducing topic of sex at end of a conversation; giving short / vague answers
- **HCP makes (incorrect) assumptions** about sexual behaviour or lifestyle e.g. using terms like husband / wife, "normal sex", advice doesn't align with pt. behaviours / needs
- **Generalised Advice Giving** - general / hypothetical situations packaged as information; not tailored to needs; more likely to be dismissed.; may limit discussion if "advice" given before we know the patient's specific needs
- **Using "Patient Talk"** - use of terms / phrases used by pt. (mirroring)
- **Depersonalisation**- use "the" instead of "your / my" penis / vagina (distancing)
- **Patient Initiated Advice**- pts initiate Q's about sex / seek advice

Communication Practices in Healthcare Conversations About Sexual Health

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Recommendations:

- **Avoid** using **vague terms**
- **Don't omit "delicate terms"** - may convey HCP discomfort & limit subsequent discussion
- **Avoid assumptive talk** e.g. heterosexist / what constitutes "normal" sex
- **Skilful Use of "depersonalised" language** e.g. "the vagina / breasts": can create distance or space for mutual talk about "delicate issues" in a discrete, objective way
- **Use "neutral" language** to avoid moral implications
- **Increase responsiveness**: ask patient about their identity, relationship status, knowledge, behaviours **before** initiating topic of sexuality
- Beneficial to **ask questions** about sex **early** in the consultation
- **Use patient-initiated talk** about their "partner" / "wife" etc. to lead onto talk about relationship / sexual concerns – "mirroring" = responsive to pt. needs
- **HCPs can create space / encourage pts to ask questions**

Top Tips for Talking About Sexual Concerns in Clinic

"Funnel Technique": start with less "sensitive" questions to build rapport & gather important context for talk about sexual issues

- Can you tell me a little about the important relationships in your life?
- How has your illness affected the relationship between you and your partner(s)?
- What do you want most from your partner(s) now?
- Has the physical / sexual side of your relationship been important to you? And your partner(s)?
- Has your illness changed how you feel about the sexual side of your relationship?
- In what ways has your illness changed the physical / sexual side of your relationship?
- What would help you most right now?
- Is there any way I could help you with that?

Top Tips for Talking About Sexual Concerns

Give Overt "PERMISSION" to Talk About Sexual Concerns

- Start with a normalizing statement that makes the person aware they are not alone in experiencing sexual concerns or difficulties related to their diagnosis or treatment(s)
- Legitimises sexuality as a topic worthy of discussion & support

"Some people experience sexual concerns or difficulties after this type of cancer / cancer treatment…."

- Follow it up with a focused / more personalized question

"I was wondering if you had experienced any changes or difficulties that I can help you with?"

"I was wondering if you had any sexual concerns or difficulties that you might find helpful to discuss?"

Top Tips for Talking About Sexual Concerns in Clinic

- **Use a practical topic / intervention with which you are confident as a route to discuss linked sexual concerns**

"Many people experience vaginal dryness as a side effect of their endocrine treatment.

Can we talk about how treatment may affect your vaginal health and your sexual relationship?

I have info about intimate lubes & vaginal moisturisers that may help your vaginal health and sexual well-being."

Top Tips for Talking About Sexual Concerns in Clinic

- **Use a screening tool or PROM as a vehicle for discussing sexual concerns**

EORTC QOL group SHQ-C22
(Sexual Health Questionnaire -22 items)

FSFI-6 Questionnaire (Female Sexual Function Index- 6 items)

IIEF-5 Questionnaire
(International Index of Erectile Function – 5 items)

SHQ-C22: During the past 4 weeks:

- How important to you is an active sex life?
- Have you had decreased libido?
- Has sexual activity been enjoyable for you?
- Has the treatment affected your sexual activity?
- Have you felt pain during / after sexual activity?
- Were you confident about obtaining & maintaining an erection when you had sex?
- Have you felt less masculine / feminine as a result of your disease or treatment?
- Have you had communication with health professionals about sexual issues?

Starting The Conversation-Patients

Adapted from Barsky Reese J et al (2021)

1. **Identify Your Current Concerns**

- Make a checklist (or find an existing one)
- Identify your top concern to discuss
- Identify who you think is best placed to help you / & or easiest to talk to

2.**Practice using the SEA model**:

- Be **S**pecific
- **E**xplain why concern is important
- **A**sk a Question

- “I’ve been experiencing vaginal dryness”
- “And it’s making sex uncomfortable”
- “Is there anything you can suggest I could try for this?”

3. **Plan & Practice Communication**

- Draft your concern statement to share with clinician
- Practice out loud
- Repeat / revise as necessary
- Write it down & bring to next clinic visit

Podcasts

Shine Cancer Support podcasts, blogs & video clips on sex & dating after cancer

https://shinecancersupport.org/information/sex/

Shine Cancer Support dating podcast
https://shinecancersupport.org/information/dating/

& Dating after Cancer Facebook group

https://dontignoretheelephant.podbean.com/

Dr. Liz O'Riordan: "Where we talk about the stuff that no-one else will!"

Digital solutions for sexual wellbeing

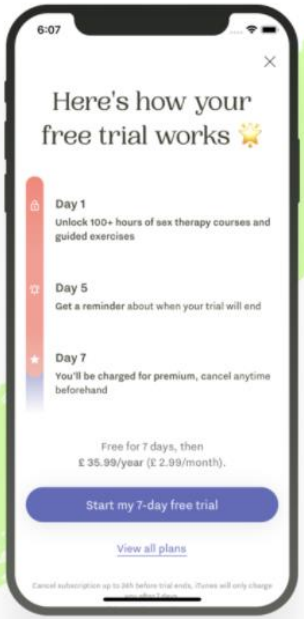
We Are Ferly App

https://weareferly.com

"…we believe that all women and folx with vulvas have the right to lead healthy, confident and pleasurable lives."

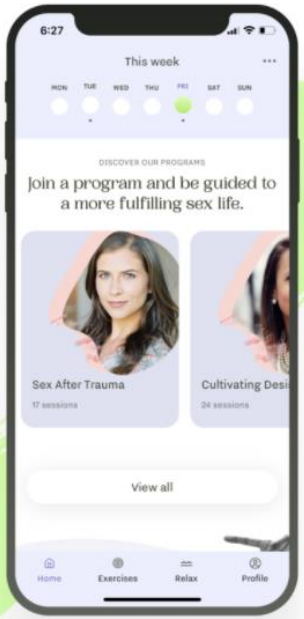
Pleasurable Sex is Possible

Whether you're struggling to get in the mood, to get out of your head and into your body or to know what you like and how to ask for it, we've got you.



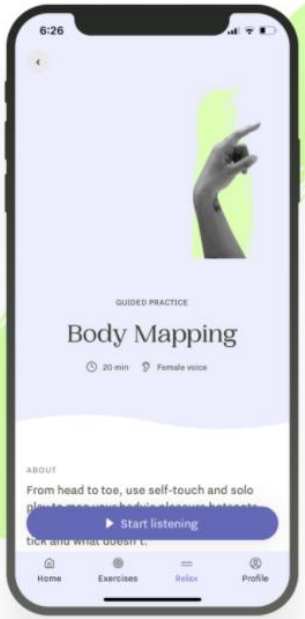
1. Start your free trial

Download the app, explore 100s of audio sessions, take our sexual wellness quiz and enjoy 7 days free.



2. Enroll in an expert program

Be guided, supported and held accountable by world class practitioners from the comfort of your home.



3. Enjoy sex more.

Overcome sexual challenges with our audio sessions, guided practices, journalling and group discussions.

Digital Sex Therapy for ED: Mojo Men

https://mojo.so/

What is Mojo?

Mojo is a digital health platform founded in 2018 by two cousins who were both struggling with erectile dysfunction. It distills decades of sex therapy knowledge into self-directed content that can be digested conveniently and discreetly.

Expert led video courses
Like sex therapy without the pressure.

Weekly group sessions
Calls to connect with guys in the same boat.

Recorded therapy sessions
Hear guys work through problems with sex therapists.

Community
Share your story and find answers with others.

Meditations
Calm your mind to improve your sexual wellbeing.

Blog
Free resources and guides created with our experts.

Cancer-related sources of advice & support

- **Shine Cancer Support podcasts (sex & dating) https://shinecancersupport.org/information/sex/**

- **OUTpatients – LGBTIQ+ Cancer Support UK Charity www.OUTpatients.org.uk**

- **Sex with Cancer website www.sexwithcancer.com**

General sources of sexual & relationship advice & support

- Sexual Advice Association (New Mobile App launched) www.sexualadviceassociation.co.uk
- Spiced Pear: Menopause & Sexual Dysfunction (2x GP's)
- https://spicedpearhealth.co.uk/
- THE MIX: essential support for under 25s www.themix.org.uk
- LGBT Foundation www.lgbt.foundation
- RELATIONSHIPS SCOTLAND www.relationships-scotland.org.uk

On-line Psychosexual Therapy

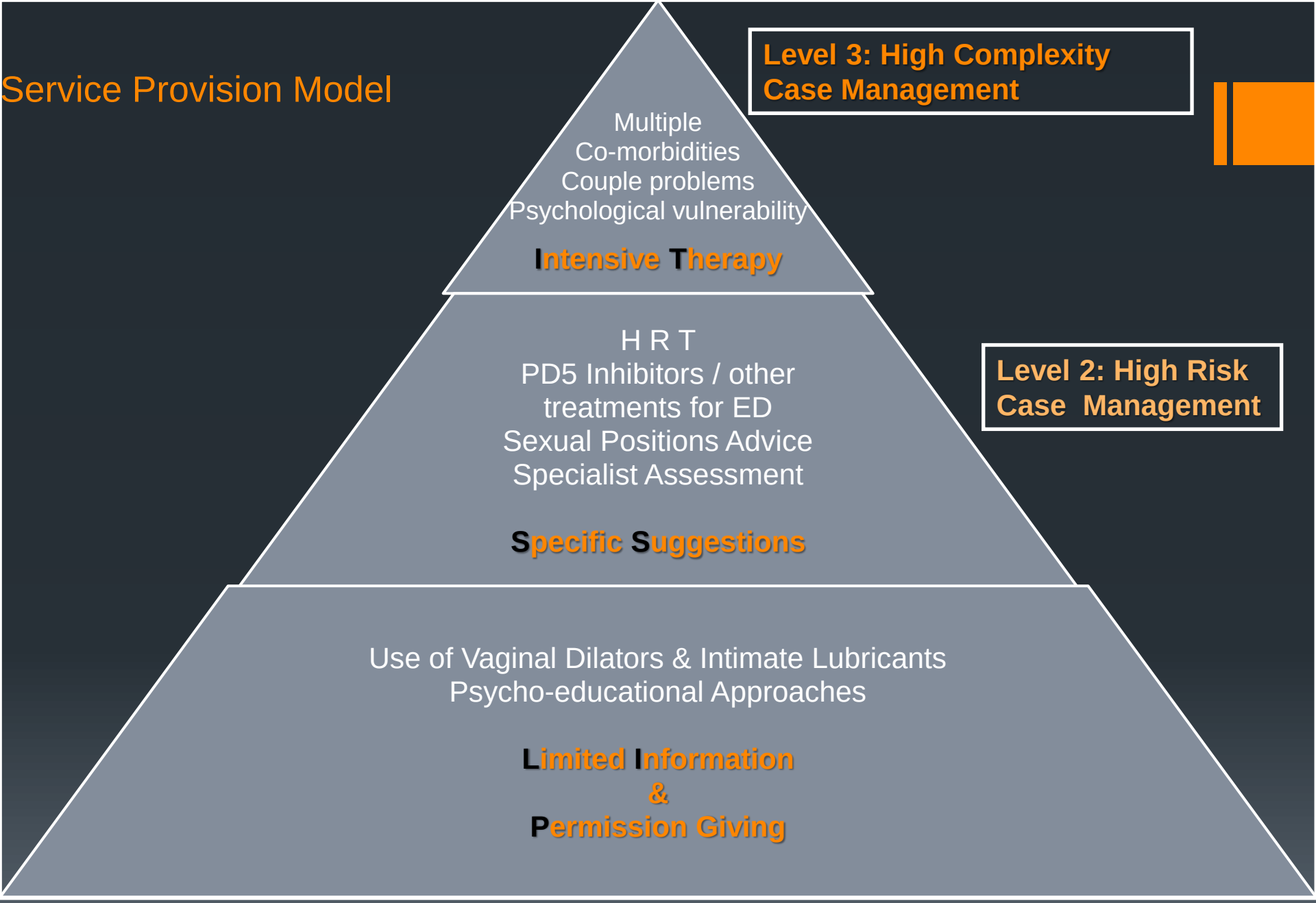
www.cosrt.org.uk - Find a Therapist

- relate the relationship people **www.relate.org.uk -Find local centre**
- **www.tavistockrelationships.org**
- Institute of Psychosexual Medicine **www.ipm.org.uk** -Find a Specialist
- Perci HEALTH **www.percihealth.com** supportive cancer care services - oncology AHPs- via telemedicine platform

Take Home Messages

- **It OUR (HCP) Responsibility** to learn how to ask about Sex & Relationship Impact of illness & treatment- **NOT the patient's!**
- **Think about how to raise profile of this topic in practice:** consent forms, patient education materials / websites embedded within treatment pathways; local management guidelines development; routine clinical screening or PROMS use e.g. EORTC SHQ-22, IIEF-5 & FSFI-6
- **Map Local / National Specialist Resources:** Knowing where & how to refer on to specialist services supports professional confidence / increases likelihood of discussions taking place
- **Organisational Support:** privacy; regular access to de-briefing / clinical supervision; **stepped service provision model – PLISSIT**; access to specialist "oncosexology" and communication training

Service Provision Model



Thank You for Listening-
All Questions Welcome!