

Development and Usability of



A web-based psychosexual resource
for **all** cancer survivors and their
partners

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Let's think about sexuality...



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Sexuality IS NOT JUST SEX!



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Sexual Concerns Amongst Cancer Survivors

- ❑ Over 40% of cancer survivors experience sexual dysfunction
- ❑ More than 90% of 'below the belt' survivors face sexual changes
- ❑ Sexual difficulties are **complex**
 - physical and psychological concerns may interact and compound
 - E.g. pain can be exacerbated by anxiety
- ❑ Changes to sexual function tend to linger beyond two years after treatment
- ❑ With intervention, up to 70% of survivors can have improved sexual functioning



Choo et al, 2010, Supportive Care in Cancer; Aerts et al, 2012, J of Sex Med; Gilbert et al, 2010, Arch Sex Behav

Partners Can Be Affected As Well

- ◆ 59% of women & 79% of men had changes in frequency of sex and intimacy
- ◆ Changes were associated with:
 - ◆ Patients' physical impairments
 - ◆ Partner's fatigue associated with caregiving
 - ◆ Changes in perceptions of sex with their partner
- ◆ As patients' physical side effects ↑
 - partners reported:
 - ↓ sexual activity & satisfaction
 - ↑ feelings of self-blame
 - ↑ sadness



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Principles for Addressing Sexual Concerns

- ✓ Facilitate communication with the partner
- ✓ Treat the underlying cause where possible (physical, psychological, social)
- ✓ Minimise effects of anatomical changes and provide symptom relief (e.g. use of vaginal dilators, moisturisers, penis pumps)
- ✓ Provide information/advice on alternative methods for showing intimacy, and for giving and receiving sexual pleasure
- ✓ Refer to specialised services where required



Barriers to uptake and retention:

- ❑ Patients are unaware of available resources
 - Lack of referral
- ❑ Embarrassment (patients &/or providers)
- ❑ Lack of engagement (either or both partners)
- ❑ Minimal attention to partners (not included or assessed)



Miles et al (2007). *Cochrane Database Syst Rev*; Park et. Al. (2009) *The Cancer Journal*.

Improving Reach and Uptake of Psychosexual Support: Assessment of Intervention Preferences of Breast Cancer Survivors Regarding Sexual Concerns

C. Lawsin, A. Ballard, H. Dhillon, K. Hobbs, P. Butow (in prep)

AIMS:

Assess how best to provide psycho-sexual support and potential barriers to uptake amongst a sample of Australian breast cancer survivors.

Methods:

- Email recruitment (e.g. Register 4, support groups)
- Oncologist referral

Prior Support for Sexual Concerns Sought

- ✓ reading a book/article (36.7%)
- ✓ the internet (33.9%)
- ✓ their GP (30.3%)
- ✓ asking spouse/partner for advice (29.4%)
- ✓ their oncologist (19.3%)



Interventions currently utilized

- ✓ Lubricant (70.6%, 70% found it helpful)
- ✓ Vibrator (22.9%, 75% found it helpful)
- ✓ Topical cream (12.8%, 57.1% found it helpful, 42.8% did not)
- ✓ Therapy (individual/ couple – 6.5%, mostly unhelpful)
- ✓ Vaginal dilator (4.6%, 50% found it helpful)
- ✓ 22.9% did not utilize any intervention

If you were to receive support in the future to address sexual concerns, what topics would you be interested in?

Topics of Interest for Future Psychosexual Support	% Interested
Education about what medical treatments are available to improve sexual function	44.0%
Education about the sexual side effects of treatment	43.1%
Education about how cancer treatment can affect your relationship/dating	36.7%
Strategies to improve intimacy (emotional and physical) with your partner	36.7%
How to communicate with your partner about sexual concerns	28.4%
Alternative sexual techniques to show intimacy towards your partner	26.6%
How to communicate with your physician about sexual concerns	23.9%
Enhance your awareness in the moment regarding your sexuality	22.0%

Modality and Format Preferences

- Please rank your preference from 1 (first preference) to 6 (last preference) of format you would like to receive any of the above support:

Top ranked support formats:

- an online education program (32%)
- Book
- DVD

Least preferred support formats:

- telephone support
- face-to-face support group
- online support group



Preferred Features of an online psychosexual resource	% Interested
Written stories of cancer survivors sharing their experience surrounding sexual changes after cancer treatment	68.8%
Videos of cancer survivors sharing their experience surrounding sexual changes after cancer treatment	50.5%
Online forum available to all users of the educational resource	46.8%
Videos of health professionals explaining the educational material provided	44.0%
Animated videos of how to utilize medical devices to improve sexual functioning (e.g. vacuums, dilators)	28.4%
Animated videos demonstrating alternative sexual techniques to enhance intimacy after cancer treatment	27.5%
Videos of actors demonstrating alternative sexual techniques to enhance intimacy after cancer treatment	24.8%
Videos with actors demonstrating how to utilize medical devices to improve sexual functioning (e.g. vacuums, dilators)	14.7%

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Qualitative Interviews

- Participants 32 survivors (18 male) and 8 partners (4 female)
- Highlighted the importance of communication and the need for self-guided communication skills training
- Ideas for retaining male cancer survivors in *Rekindle*:
 - Simplicity & brevity
 - Targeting the male perspective
 - Testimonials & normalization
 - Tailoring to the individual

The last time I saw my oncologist – you know, I talked to the registrar - it was like, "Well, is your sex life okay? Do you have sexual function?" "Yes." And then it was on to the next thing (Joel)

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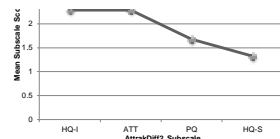


Rekindle Usability Testing

System Usability Scale (Brooke, 1986)

- Ave = 81.25/100 (SD = 15.07)
- Above the average of 70.1
- 4th quartile of high acceptability rating
- Aligns with the descriptive rating of 'good' for composite system usability referring to the overall ease of use

Mean participant scores for each AttrakDiff2 subscale



Note. HQ-I = Hedonic Quality Identification; ATT = Attractiveness; PQ = Pragmatic Quality; HQ-S = Hedonic Quality Stimulation.

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Rekindle Stakeholders

- | | | |
|-----------------|-----------------|--|
| Catalina Lawsin | Annie Miller | |
| Phyllis Butow | Amelia Beaumont | |
| Ilona Juraskova | Trisca Kumar | |
| Judy Kay | Lori Brotto | |
| Kevin McGeechan | Lee Ritterband | |
| Haryana Dhillon | George Fishman | |
| Fran Boyle | Wanda Lawson | |
| Zac Seidler | | |
| Sylvie Lambert | | |
| Kim Hobbs | | |
| Sandra Turner | | |

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Rekindle will be tailored according to:

- Type of user (patient &/or partner)
- Gender of user
- Sexual orientation

→ 12 Versions

Survivor and Partner Testimonials

Alice, 27

Andrew, 37

Sam, 25

Carol, 55

MULTIDISCIPLINARY HEALTHCARE PROVIDERS





Professor Fred Boyle AM
Sexologist



Associate Professor Sarah Turner
Sexologist

This instructional video is narrated by Dr Michael Lowy.

This instructional video is narrated by Kim Hobbs.






Terri Kim
Sexologist



Creating an Environment for Safe Sex Talk

Previous
Next

rekindle

Dispelling Myths

It's the basics, it's the 70s and it's happened: myths about cancer are out there and need to be set straight.

Turn each of the below circles to see the reality behind common myths.

MYTH

If I have cancer, I'll lose my partner when they find out about my diagnosis.

MYTH

You can prevent your cancer by your partner through sexual intercourse.

MYTH

I should never see a gyn.

MYTH

MYTH

MYTH

rekindle

How is this woman feeling?

Can you tell how people are feeling from their expressions? Test yourself by selecting the expression that best fits the image.



ANSWERED 0/10

Happy

Worried

Embarrassed

None

Previous
Next

rekindle.org.au

Here are some helpful Questions

Effective communication is key to relationship. However, communicating clearly when you need can sometimes be a challenge, especially if you're talking about a sensitive topic, such as sex.

How are some helpful questions to ask your ONE/LOVER, CP OR MINE

Choose the health care provider with whom you feel most comfortable asking your sexual concerns and:

1. What can I get help to improve how I talk about my feelings and needs when it comes to sex?

Ask to Your Provider

How are some questions to ask a PSYCHOLOGIST OR SEX THERAPIST

1. How can I talk with my doctor/partner about physical sexual changes after sex/sex?
2. How can I get my doctor to feel like I've talked about sex to me. Has this been a challenge for you?

