

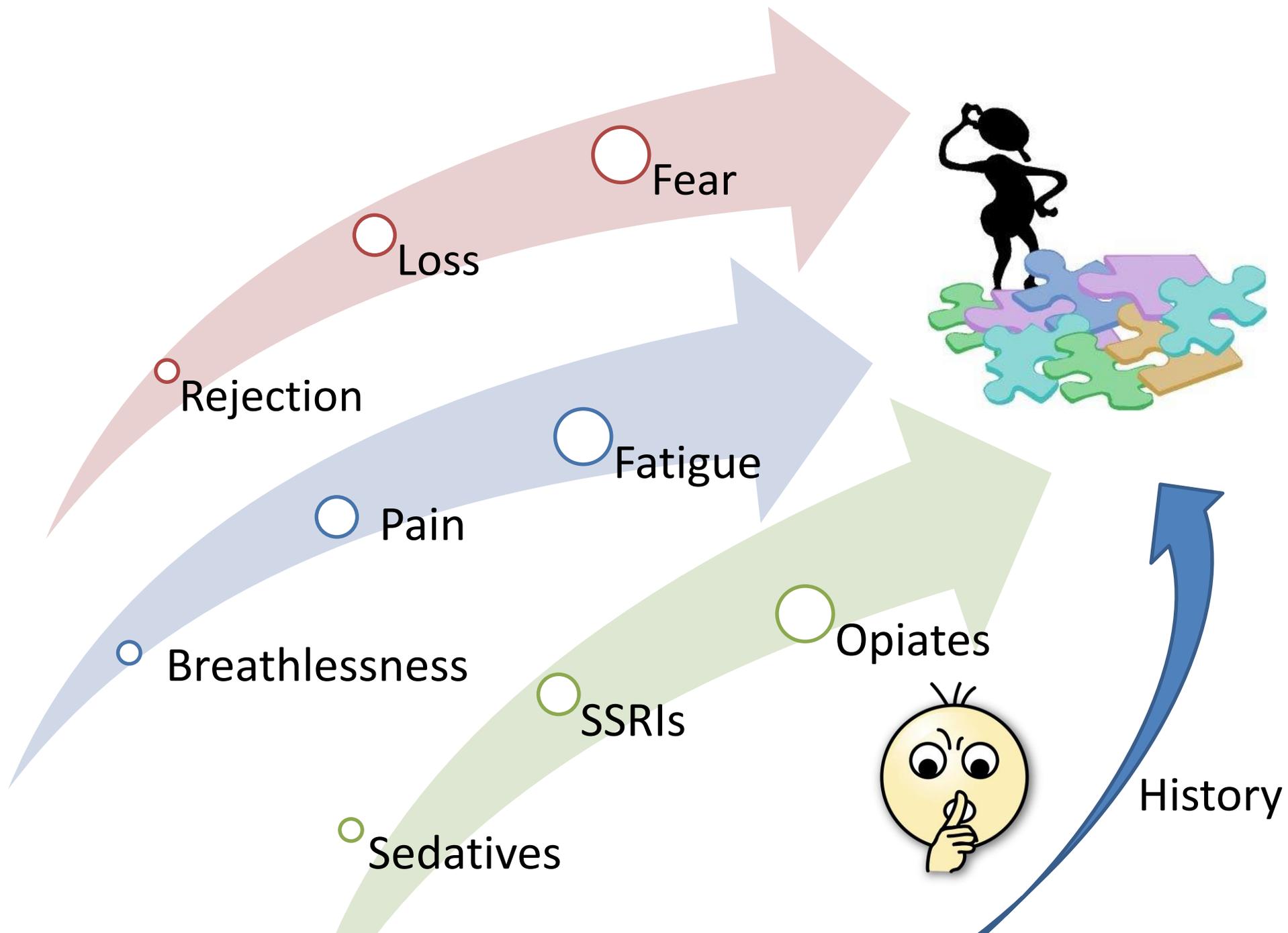
Sexual issues

Bridget Taylor

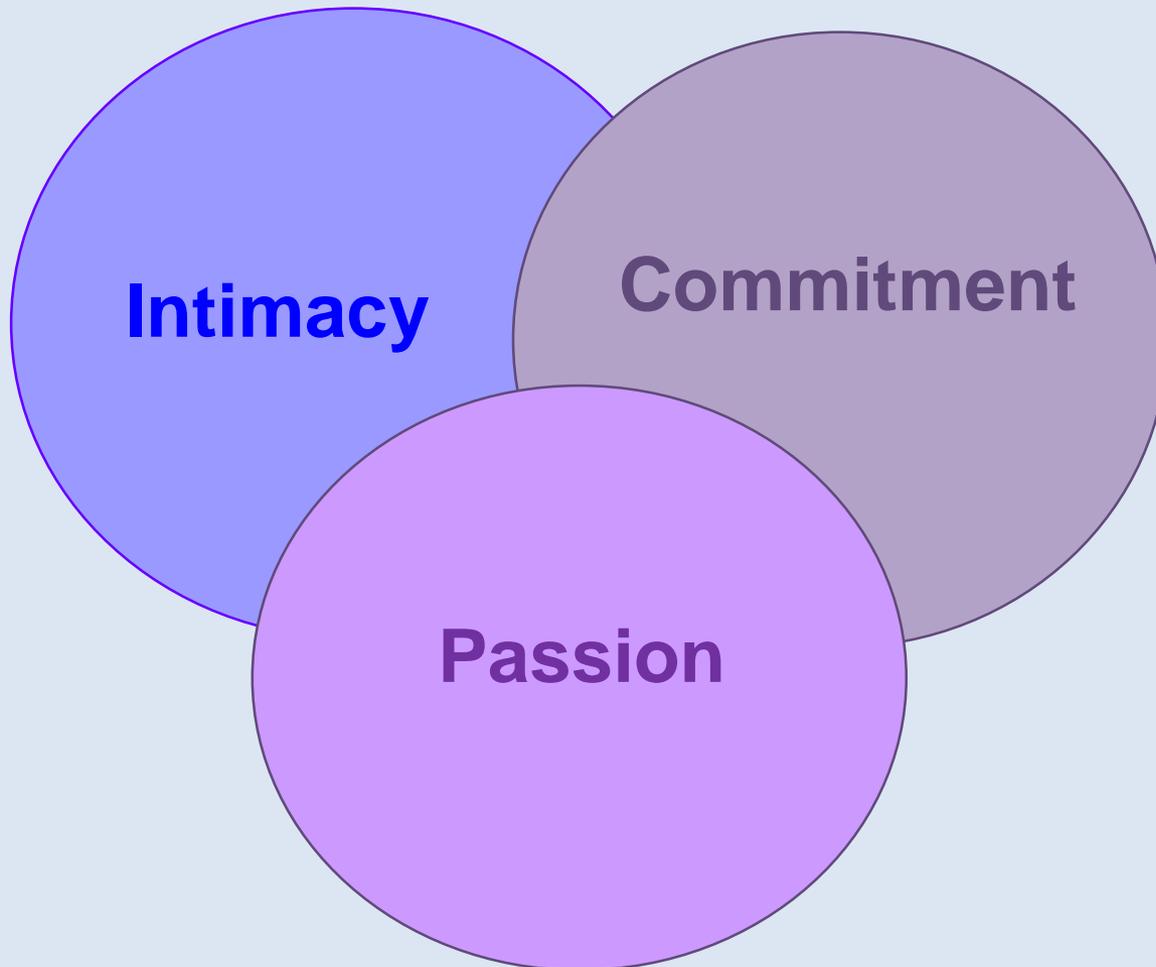
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What we do know

- Research emphasis on cancer and treatment effects:
 - Altered sense of sexual self
 - Reduction in sexual interest
 - Increase in sexual problems
 - Not always associated in a decrease in relationship satisfaction
- The views of partners tend to be overlooked



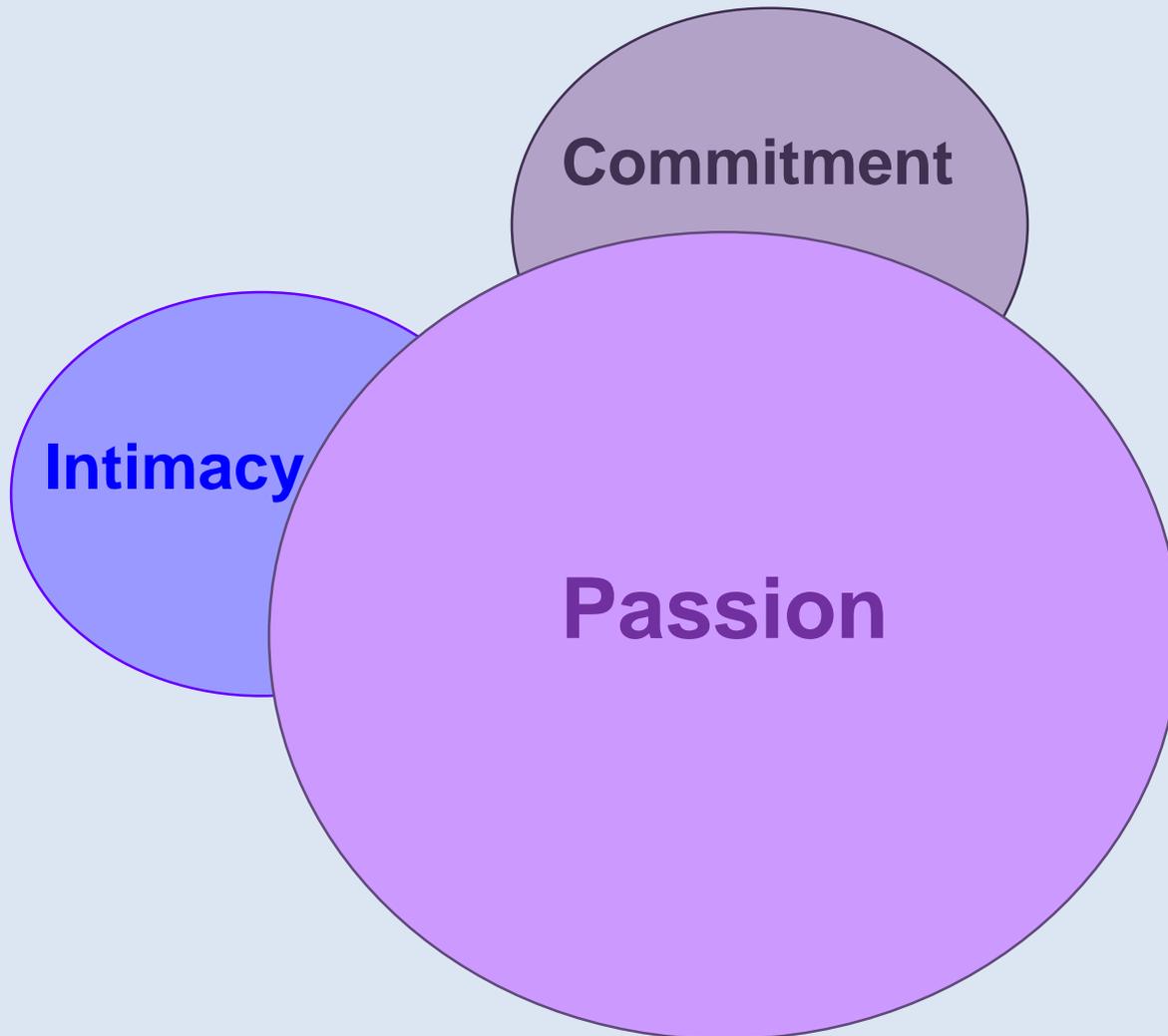
Sternberg's Theory of Love (1986)



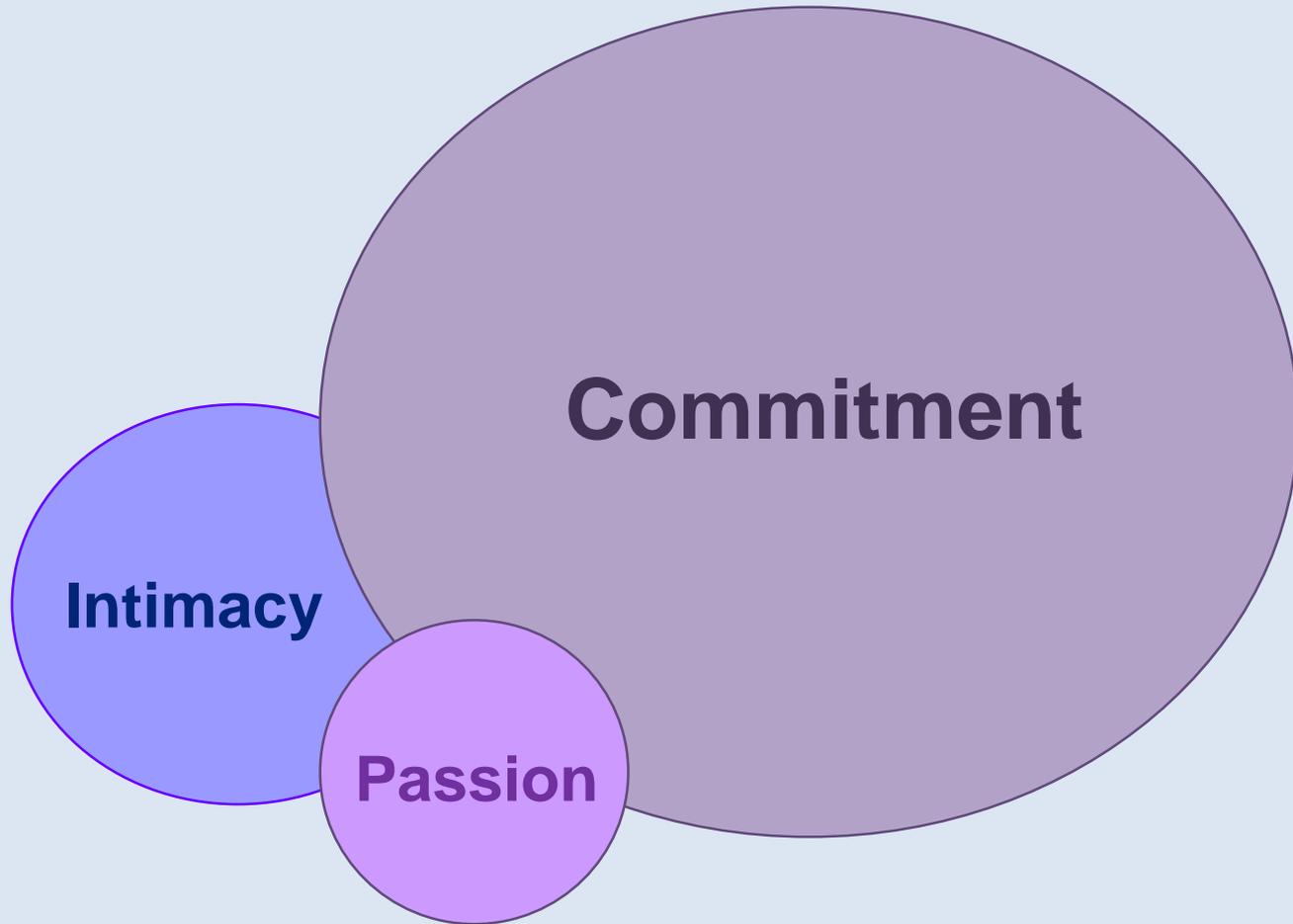
Sternberg's Theory of Love (1986)

- Components are defined uniquely by individuals
- Good quality relationships usually have a close match between partners' patterns
- Partners need to be able to match each other's interpretation of love if their needs are to be met
- Interpretations need to be translated into action
- Illness can re-shape components to the couple's benefit or detriment

Sternberg's Theory of Love (1986)



Sternberg's Theory of Love (1986)



Commitment vs intimacy ... and passion?

“You know my wife used to kiss me on the lips, then she kissed me on the forehead, then she patted my shoulder, and this morning when she left, she wiggled my toes.”

(Toombs 2008)

Organisational issues

- Lemieux et al (2004)
- Canadian study - hospice
- 10 patients with cancer
- All had partners



“While I was in that group of four or five patients ... I did not show my intimacy. We still held hands, but I would not try to grab her and kiss her and cuddle... But once we got our private room, things changed. She was sitting on the bed, we were holding, kissing, hugging... I could be more open, I could let my feelings go (crying)... in the private room, you can open up and be more yourself.”

What are the experiences of patients and partners of patients with a life-limiting illness in relation to sexuality and intimacy?

Supervised by: Prof Mary Boulton and Dr Jane Appleton

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Methodology and Method

- ❑ Heideggerian hermeneutic phenomenology
- ❑ Purposive sample of patients and partners
- ❑ Motor neurone disease and terminal cancer
- ❑ Unstructured conversational interviews
 - Two interviews per person
 - Couples interviewed separately

Sample

	Patients		Partners	
	Male	Female	Male	Female
MND	8	5	5	5
Cancer	5	9	1	3

Two cases



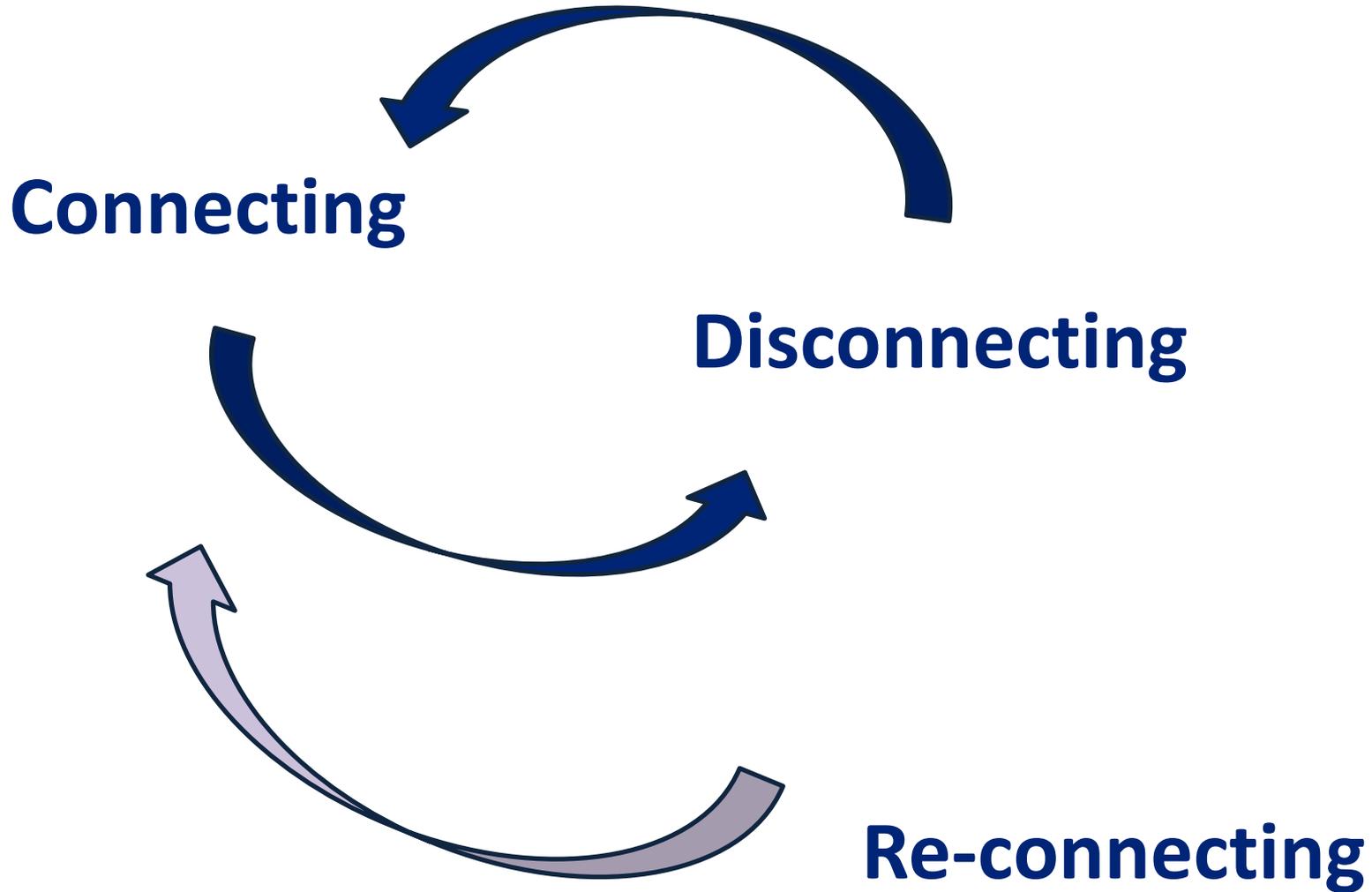
Jim (82) and Betty (70)

- Jim – MND 4 years
- Wheelchair dependent
- Only movement was in one finger
- Totally reliant on QDS package of care

Ray (50) and Julie (45)

- Ray – MND 4 years
- Wheelchair dependent
- Only movement was in one shoulder and wrist
- Totally reliant on Julie for all care
- Needed repositioning at night +++
- Non-invasive ventilation at night

Being-towards-death-of-the-couple



Re-connecting

“A few months ago I was lying in bed next to him and this finger came out and actually touched me and that’s never happened before, never ever. He touched me because he wanted to and... I would’ve loved to have been touched [eyes filled with tears] ... and now occasionally he puts his hand over and just rubs my back.”

Our role?

“I think it would be nice to be given the choice”



“It brings things to the surface ... things that have been rumbling around in the back of your mind”

“An opportunity to talk if you want to”

BLISS (de Vocht 2011, p.99)

Bring up the topic in an appropriate way

- ‘People sometimes have concerns about how their intimate relationship has been affected. Is this something you might find helpful talking about?’
- ‘Some people taking this type of medication / having this treatment find that it has reduced their interest in sex / sexual feelings / the ability to make love. Is this something that concerns you or your partner?’

BLISSS

Bring up the topic in an appropriate way

Listen actively to the **I**ndividual experience

Support the individual

Stimulate communication between partners

Supply personalised advice and information (if necessary, refer to a specialist)

(de Vocht 2011:99)



to 'review' (Taylor and Davis, 2007)

We need to...

- Challenge our assumptions and prejudices
- Overcome our reticence at broaching this subject
- Recognise and overcome our need to 'fix' things
- Be comfortable with not being the 'expert'
- Recognise the experience / expertise within the individual / couple
- Be alongside the individual / couple in distress, creating safety and support in the spirit of boundaried exploration



Practical suggestions

- How is love and affection expressed within your relationship?
- Create a wish-list of things you would like to change within your relationship:
 - What feels manageable / achievable?
- Intimate communication
 - What I like is ... /
 - When you ... I feel ...
- Do they know how you feel / what you have just told me?
 - Would it help to write to your partner?
 - A facilitated conversation?

Organisational considerations

- Challenge assumptions and stereotypes
- Education
- Environment:
 - Who manages the 'do not disturb' notices?
 - Locks on the inside of doors?
 - Equitable access to all facilities?
- Sensitivity and confidentiality in written records
 - *"Impact on personal relationship discussed"*
- Who to refer to?
- Policy development

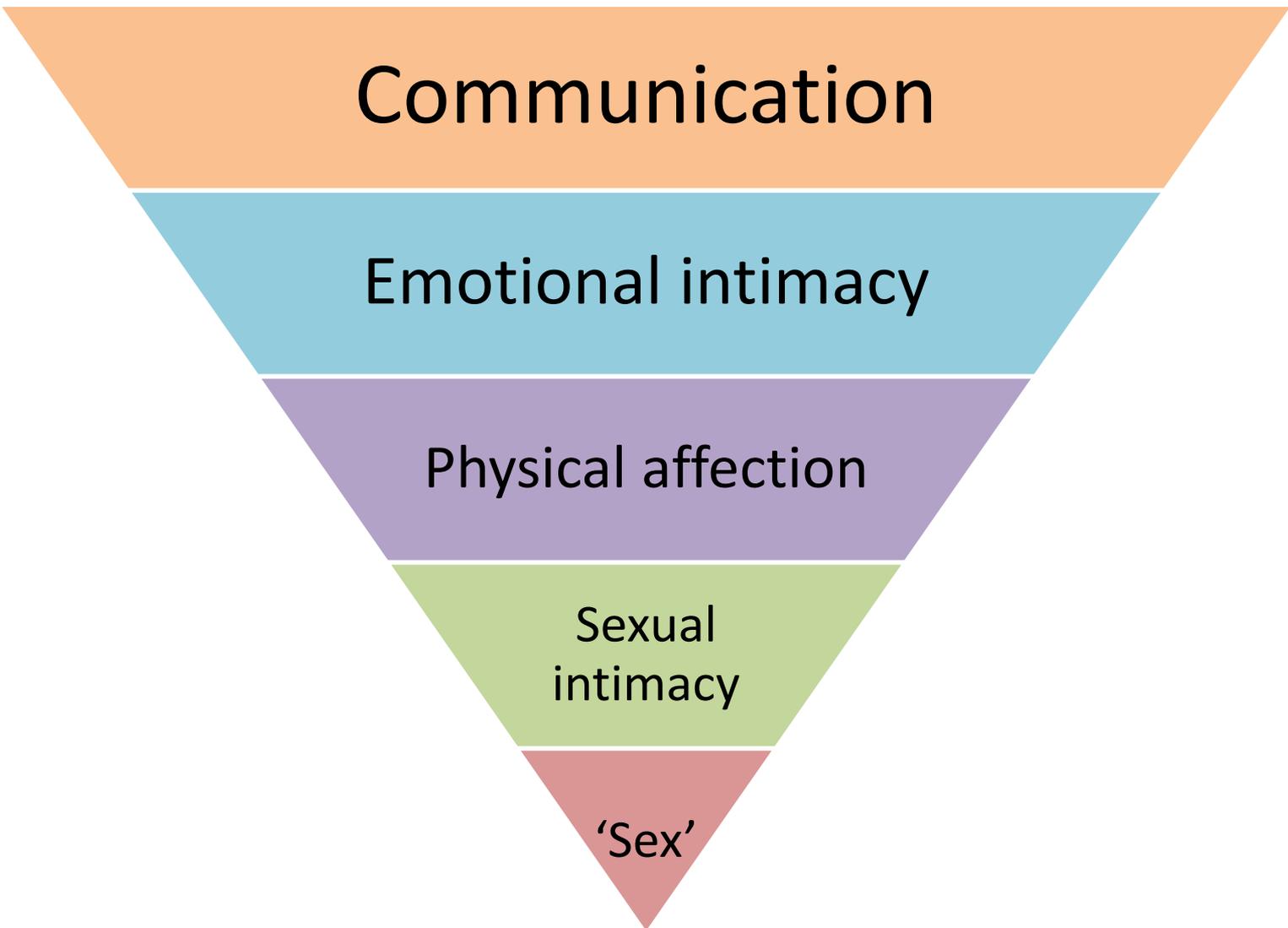
Treating the whole person

“Don’t just focus on my body, but help with the relationship”

(Matzo and Hijjazi 2009: 279)

“There is support for the carers [from a local hospice], there is support for the patients, but there is not much support for the actual relationship between the two ... Some couples come closer together, some it drives them apart, and there doesn’t seem to be any sort of help in that area.”

(Taylor, 2014a: 444)



Communication

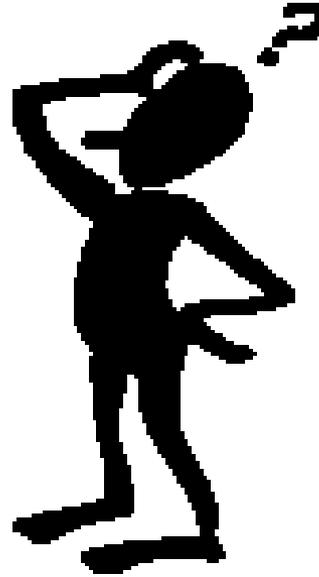
Emotional intimacy

Physical affection

Sexual
intimacy

'Sex'

The next step?



Useful resources

Intimacy & Sexuality

For Cancer Patients and their Partners

A Booklet of Tips & Ideas for your Journey of Recovery



By:

Dr. Darja Brandenburg, Macmillan
Clinical Psychologist & Sex
Therapist (ed.)

Lorraine Grover, Clinical Nurse
Specialist & Sex Therapist

Barry Quinn, Senior Nurse for
Oncology & Lead Chemotherapy
Nurse

Provided by the Sexual Advice Association
www.sexualadviceassociation.co.uk

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mnda
motor neurone disease
association



13B

Sex and relationships

Information for partners of people with motor neurone disease

This information sheet provides guidance if you have concerns about sex and intimacy when your partner has MND.

The content includes the following sections:

- 1: **How might MND affect sex and intimacy?**
- 2: **How can sex and intimacy be maintained?**
- 3: **Are there other ways we can be close?**
- 4: **Where can I get support if I have experienced sexual violence or abuse?**
- 5: **How do I find out more?**

- Sexual advice Association
- MND Association
- National Association of People Abused in Childhood

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Further Reading



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<https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2016/reality-end-of-life-care-lgbt-people.pdf>

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Further reading

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Marsden R, Taylor B (2016) *Leaflet 13B: Sex and Relationships: for Partners of People Living with MND*. Available from:
<http://www.mndassociation.org>