

# An Elephant in the Room

## (Sex & Intimacy)

**Lois Quick**

**Clinical Nurse Consultant**

**Metro South Chronic Disease MND**



# Aim:



Identifying the Elephant



Some possible solutions



How to talk about the Elephant

# Metro South Chronic Disease MND

- A multidisciplinary community chronic disease team
- Provide an ongoing, proactive and responsive service supporting clients and their families from referral through to end of life
- 143 clients through service in 6 years.
- Highly experienced and skilled clinicians
- All care delivered at home which builds relationships and facilitates difficult conversations

The worst thing about MND is having an erection I can't do anything about...

My hubby is struggling with changing pads, never mind sanitary products!

I can't masturbate. Is it due to MND? And it's not because my hands are weaker although that's making it hard.

My wife is 3 months pregnant...



Yes, I have MND but I don't have to worry about falling pregnant, surely!

# So why do we respond that way ?

- concern about our own knowledge and abilities
- personal discomfort
- lack of awareness about sexual issues
- fear about "opening up a can of worms"
- lack of time, resources, and training



# The Evidence

Patients stated that health and social care professionals tended not to speak to them about sexuality or intimacy.

- Taylor, 2014

The majority of healthcare professionals do not proactively discuss sexuality issues with service users

- Dyer, 2013

# Pregnancy and MND



Effect on  
respiratory  
function



Effect of  
Riluzole on  
foetus



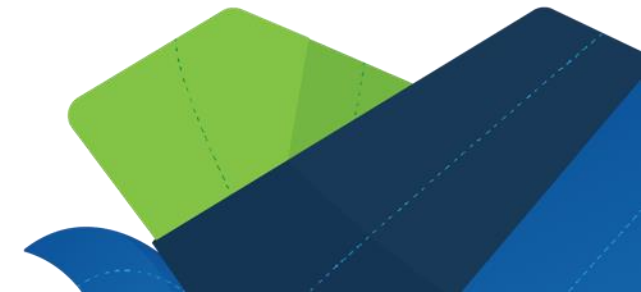
Effect on  
disease  
progression



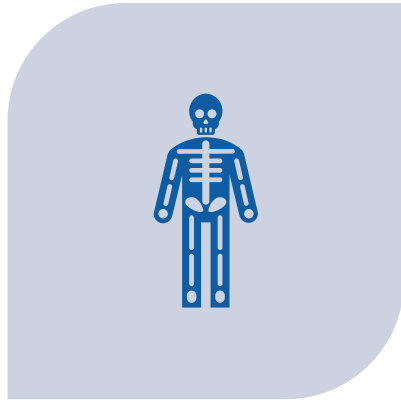
Energy  
demand &  
nutritional  
requirement



Need  
Caesarean for  
delivery



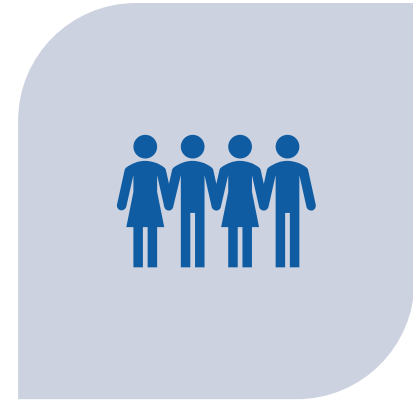
# Menstruation



LESS OBVIOUS  
ASPECT OF CARE



ALL THE  
GUIDELINES  
ENCOURAGE  
INTIMACY



CLIENTS EARLY ON  
IN THEIR DISEASE  
REMAIN SEXUALLY  
ACTIVE



# Which contraception?



Discuss with GP best option



Long acting reversible  
contraception (LARC)

injections

hormonal intrauterine devices

subdermal implants



AIM: to help carer with care

# Pregnant carer



Lifting / transfers /  
hoists



Fatigue



NDIS carer availability



Emotional challenges  
– new baby and  
palliative care



# Sexual needs



MND DOES NOT  
DIRECTLY AFFECT  
SEXUAL FUNCTION  
AND NEEDS



OTHER CONDITIONS



MEDICATIONS



# Things do change



PHYSICAL



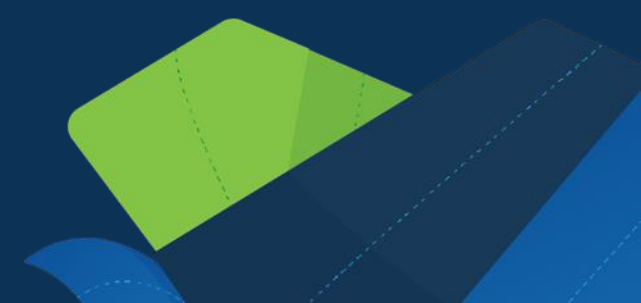
PRACTICAL



RELATIONAL



EMOTIONAL



# So what can we do?

Ask the question  
at assessment



- people with illnesses often experience sexual problems / change in their sexual relationship due to the illness. Is that an issue for you?

Would you like to  
talk about it?

- You are welcome to talk about it another time if you change your mind.

# So what can we do?

## Information in a resource book





13A

### Sex and relationships

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**Information for people living with motor neurone disease**

This information sheet offers suggestions to concerns you might have about sex and intimacy when living with MND, whether or not you are in a relationship. It includes the following sections:



13B

### Sex and relationships

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**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.

# So what can we do?

## Come back to the subject at trigger times

- Hospital beds
- Mattress changes
- Unable to roll in bed

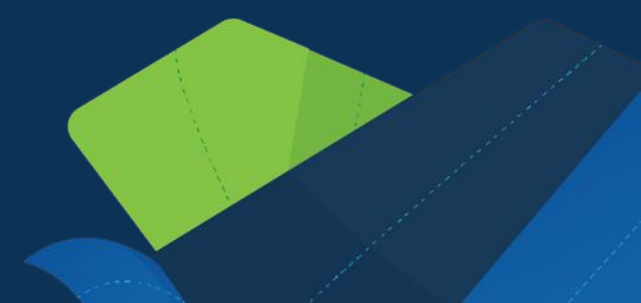
## Refer

- If unable to discuss

Just have a go?



Just address it so people aren't left with it





# References

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# Thankyou

- Contact details

Lois Quick

- [lois.quick@health.qld.gov.au](mailto:lois.quick@health.qld.gov.au)
- 0411 075862

