

TSC & SEXUALITY

Wednesday 15th July

7pm ACT/NSW/QLD/TAS/VIC

6.30pm NT/SA

4pm WA

Dr Elizabeth Thompson

MBBS FAFRM

WHO I AM...

- Rehabilitation Specialist at SIDHT
- New service established in 2020
- Provides service across two NSW local health districts (HNELHD and CCLHD)

FACTSHEET LINKS:

- [for Carers](#)
- [for GPs](#)
- [for NGOs](#)
- [for NSW Health Staff](#)

CONTACT:

(02) 4924 6067

HNELHD-IntellectualDisabilityTeam@health.nsw.gov.au



AIMS

- Reduce stigma and open the discussion by inviting people into having a frank and fun talk about sex and sexuality.
- You were young once too and... sexuality is not age limited 😊
- Research shows that young people want to talk to their parents about these topics; and those that do, acknowledge their parents as a trusted source of information, and are often more responsible in their relationships.
- Answer your child's questions honestly and directly when they occur.
- If you don't know the answer, find it out together.
- If your child is already in their teens, it's still not too late to start the conversation.

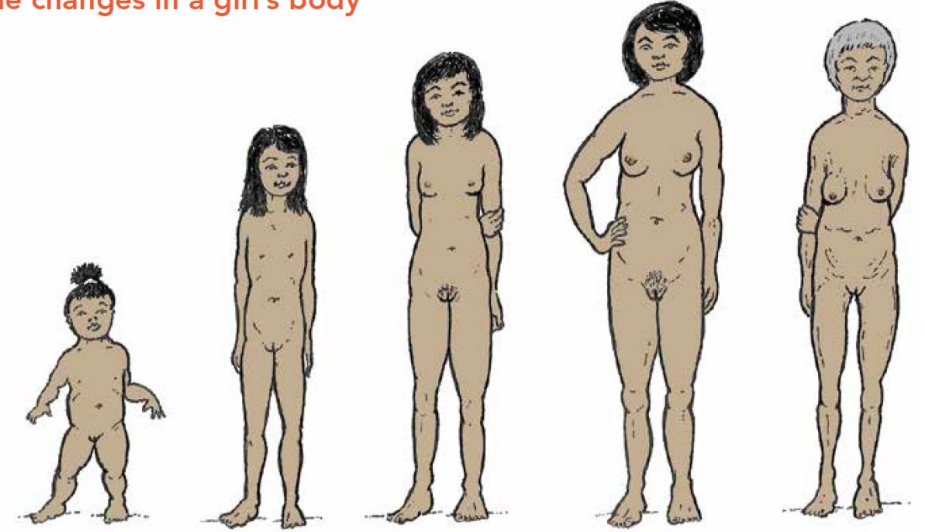
TSC & TEENAGE YEARS

- Tuberous sclerosis complex (TSC) has a wide clinical spectrum, and some people may have minimal symptoms
- Clinical conditions commonly associated with TSC:
 - Skin lesions
 - Socially appropriate expressions of attraction or safety awareness
 - Some have increasing seizure frequency during puberty, others don't
 - Hormones
 - Cardiac rhabdomyomas.
- **When teenage relationships start**
 - There isn't a 'right age'
 - From 9-11 years, more independence, more interest in friends
 - From 10-14 years, more time in mixed gender groups
 - From 15-19 years, romantic relationships
 - **It's also normal for children to have no interest in romantic relationships until their late teens**

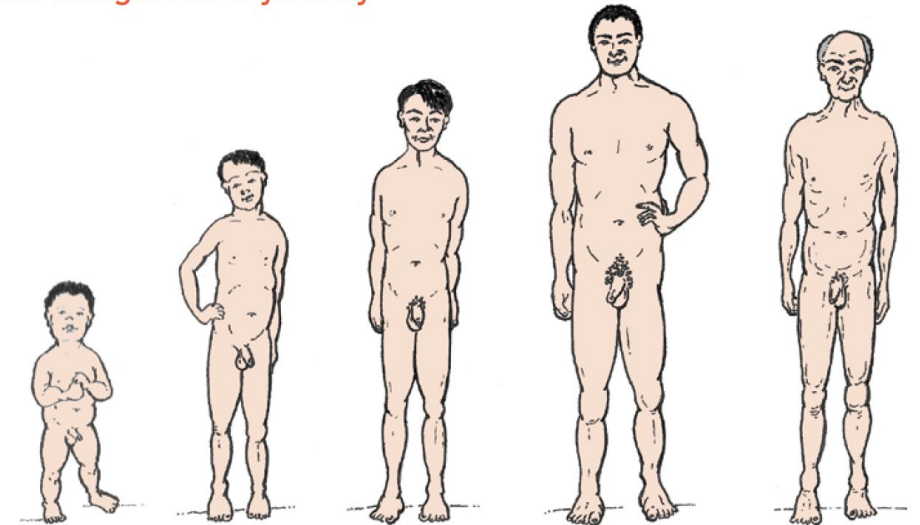
HOW TO TALK TO CHILDREN

- Try to be approachable, unshockable, and available
- Acknowledge any awkwardness or discomfort
- Talk about how you feel
- Be willing to answer questions openly and honestly
- Provide the correct information
- Have a sense of humour
- Encourage questions
- Know your own values
- Acknowledge that your child may have different views
- Know your boundaries
- Discuss issues relating to both males and females
- Be technologically aware
- Be positive

The changes in a girl's body



The changes in a boy's body





BREAK OUT SESSION

**Where is your child/
where are you at?**

FAMILY PLANNING NSW

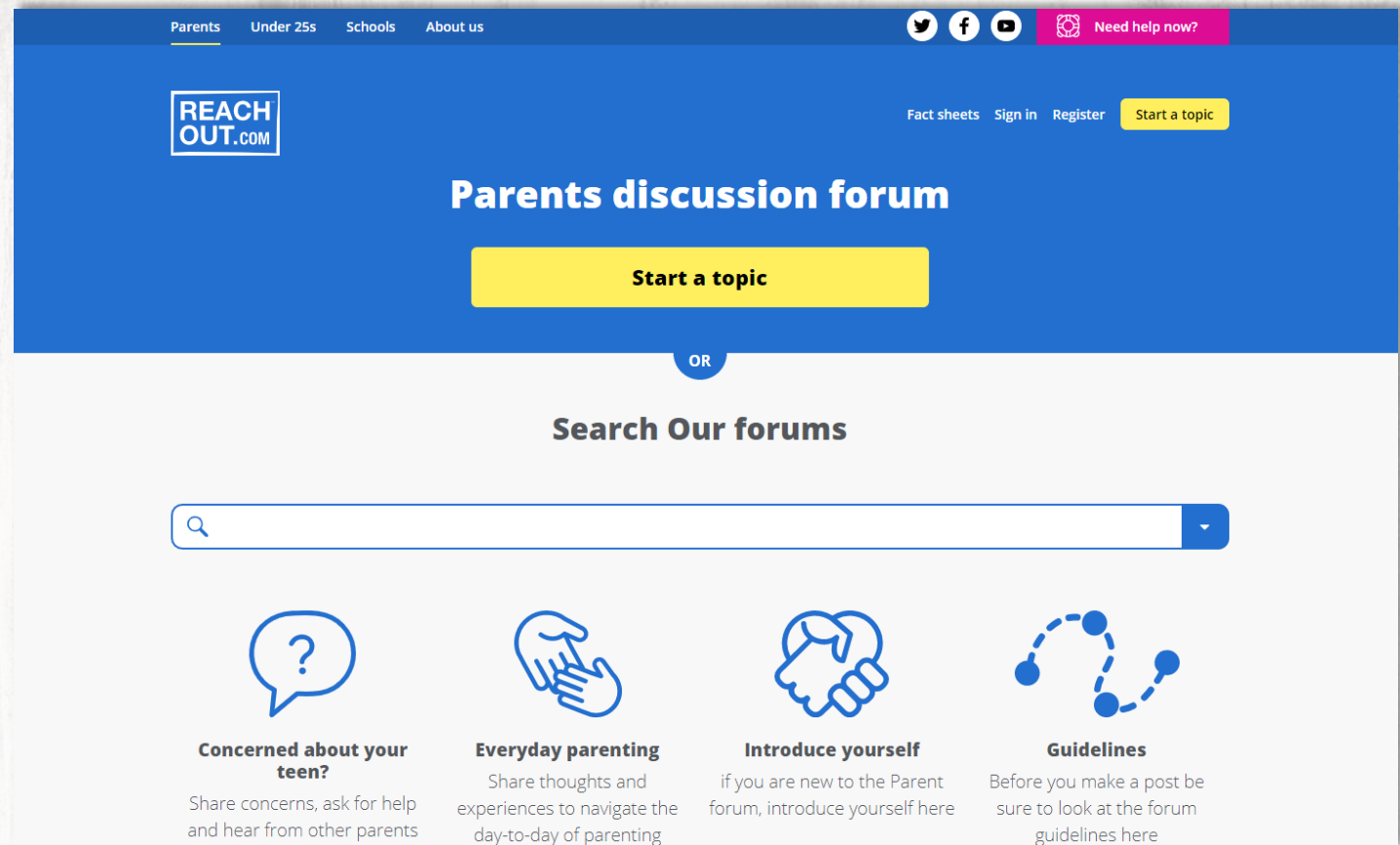
- fpnsw.org.au/health-information/individuals/parents-and-carers
- **Body Talk Website:** bodytalk.org.au/
- Other helpful FPNSW services:
 - **Youth Drop-In**
 - **The Condom Credit Card**
 - **Talkline 1300 658 886**
 - ***All About Sex Factsheets***

The Body Talk logo consists of the words "BODY" and "TALK" stacked vertically in a bold, white, sans-serif font. This text is contained within a red speech bubble shape that has a white outline and a small tail pointing towards the bottom right.

**BODY
TALK**

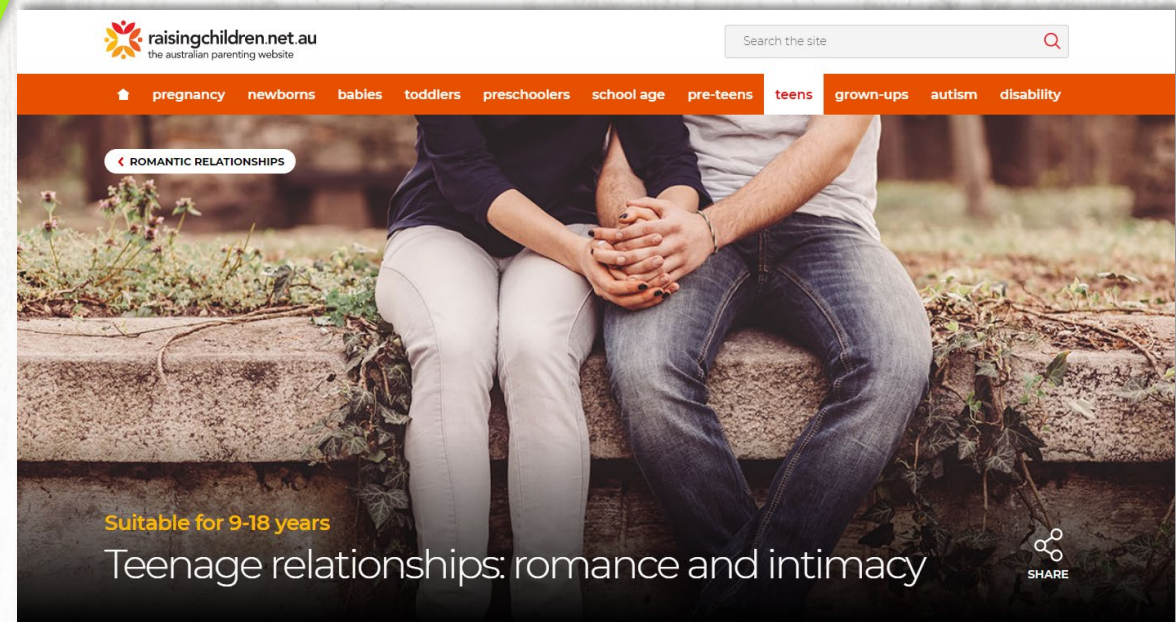
REACHOUT

- ReachOut.com



RAISING CHILDREN NETWORK

- [RaisingChildren.net.au](https://raisingchildren.net.au)





BREAK OUT SESSION

**As a result of tonight's
presentation, what do you
plan to do next?**

Resources

- <https://mycarespace.com.au/resources/s-ex-and-the-ndis-funding>
 - A great list of resources and suggestions 😊

Touching Base- access to specialist sex workers

- a charitable organisation, based in Sydney
 - active since October 2000.
 - offers training workshops.
 - does not receive any government funding
 - Online order form for available for their social story on seeing a sex worker
 - Operate a referral list of disability-friendly sex service providers in Aus
- As of May 2020:
decision by Federal Court to allow an NDIS participant be funded to see a sexual therapist stands (NDIA has threatened to appeal the ruling)

Liz Dore



- NDIS Provider
- Offers counselling and education

<http://www.relationshipsandprivatestuff.com/>

Love On The Spectrum

- ABC TV series about young adults with ASD dating

- Openly talked about the need for education regarding relationships and how to build intimacy appropriately



Not just the negatives, however...

- National Sexual Assault, Domestic and Family Violence Counselling Service (Australia)
Tel. 1800 RESPECT (1800 737 732, telephone counselling service operating 24 hours, 7 days)

- All people have the right to enjoy relationships and sexuality without being abused or exploited.
- Unfortunately, statistics show that people with disability experience all forms of abuse at much higher rates than people without disability.
- Reasons for this include:
 - inadequate sexuality education on where and when it is acceptable to be touched by other people
 - inability to resist, protest against or stop abusive behaviour from happening
 - not knowing that a person has the right to decide what happens to their body, especially if they are used to other people constantly attending to their physical needs
 - being raised in situations where they are used to being told what to do and therefore going along with requests or demands made by an abuser
 - agreeing to engage in sexual activity to fulfil unsatisfied cravings for attention, affection or rewards