

Cradle to Grave

The Role of Nurses Supporting and Advocating the Health Needs of People with Intellectual Disability Across the Lifespan

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10 years on...

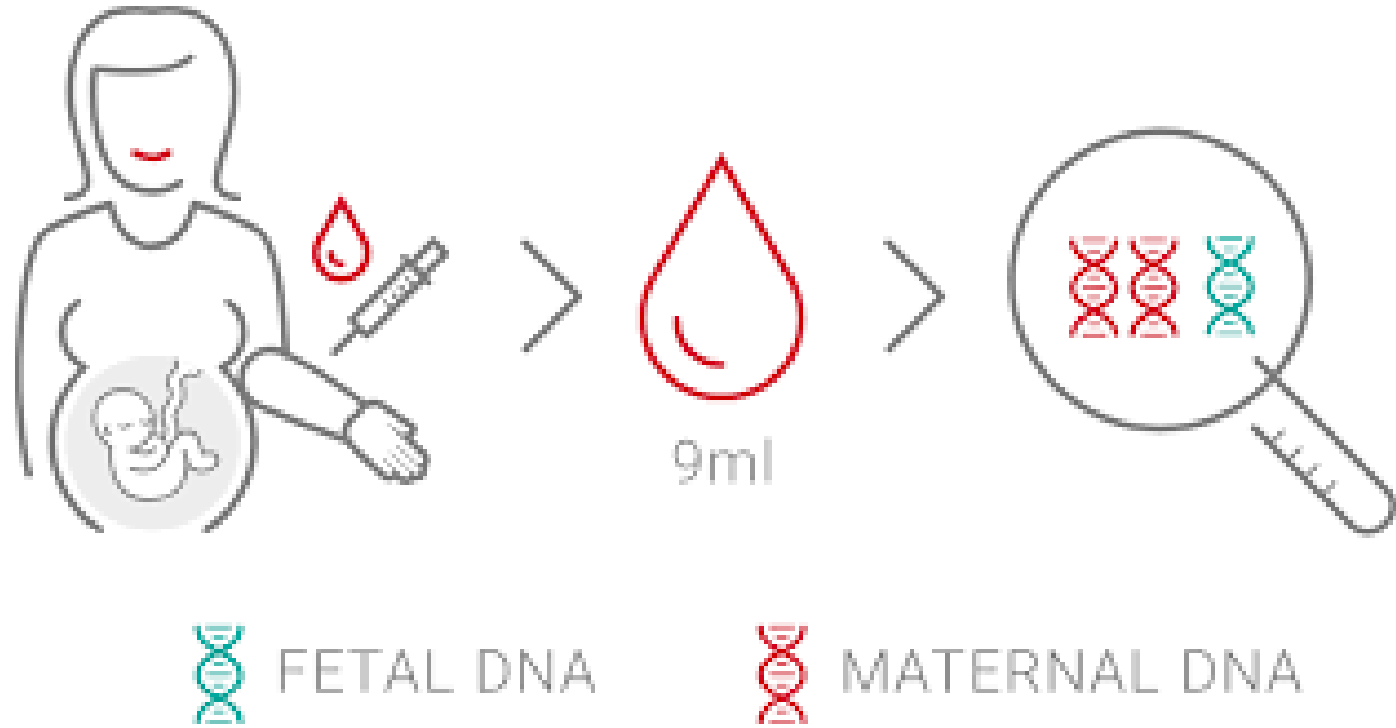
pandda
Celebrating 25 years in 2014

25th CONFERENCE & AGM
15 & 16 October 2014 Novotel Hotel Parramatta NSW Australia

The Organising Committee of PANDDA Australia Inc. is delighted to welcome you to the annual PANDDA Conference.



Prenatal genetic screening



Language

- a condition not compatible with life vs a baby with a life limiting condition
- risk vs chance
- value of life



“We Need to Talk”: Social and ethical dialogue
around genomics and disability

[https://hass.uq.edu.au/research/
we-need-to-talk](https://hass.uq.edu.au/research/we-need-to-talk)

<https://throughtheunexpected.org.au/>

<https://prenatalscreening.org.au/prospective-parents/>



Through the Unexpected



Prenatal
Screening

Breastfeeding

"Breastfeeding is an integral part of the reproductive process, the natural and ideal way of feeding the infant, and a unique biological and emotional basis for child development." Joint WHO/UNICEF Meeting on Infant and Young Child Feeding in Geneva, 1979.

Breastmilk is



- Anti-anorectic: Easily digestible, reduces constipation
- Anti-inflammatory: Boosts immune system, protect against illness
- Anti-oxidant: Reduces oxidative stress

Mitigates against



- Gastrointestinal infections
- SIDS
- Sepsis in premature babies
- Respiratory infections
- Ear infections
- Necrotising enterocolitis in premature babies
- Dental malocclusions
- Overweight and obesity
- Lower IQ

Promotes

- Forms close mother-baby bond
- Reduces emotional impact of diagnosis
- Provides control during uncertainty
- Promotes cognitive and emotional development through bonding, eye contact, touch, smell, and sensory experiences




Australian Breastfeeding Association
For Health Professionals

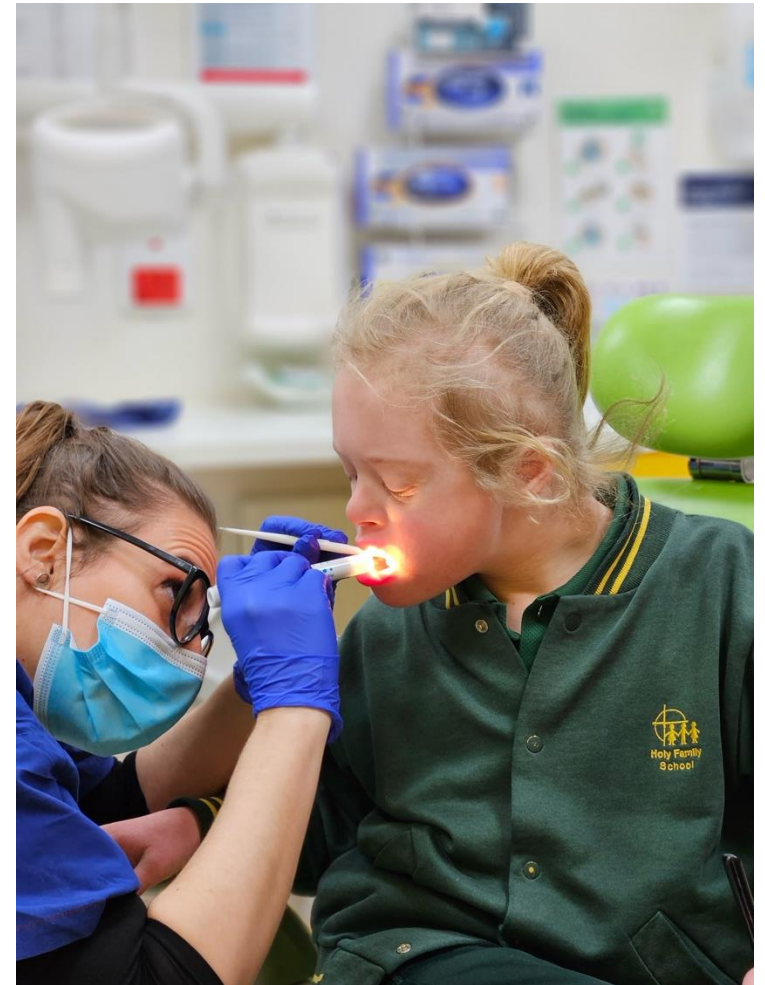
An interactive eLearning module for health professionals

Breastfeeding support for babies with Down syndrome

FREE Australian College of Midwives CPD Endorsed hours: 2.5 RTO: 21659

Enrol today aba.asn.au/emodules

Childhood



Health care for adolescents/young adults during the period of transition addresses...

- a. Physical health
- b. Pubertal health
- c. Medications
- d. Developmental/cognitive/academic progress
- e. Sexual health and education
- f. Nutrition, exercise, and other health promotion activities
- g. Mental health
- h. Relevant entitlements such as disability allowances and benefits, health care subsidy systems
- i. Substitute decision-making and guardianship laws.
- j. Ethical decisions such as need for respiratory support, end of life decisions, major surgical interventions.

Adulthood



Australian Government
Department of Health and Aged Care



**Annual Health Assessment for People
with Intellectual Disability**

YOUNG PERSON (12 to 18 years)

The logo for the National Disability Insurance Scheme (NDIS). It consists of the lowercase letters 'ndis' in a white, sans-serif font, with a small green dot above the 'i'. The logo is set against a solid purple square background.

ndis

Genetic testing & pharmacogenetics

Chromosome Microarray (CMA) Testing Guide – Children and Adults

Adapted from: Palmer et al. Chromosome microarray in Australia: A guide for paediatricians. Journal of Paediatrics and Child Health 48 (2012) E59–E67

1. CMA testing checks for extra or missing segments of a person's DNA. DNA is the building block of our genes and it is important that there is the correct amount of DNA in each cell of the body for normal health and development. If there is extra or missing DNA, the test results show a "variant" is present.
2. This is not a comprehensive genetic test for all health problems and further testing may be considered.
3. The test is carried out by collecting a small sample of blood or other sample such as saliva.
4. It is important that you discuss the possible test results with your doctor when you are considering a CMA test.
5. Possible test results may include the following:

No abnormality found

- Also called negative result or uninformative
- A balanced amount of DNA was found at this time.
- You or your doctor may consider more extensive testing such as genomic testing referral to a genetics clinic.

DNA variant found which explains the condition being tested for

- An extra (duplication) or missing piece (deletion) of DNA has been found
- This DNA imbalance (variant) is known to be the cause of the type of condition being tested for.
- An appointment at the genetics clinic or another specialist may be recommended.

DNA variant of uncertain significance (VUS) has been found

- An extra or missing piece of DNA has been found
- This DNA imbalance (variant) is not a known cause of a condition or the presenting health condition
- Your doctor may need to check if the imbalance is causing a health problem or not by doing the same test on other family members such as parents.
- An appointment at the genetics clinic may be recommended.

DNA variant with unexpected implications has been found

- Also called an incidental finding
- An extra or missing piece of DNA has been found
- The DNA imbalance (variant) is known to be the cause of a condition which you may not have expected (e.g. CMA test done for learning disability but result shows a DNA variant related to heart disease).
- An appointment at the genetics clinic or with a specialist may be recommended by your doctor as well as further testing.

For a more detailed [fact sheet about CMA testing](#) and contacts for [local genetic services](#) see [Centre for Genetics Education](#) www.genetics.edu.au



Health

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Technology



MySigns

3DN AT UNSW SYDNEY HAVE DEVELOPED

MySigns

an app to facilitate mental health assessment for people with intellectual disability

MySigns is free to access on phone and computer. Find out more and sign up at

www.mysigns.health

NSW UNSW 3DN

Healthy Mind is an online Easy Read tool for building good mental health

Watch video

Get started

Mobile phone technology

- Social connection – text messages, audio calls, video calls, or chat
- Convenience
- Physical health monitoring
- Stay updated with information e.g. YouTube, specific websites MyLived ID
- Communication

Ageing

- Complications for ageing
- Advanced care directives
- Advanced care planning
- Palliative care

Death & dying

- *Dying is a normal part of life and a human experience, not just a biological or medical event*

A good death



End of Life F



I want to ha



Preferred Priorities for Care

(Easy read)



Mark,
Community
Learning Disability
Nurse

- “Supporting someone who was dying was all very new to me. It was the first time I ever had to deal with something like this.we managed to sort things out for him, but at the time I felt like I was a passenger in the back seat of a fast moving car. Now, I accept that things can feel out of control and not ordered. ...maybe next time I would be a bit more proactive. I would want to make sure that everyone involved knows what is happening, and that we plan for the changes as much as possible.”

Conclusion

- The role of intellectual disability nurses is vast and vital across the lifespan
- We advocate, educate, and support individuals and families to navigate healthcare with dignity and respect
- Reflect on your practice and the impact you can make now and 10 years on

References

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