

# Aboriginal and Torres Strait Islander Women's Experiences of Living with Urinary Incontinence

Medical Aids Subsidy Scheme

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# Aboriginal and Torres Strait Islander women's experiences of living with urinary incontinence (UI)

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ICARE<sup>2</sup> values



## **Program of research on UI: 3 projects**

1. Prevalence of UI among women aged  $\geq 18$  years: analysis of ICS Short Form questions included in health checks - introduced in August 2019.
2. Nurses and GPs' survey of assessment and management of UI -2019.
3. Women's experience of UI and evaluation of 7 brochures about UI – **today's presentation for the two parts of the study.**

## What was done?

We yarned with 23 women, aged  $\geq 40$  years, about their experiences of living with, and managing UI and their evaluation of 7 brochures about UI.

Each woman was provided a supermarket voucher for taking part in the research and copies of their selection of brochures.

## Interview Guide: Questions

- How would you describe incontinence?
- How long have you had incontinence?
- How do you manage leaking of urine?
- How does incontinence affect your life?
- How did you find the services provided at CoE and local hospitals?

## **Key Findings: Five themes**

- Understanding incontinence
- Strategies for managing incontinence
- Treatments for incontinence
- Challenges of living with incontinence
- Strengthening the delivery of health services

# 1. Understanding incontinence

- Unpredictable, happens when I can't reach toilet in time
- Break in the normal connection between brain and the bladder functioning
- Normal continence – three steps:
  1. Feeling of wanting to go to the toilet
  2. Urgency to go to the toilet
  3. Being able to hold on until you get to the toilet

Incontinence- miss first 2 steps and don't make it to the toilet.

*You have three stages of when you need to go to the toilet. You've got the urge you need to go, and you have to go. I always miss the first two and its always the have to go, and nine out of ten I just don't make it. It just comes away.*

## 2. Strategies for managing incontinence

- Containment aids (pull-up pants & pads) - most common.
- Being prepared when leaving the house: spare pants, pads, wipes & disposable bags.
- Protection of mattresses and furniture.
- Frequent emptying of bladder before leaving home (some participants).
- Knowing location of toilets, staying close to toilet at home.
- Wearing appropriate clothing –loose, easy to put on and take off
- Seeking help from GPs, especially female GPs.
- Cutting down on fluid intake, which was not ideal and not followed by some:

*I just drink normally. Because that was one of the things, I think the dietitian told me too, not to just cut back just because drinking your water – it impacts on the other parts of your health.*

### 3. Treatments for incontinence

- Pelvic floor exercises – most common, but some women were not sure if doing it properly
- Pessary- not common
- Surgical repair – not common
  
- Reasons for not seeking treatment :
  - UI considered normal part of child-birth and ageing
  - Feelings of embarrassment, shame
  - UI not bad enough to seek help
  - Other more important health priorities
  - Fear of the results of any investigations for UI
  - Little knowledge of incontinence and treatments

## 4. Challenges of living with incontinence

Incontinence has *'taken over my life'* :

- Unable to take part in social activities such as ten-pin bowling
- Unable to travel - interstate or overseas
- Difficulties in establishing intimate relationship
- Embarrassment, low morale, fear, worries, frustration
- Cost of containment aids
- Acceptance of UI was important in reducing the impact of UI on daily life

*"Your life changes - - - and you have to learn to accept, don't think you can just go out and oh, one pad will do. It might. Always be prepared."*

*"It doesn't really bother me as long as I'm protected for it. It won't stop me from going out ..."*

## 5. Strengthening the delivery of health services

### What we are doing well

- Referral to specialist services
- Long-term relationship with staff – easier to discuss UI
- Health professionals understood impact on her life and her wanting to get help
- Questions in Health Check gave opportunity to discuss UI with GP/nurse

### What we could do better

- More information:
  - pelvic floor strengthening exercises
  - types of containment aids and where to get them
  - ‘pad and pull-up pants trial service’, try before buying
  - excoriation/rash treatment
- Increase awareness of UI to stop it being a silent issue
- GPs to ask women and not wait for women to bring it up

# Aboriginal and Torres Strait Islander women's evaluation of continence information brochures

ICARE<sup>2</sup> values



## **7 most appropriate brochures for women :**

*Diabetes and bladder or bowel problems: Let's yarn about this*

*Women's bladder problems: Let's yarn about women's business*

*Pelvic floor muscle exercises for women: Let's yarn about women's business*


*Pads, clothes and bedding to help if you are getting wet: Let's yarn about this*

*Constipation (hard poo): Let's yarn about this*

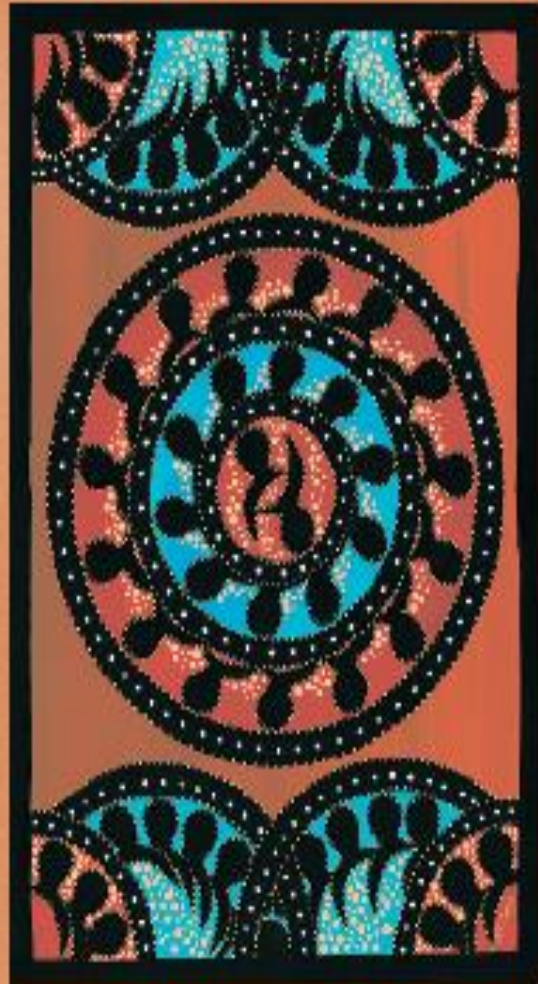
*Training the bladder: Let's yarn about this*

*Help getting to the toilet: Let's yarn about this*

<https://www.continence.org.au/aboriginal-and-torres-strait-islander>



Women's bladder  
problems



Let's yarn about women's business

Pelvic floor muscle  
exercises for women



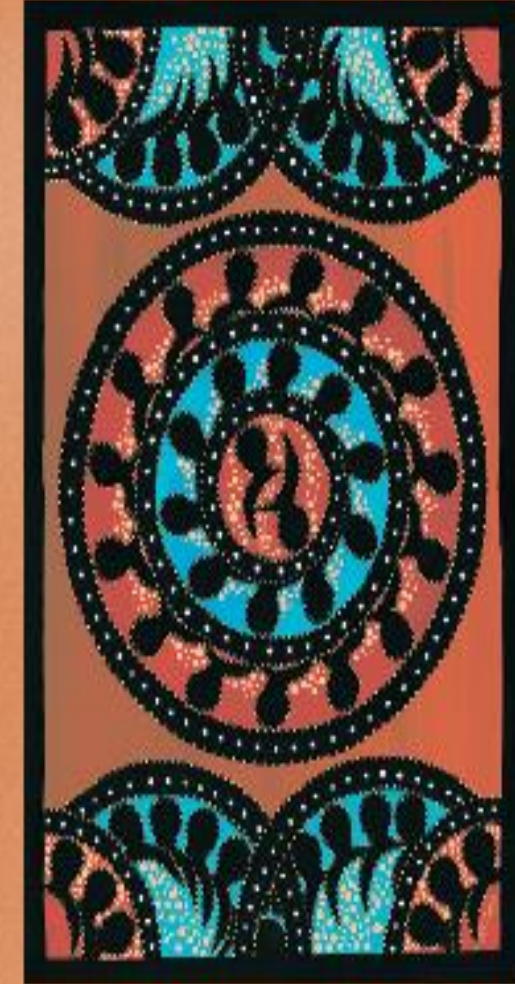
Let's yarn about women's business

Pads, clothes and  
bedding to help  
if you are getting wet





Let's yarn about this

Training the  
bladder

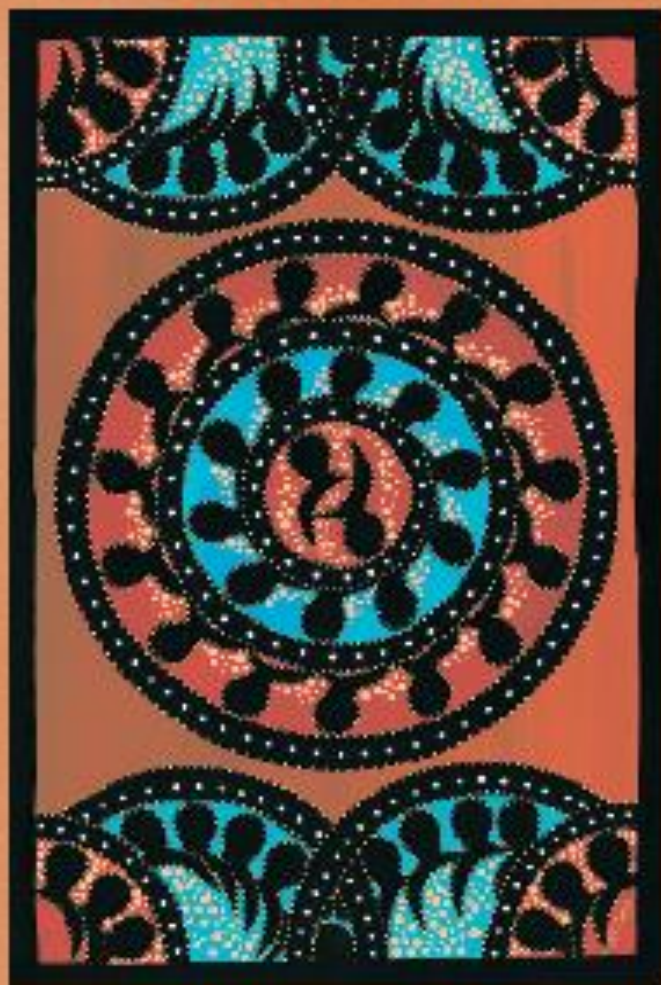


Let's yarn about this







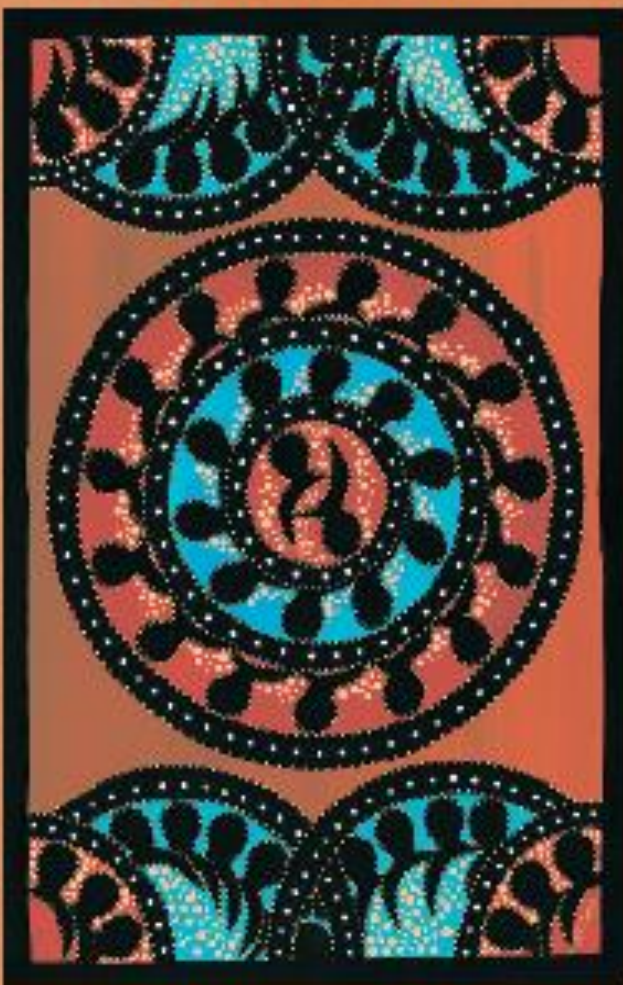
Help getting  
to the toilet




Let's yarn about this



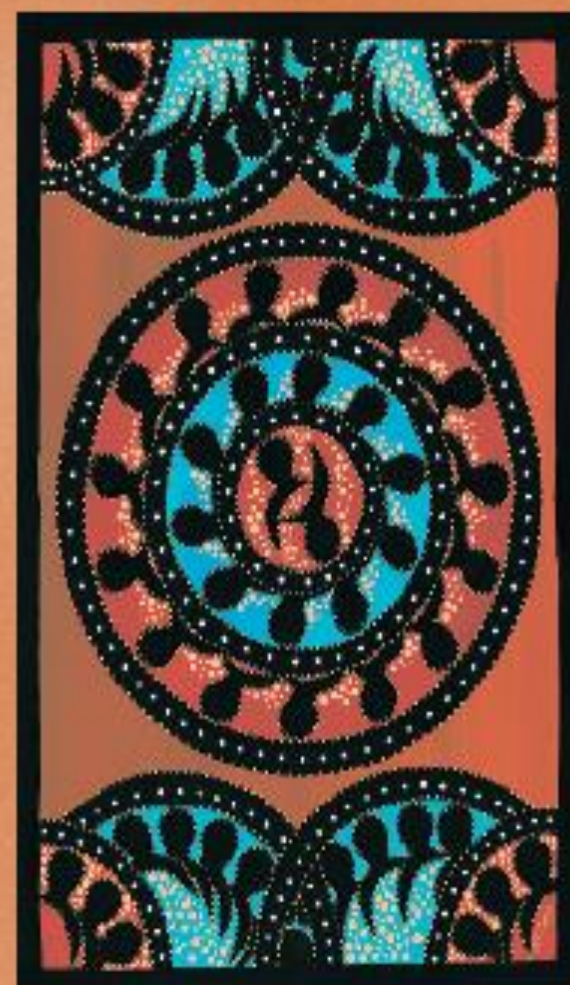
Diabetes  
and bladder or bowel problems




Let's yarn about this

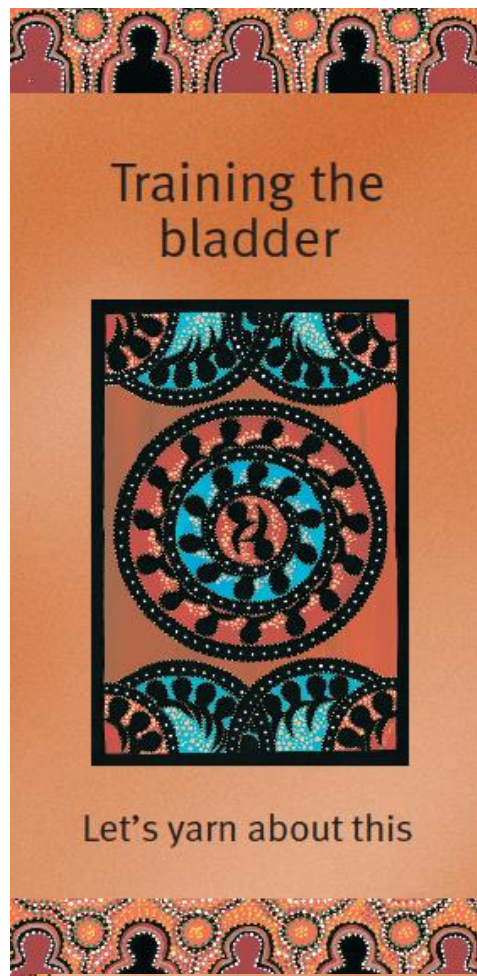


Constipation  
(Hard poo)

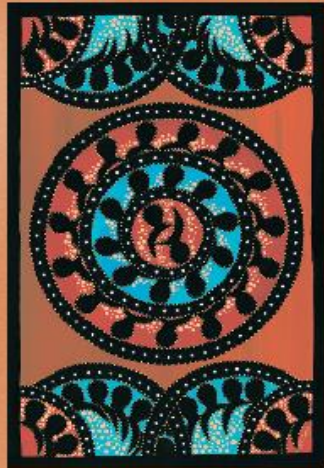


Let's yarn about this





# Training the bladder



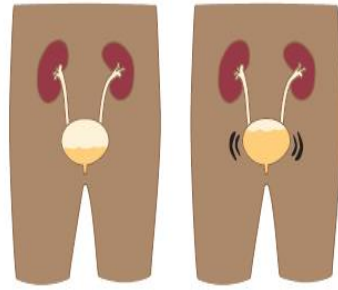
Let's yarn about this

## The bladder

The bladder holds the urine (wee) in your body until you are ready to go to the toilet.

Bladder training teaches the bladder to hold on longer and keep filling up until it is full.

Bladder training helps people who hurry to the toilet to wee little bits of wee many times in the day and night.



## A healthy bladder:

- holds about 2 cups of wee
- empties about 5 times a day and once during the night
- doesn't leak
- gives us time to get to the toilet without leaking.



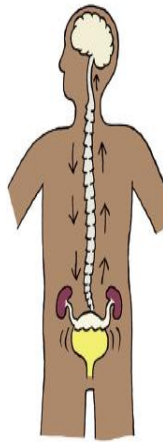
## Sometimes the bladder wants to empty quickly and it leaks

Things that can make this happen are:

- drinks with caffeine in them, like tea, coffee, fizzy drinks and energy drinks – they upset the bladder
- grog or alcohol
- an infection in the bladder



- wrong messages being sent from the brain to the bladder (nerve damage) – this can happen when people have a stroke, diabetes or are confused
- constipation (hard poo) pushing on the bladder – this upsets the bladder and means it can't hold as much wee.



Sometimes we don't know why we need to rush to the toilet or why we leak.

## How to teach the bladder to hold more urine (wee)

Try to wait longer before you go to the toilet:

- sit down
- think about something else
- wait a few more minutes before you go.

hold on!

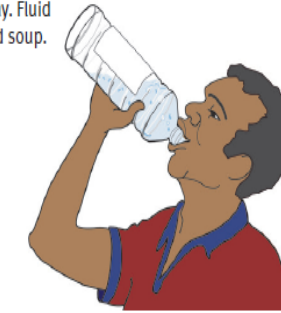


## Hold on as long as you can:

- The strong need to wee can sometimes go away.
- Walk slowly to the toilet. Don't rush.

## Other things you can do to help:

- Try to keep the bladder filling up. Drink fluid every day. Fluid is everything you drink. Fluid includes milk, juice and soup. The best fluid to drink is water.
- Drink less caffeine, like tea, coffee, fizzy drinks and energy drinks.
- Try to drink less grog or alcohol.
- Don't let your poo get hard. Eat lots of fruit, vegetables and grains.



## How to tell if your bladder is holding more wee

- Count how many times you go to the toilet the day before you start training your bladder.
- After 1 month of training, do this counting again.
- See if you are going to the toilet less, and passing more wee when you do.



## See your health worker, nurse or doctor:

- if you are an older man (about men's business)
- if you are a woman (about women's business)
- to make sure you haven't got an infection in the bladder
- if your poo is hard
- about medicines that may help.

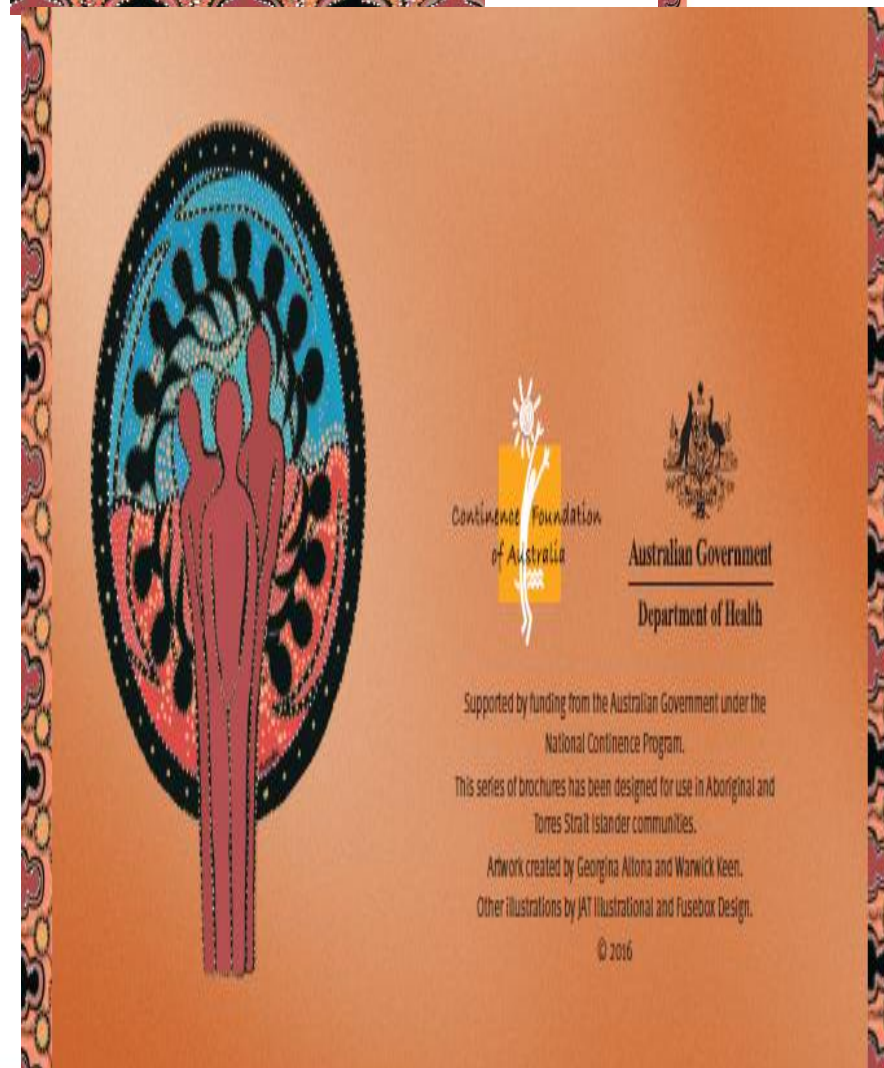
## Talk to your health worker, nurse or doctor



### Who can help?

- Aboriginal and Torres Strait Islander health service
- Health workers
- Nurses
- Doctors
- Physiotherapists
- National Continence Helpline 1800 33 00 66

### Notes



Supported by funding from the Australian Government under the National Continence Program.

This series of brochures has been designed for use in Aboriginal and Torres Strait Islander communities.

Artwork created by Georgina Allona and Warwick Keen.

Other illustrations by JAT Illustrational and Fusebox Design.

© 2016

## What was done?

Women read and provided feedback about one or more of the 7 brochures.

Each woman was provided copies of brochures at the end of interview.

## Interview Guide

- How useful was the information in the brochures?
- How easy was it to read and understand?
- Do you have suggestions for improvements to the brochures?
- Would it be useful to give to other women with UI?

## Key findings: 4 themes

- Usefulness of the information in the brochures.
- Readability (how easy it was to read) and comprehensibility (how easy was it to understand) of information presented in the brochures.
- Suggestions for refining the brochures.
- Aboriginal and Torres Strait Islander women having access to the brochures.

## 1. Usefulness of the information in the brochures

- All participants found the information in all 7 brochures was useful.
- Information was helpful in validating recommendations that they were already following, or which required lifestyle changes such as reducing sugar intake.

*I can identify with the information, it is good. (Training the bladder brochure)*

*it cuts out all the things I like, Coca-Cola and coffee and tea is a bad one for me. I'm not much of an alcohol drinker, but I'm really bad with coffee and tea, and I've been drinking a bit of Pepsi Max lately, so I'm bad with sugar too. I consume a lot of sugar [Diabetes brochure]*

# New information

- Anatomical information about organs and the pelvic floor muscles surrounding the bladder

*I think it's good ... because of the diagrams in it. It's actually showing what a perfect bladder looks like with all the muscle ... and then you'll see the saggy pelvis. So, ...you just assume that something has happened there. You've got older. You've had your children. This has happened. It's a natural way of life ... just deal with it ... but you don't seem to understand, things that can possibly help (Women's Bladder problems brochure).*

- Causes (e.g. constipation) and management of UI (different types of pads and pants, protection of chairs, mattress etc, high fibre diet for treating constipation).

*Well, I never knew that pushing out hard poo weakens the muscles* [Constipation brochure].

- Telephone number of National Continence Helpline

- Some recommendations were not easy to practice

For example, recommendations in brochure Training the bladder : holding on for as long as possible, and using distraction techniques (to train the bladder to function normally, reduce the urge and the frequent episodes of voiding), or walking slowly to toilet :

*walk slowly to the toilet, don't rush [information in brochure]. Sometimes I bust, you know. I've got to run to the [toilet] I rush, the moment I'm in bed -I rush there that's probably why I have more leakage than I could. See, that's interesting, drink less caffeine. You know, well I can't do without my coffee..*

## 2. Easy to read and understand?

### Language:

- Simple, brief, not offensive, including words 'wee', 'urine', 'leak wee'.  
*really informative, excellent, nothing offensive or sensitive*
- Phrase '*Lets yarn about this*' in the titles is appropriate for Aboriginal and Torres Strait Islander people

### Presentation: 3 aspects

#### 1. Pictures

- Related to pictures, useful in explaining written information e.g. location of bladder in body, healthy foods.
- None were offensive

#### 2. Design of brochures

- Earthy brown colours
- Indigenous art-work  
*Aboriginal and Torres Strait Islander people would get a 'buzz' out of it, and immediately recognise these as being for their specific use.*

#### 3. Structure

- Consistent structure across brochures
- Privacy, especially with topics like constipation, since visibility of content was limited to title and back pages.

### 3. Suggestions for refining the brochures

- **Change title page - all look same**

*People would look at them and think it's all the same brochure, yeah. ...The only other thing, would be a change of colour...*

- **Add a 'Notes Section' in Women's Bladder Problems**

- **Constipation brochure:** tick (✓) next to the picture of healthy foods; add another picture with a cross (X) to include unhealthy foods, add other foods to soften the stool such as pawpaw, and in the dietary advice add bush tucker foods such as kangaroo meat.

## 4. Give women the brochures and reasons?

- **Yes, provide to all women with incontinence - simple and lots of pictures**

*a lot of stuff I didn't know. CFA Helpline in all is good.*

- **Women can relate to the information**

*I relate to the information and pictures, really stands out*

- **Useful in training carers of women with incontinence**

- **Promotes incontinence as a common problem and not to be ashamed**

*definitely would recommend them to others, family, friends, people don't know about this, others need to know*

## Implications for clinicians

- **Increase awareness of UI and reduce stigma – UI not normal part of aging and childbirth... consider brochures on UI; refer to Continence Foundation of Australia website, National Continence HelpLine**
- **Information about management: types of pads and pants, eligibility requirements for discounted aids or financial assistance e.g. MASS.**
- **Early identification and referral for appropriate treatments and specialists.**

# What have we done so far?

## Helping women

- Pads/pants trialling service started in the clinic
- Unisex free packets of pull-up pants available
- Free jars of zinc creams to avoid rash for women
- Women provided information at HEAL program, Wellbeing day, Yarning Cloth
- Presentations at national and international conferences on incontinence
- Presentation of findings to the Community Jury

## Educating staff

- Education provided by Medical Aids Subsidy Scheme at whole of staff meeting
- Two female health workers completed a Certificate course on urinary incontinence
- Staff education on UI assessment and management by physiotherapist
- Information added to Best Practice to help GPs in managing incontinence

## **Key principles in engaging women in conversations about UI in primary health care settings**

- All women need to feel safe and comfortable when discussing about a sensitive topic, such as UI.
- The discussions and education about incontinence should be enjoyable, engaging, encouraging, empowering to enable women to participate and seek help.
- To lessen the stigma of UI, take time to listen, acknowledge, support, respect and inform.

*Ref: Audrey Burgin slide presentation at ICS conference 2021*

## **Yarning : an informal way of increasing awareness about UI**

- Yarning is an important and a common and respectful way of sharing and discussing experiences and ideas in Aboriginal and Torres Strait Islander peoples' culture.

***“Across Australia, Aboriginal people constantly refer to and use yarning in telling and sharing stories and information... When an Aboriginal person says ‘let’s have a yarn’, what they are saying is, lets have a talk or conversation. This talk/conversation/yarn can entail the sharing and exchange of information between two or more people socially or more formally.”***

Bessarab & Ng’andu (2010) Yarning about yarning as a legitimate method in Indigenous Research. *International Journal of Critical Indigenous Studies*. 3 (1) 37-50.

## Development of the Yarning Cloth

- Aboriginal peoples put a lot of emphasis on visual learning, based on their long tradition of using symbols, images, art and story-telling.
- The Yarning Cloth is an example of a method that promotes this visual way of learning about UI.
- Two Advanced Aboriginal Health Workers provided information about causes and management of UI to members of the US Mob Women's group in a safe and caring environment.
- Women used this information and art-work to create the Yarning Cloth, where the whole of the learning is mapped out in a clear and concise way.
- For details of development of the Yarning Cloth, please listen to presentations by the developers of the Yarning Cloth and Indigenous ways of learning.  
<https://www.ics.org/2021/session/7299>



## Importance of the Yarning Cloth in engaging women

- Concept developed into a meaningful, interactive, communication and learning activity.
- Innovative tool for engagement, sharing, learning about bladder/bowel health and urinary incontinence facilitated in a culturally safe, appropriate way
- Gives women ownership/empowerment of their art and story in a creative way
- Helps encourage help seeking
- Health workers benefit with confidence and learning with facilitator resource book/kit .

**(Reference: Audrey Burgin slide presentation at ICS conference, 2021)**

## ***Acknowledgments***

***We sincerely thank and gratefully acknowledge the women who took part in this research and shared their knowledge and experiences.***

***We thank members of the Inala Community Jury for Aboriginal and Torres Strait Islander Health Research for providing approval to do this research.***

***We acknowledge the support of CN Sarah Hartin in the design and conduct of some interviews for the research, and assistance with obtaining grant for the study.***

***We acknowledge the Australian Bladder Foundation and Continence Foundation of Australia for the grant to conduct this study.***

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