

Your guide to

**Promoting and
managing continence
for people living
with dementia
mate wareware**



You are not alone

Promoting continence and managing incontinence is a common concern for people living with dementia mate wareware, their family, whānau and care partners.

In 2020, there were almost 70,000 people living with dementia mate wareware in Aotearoa New Zealand.

Around 35,000 of them were affected by urinary incontinence and approximately 18,500 were affected by faecal incontinence.

Disability Support Services are there to help.



Index

Part one: Getting into the system

- System Map
- Visiting a General Practitioner
- Needs Assessment & Service Coordination Agency
- Community Continence Nurse Specialist
- Disability Allowance
- Specialist Community Support Groups
- Allied Health Professionals
- Mobility Parking
- Checklist

Part two: Practical everyday strategies

- Locating public toilets
- Accessing public toilets
- Using public toilets
- Locating home toilets
- Accessing home toilets
- Using home toilets
- Accidents happen
- Personal continence products
- Directory of resources

Part One: Getting into the system

Start here:
General Practitioner (GP)

GP Signature required

Disability Allowance
Funding for extra costs related to dementia and / or incontinence

Mobility Parking
Use Disabled Parking

Specialist Services referral

Treating incontinence
Urology, Gastroenterology
Gynaecology, Neurology

Dementia care warehousing focus
Older persons specialist services

Private providers are another option

Community Services referral

Needs Assessment & Service Coordination Agency
Access and eligibility for Disability Support Services

Community Continence Nurse Specialist
Assessment, advice and access to continence products

Allied Health Professionals
Occupational therapist & physiotherapist:
Equipment and advice to access the toilet
Social worker:
Support to navigate the system
Speech language therapist & dietician:
Swallowing and nutrition

Specialist community support groups
Dementia support, Carers' groups, Age Concern, Kaupapa Māori services

Private providers are another option

General Practitioner

Ask GP about:

- Reversible causes of confusion, memory loss or dementia
mate wareware (e.g. delirium, vitamin deficiency)
- Reversible causes of incontinence (e.g. infections,
enlarged prostate, gynecological prolapse)
- Having a health review (includes medicines that may
worsen or improve incontinence and/or dementia
mate wareware)
- Enduring power of attorney
- Driving safety
- Regular cognitive assessments (memory tests)
- Authorisation signatures on applications for Disability
Allowance and Mobility Parking.



Top Tip

- Talk to the practice nurse about what you need from the appointment. A 15 minute appointment may not be enough.

General Practitioner

Ask about referrals for:

- **Specialist services:** for investigation, diagnosis and potential treatments of incontinence and dementia care
- **Community services:** for supporting home management of continence and dementia care.



Top Tip

- Of all community services available, prioritise Needs Assessment and Service Coordination Agency (NASC) and Continence Nurse Specialist referrals.



Top Tip

- Be aware that Continence Nurse Specialist referrals require a urine sample.

Needs Assessment and Service Coordination Agency

This is a regional service that goes by different names according to the region. The term 'NASC' (pronounced 'NASK'), is widely understood regardless of region.

Find your local service [here](#).

What to expect:

- The assessor will come to you. Ask for a time that suits. They will complete an assessment of need and eligibility for disability services.
- You can request a Māori assessor, ask your local service.
- Carer partners need support too. You can have a separate assessment, ask the assessor or your GP for a referral.

Why?

- This is the gateway to many disability services e.g. personal care, household management, respite care, dementia specific day time care, meals on wheels. You can find more examples [here](#).
- Being assessed now makes things quicker and easier later.
- Assessors often know the locally-available services.

Top Tip: moving Health NZ regions



- NASCs are regional. Find the local agency.
- Community services vary across regions, talk to the local NASC about service availability before you move.
- Continence product delivery is also regional. Before you move, find local supplier and Continence Nurse Specialist.
- Expect and plan for delays.

Community Continence Nurse Specialist

A Te Whatu Ora Health New Zealand-provided specialist service for continence assessment, advice and products (pads, catheters, stoma bags) to manage continence.

There is an eligibility criteria for free pads. If this is not met, or you want additional pads, there are other options:

- You may be eligible for **Disability Allowance** to cover the cost of pads.
- You may be able to purchase via Te Whatu Ora Health New Zealand (ask your Continence Nurse Specialist).
- Purchase pads yourself at one of the retailers listed on **slide 23**.
- Seek a private assessment and supply **here**.



Top Tip

- You may be seen by a Continence Nurse Specialist or a district nurse.
- Continence needs change over time, ask for reassessment, even if you did not get free products last time.

Disability Allowance

This is a regular payment for people who have additional ongoing costs because of disability (dementia mate wareware is a disability).

It may cover the cost of incontinence products if you are ineligible for a free supply from Te Whatu Ora Health New Zealand, as well as some other expenses.

There are eligibility criteria and an application process. You can find more information [here](#).

To apply, you need to complete an 'Extra Help' application form. Your GP must complete and sign the Medical Certificate part of the form. Find the form [here](#).



Specialist Community Support Groups

Support groups offering practical tools, tips and resources. Find a local group:

- Alzheimers New Zealand: [here](#)
- Dementia New Zealand: [here](#)
- Age Concern New Zealand: [here](#)
- Carers New Zealand: [here](#)
- Kaupapa Māori wellbeing services: [here](#)



Why?

- These groups include experts in their subject.
- They will often provide a key worker to help you understand, learn to live with and manage challenges related to ageing, dementia, mental health and caregiving.
- They often provide social activities that are inclusive, safe and supportive.
- They can connect you with other services.



Top Tip

Walking and activity groups provided by dementia groups can help care partners feel less alone.

Allied Health Professionals

This includes occupational therapists (OT), physiotherapists (PT) and social workers and can be accessed via GP referral.

Occupational therapists and physiotherapists often work together to provide personal and environmental equipment to support mobility and improve access to the toilet.

Social workers are great allies for people living dementia mate wareware and their care partners. They can support access to services, funding and help navigate the system.

Find private providers: [here](#).

Why?

- The right equipment and the right advice reduces stress and enhances wellbeing.



Top Tip

- Occupational therapists and physiotherapists supply standard equipment.
- If you want additional equipment or something special, shop around. Big box retailers, online providers and disability stores are good options.

Mobility Parking

Mobility parking is for people who require close supervision due to disorientation, confusion or anxiety as well mobility issues.

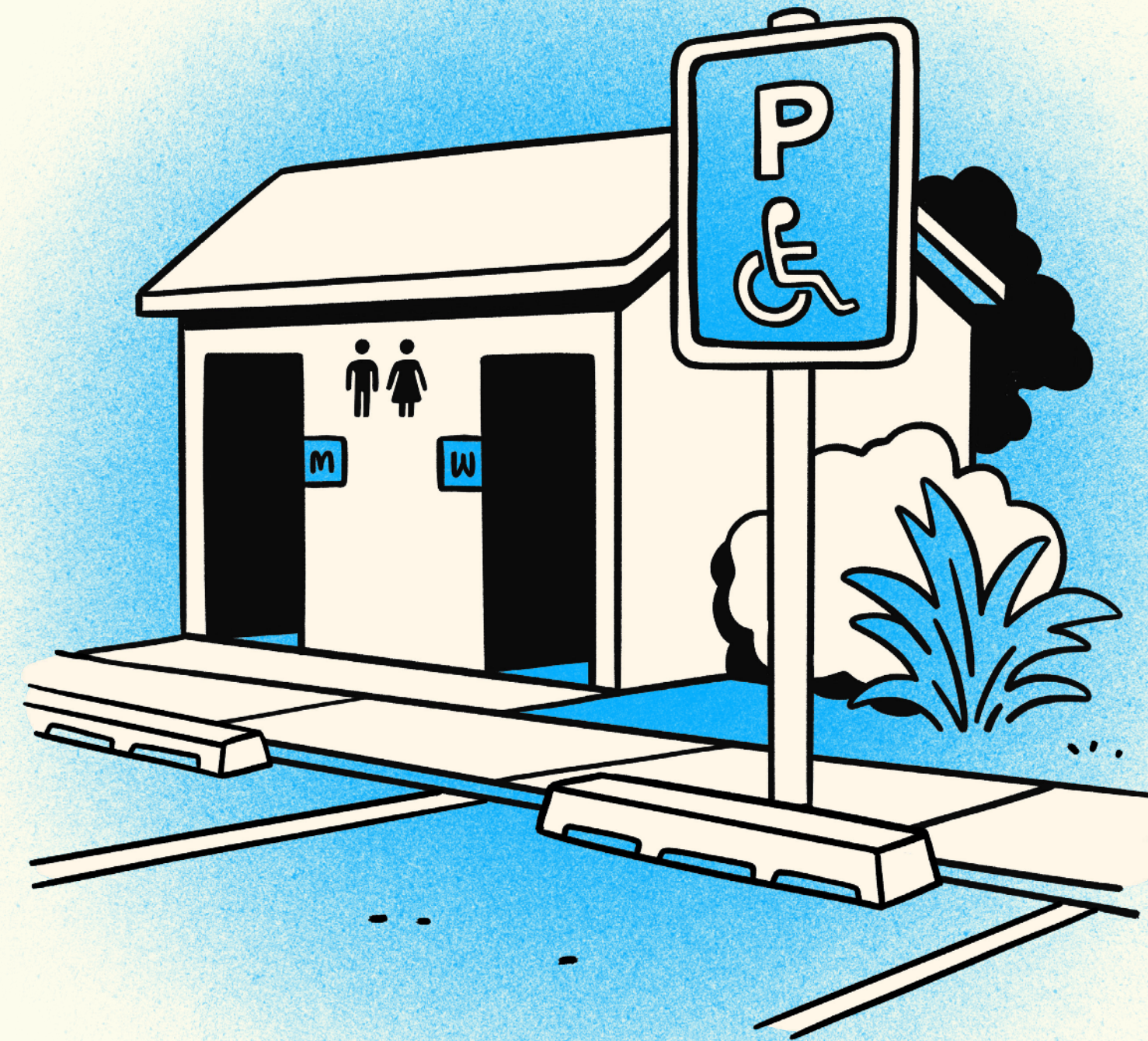
Find mobility parking information and permit applications, [here](#).

Or call 0800 622 7275.



Top Tip

- A mobility permit allows you to park in Disabled Parking. These spots are usually close to public toilets and other key services.
- There is a cost for mobility parking, you may be eligible for **Extra Help Disability Allowance**.



Checklist

Community Services

- Needs Assessment & Service Coordination Agency assessment
- Community Continence Nurse Specialist accessed

Allied Health Professionals

- Occupational therapist & Physiotherapist: equipment and advice to access the toilet
- Social worker: support navigation the system
- Speech Language Therapist & Dietician: swallow and nutrition (if required)

Specialist community support groups

- Dementia support
- Carers groups
- Age Concern
- Kaupapa Māori services

Applications

- Mobility Parking
- Disability Allowance (if eligible)

Specialist Services

Treating incontinence

- Discussed treatment options/referrals with GP

Dementia care wareware focus

- Been seen by Older Persons Specialist Services

Private Providers

- Considered my options

Practical Strategies

The advice on the next few slides was given by volunteers in a promoting continence and managing incontinence study. They are experts by experience.

Their key pieces of advice were:

“People living with dementia mate wareware are resourceful adults who will have developed their own continence strategies. Some will work, others may not. Observe their strategies, meet them where they are and laugh! We have all been there!”

“Friends, family, whānau and even the general public are often willing to help, but don’t know how to help. Explain the situation and ask for what is needed.”

Locating public toilets

Challenge:

Can't find a parking space near the toilets and it is unsafe to drop off the person living with dementia mate wareware

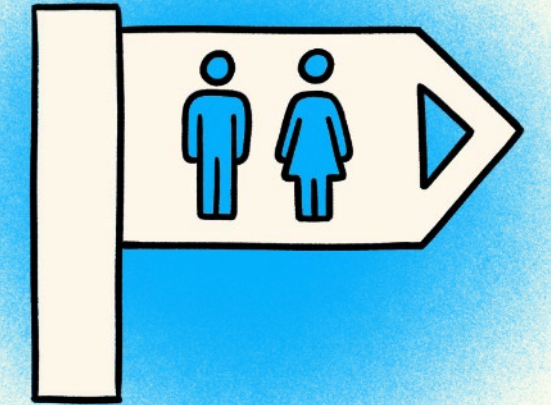
We need to stop frequently to use the toilet when traveling

Visiting supermarkets and large retail stores

Changing rooms in clothes shops can be mistaken for toilets

Try this:

- Park in the most accessible spot. If you get a ticket, write or email in to explain the circumstances. It may be forgiven.
- Mobility cards allow access to Disability Parking spots. They are for people with dementia as well as physical limitations (see [slide 12](#)).
- Use familiar routes and plan toilet stops.
- Carry a urinal in the car in case of traffic jams.
- Include toilet stops in your travel time calculations to avoid the stress of being late.
- A surprising number have public toilets or toilets that can be accessed on request.
- Be prepared to ask for help, explain the situation to the manager for quick access when needed.
- Use a [Can't Wait card](#).
- Explain the mistake to staff to avoid unnecessary confrontation.
- Provide feedback: this is useful information for retailers who may want to be accredited as dementia mate wareware-friendly.



Accessing public toilets

Challenge:

I am not allowed in the opposite sex toilet block to help or check on the person living with dementia wareware

Cannot tell the difference between mens and womens toilet

The person living with dementia mate wareware has limited mobility

Try this:

- Use disabled/wheelchair accessible toilets, there is usually room for two people.
- Use parents rooms, there is usually room for two people.
- Use single toilets with a door that opens directly to the outside.
- Use gender neutral toilets.
- Allow time for queuing before worrying (use a timer for an objective measure). Remember men using continence products have to wait for a cubical.

-
- Supervised use of toilet using the strategies above.
-

- Disabled toilets usually have grab bars for support, may have higher toilet seats and there is usually room for two people.



Using public toilets

Challenge:

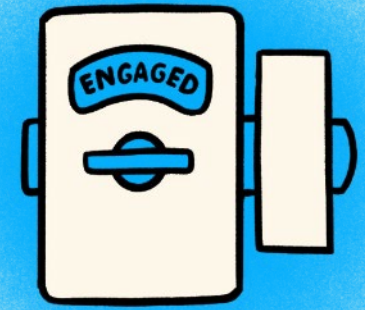
There is nowhere to put the used continence product

Hand washing equipment is complex and can be difficult to understand

Try this:

- Parents rooms have larger disposal bins.
- Take a plastic bag for the used product and take it home.

- Keep hand sanitiser and wipes in the car/your bag.



Locating home toilets

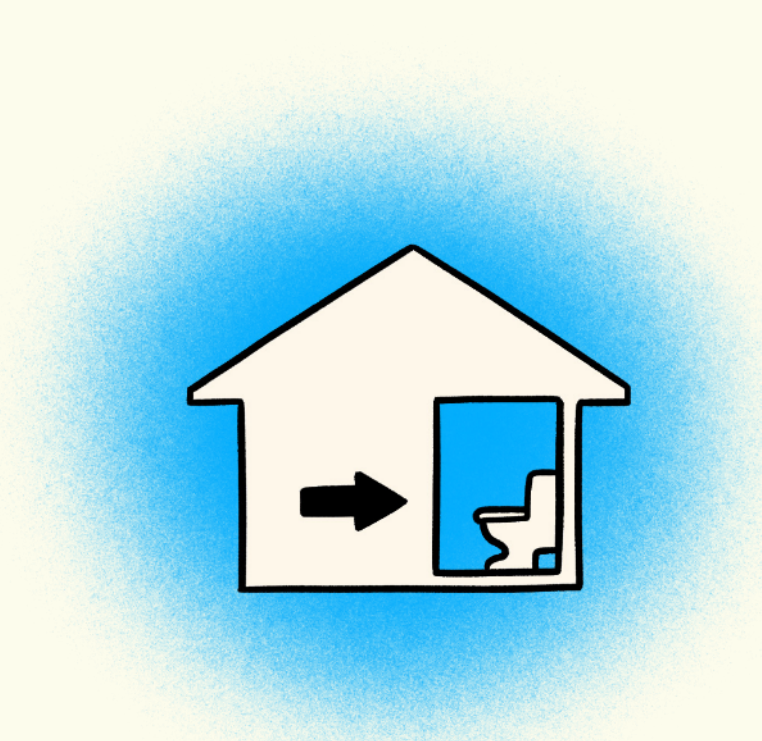
Challenge:

Difficulty finding and recognising the toilet at home

Not knowing the location of the toilet in the home of friends, family, whānau can create anxiety

Try this:

- Allow the person to search for the toilet – extra exercise is a bonus.
 - Be prepared to offer direction when they are tired.
 - Experiment with signage (pictures, symbols, arrows, words). Find what works and remember what works can change.
 - At night, use low-level lighting on the route from bedroom to bathroom.
 - Lighting tends to attract people. Try LED strips on the bathroom door.
 - Light sensors, solar lights, and LEDs are all cost effective.
-
- Point out the toilet as “business as usual” on arrival.
 - See above (signs and lights can be temporary measures).



Accessing home toilets

Challenge:

Mobility restrictions can make toilet-use difficult

Try this:

- Being close to the toilet helps: use the bedroom closest to the toilet, use lounge chair with most direct toilet access.
- Keep access ways and floor surfaces clear.
- Equipment can help: walking aids, raised seat heights (get physiotherapist and occupational therapist advice. See **slide 11**).
- Even with equipment in place, there may be times of the day when the person living with dementia may need additional help, particularly if they are tired.
- Install equipment like raised toilet seats, toilet frames, grab rails.
- The district nurse can provide short term loan of equipment.
- The occupational therapist can provide long term equipment.
- Shop around for additional equipment, it can be found at large retailers (e.g. The Warehouse, Kmart, Chemist Warehouse) online suppliers, specialist disability shops and DIY stores.
- Take a raised toilet seat when visiting friends, family, whānau or ask them to keep one for your visits.
- If renovating or building, consider installing a higher toilet.
- Removing internal doors or installing sliding doors may increase access.



Using home toilets

Challenge:

Difficulty recognising and therefore using the toilet

Zips, buttons, buckles and belts can cause delays removing clothing to successfully use the toilet

Taking off more clothes than necessary to use the toilet can cause delays

Difficulty getting urine/mimi into the toilet bowl

Successful clean up after toilet use

Try this:

- Replacing the white toilet seat with a brightly coloured one (red or blue) may aid recognition.
- Wooden toilet seats and toilet seat covers avoid cold seats.
- Consider tech solutions, infrared triggered recorded messages, for example.
- Toilet seat lighting may also be attractive.

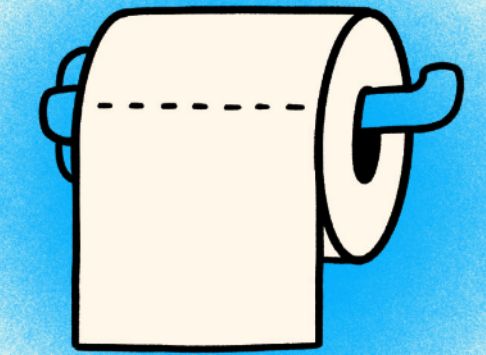
- Transition to clothing with elastic waists.
- Clothing with easy open seams (e.g. “stripper pants”) can be helpful. These can be made at home by opening seams and sewing in poppers.

- Providing a place to put clothes, like a hook on the wall, may prevent soiling.

- Encourage men to sit on the toilet to urinate.
- Ping pong ball in the toilet provides something to aim at.
- Standing close to the toilet bowl (knees touching bowl) can help.

- The person living with dementia may need help/direction with this process.
- Consider installing a toilet seat with a built-in bidet.





Using home toilets cont.

Challenge:

Using excess toilet roll can lead to toilet blockages

It can be tempting for person living with dementia to dispose of continence pads by flushing

Forgetting to flush

Challenges with the mechanics of handwashing

Spillage

Try this:

- Consider toilet roll dispensers that provide a limited amount of toilet tissue.
 - Consider single ply tissue to reduce bulk.
-

- A large dedicated bin for pads may avoid this issue.
-

- Can be a bonus avoiding plumbing bills!
 - Consider automatic flush systems.
 - Consider tech solutions, infrared triggered recorded messages, for example.
-

- Lever taps can be simple to use.
 - Setting a maximum temperature for hot water can avoid scolding.
 - Automatic water cut off can be a solution to forgetting to turn off taps.
-

- Absorbent pads on the floor can help.
- Have a supply of old towels or disposable wipes nearby.
- If renovating, consider hard flooring which is easier to clean.

Accidents happen

Challenge:

Accidents

Leakage around
continence products

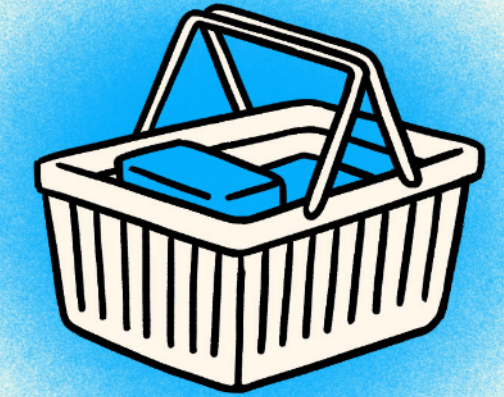
I want to go visiting/on
holiday but am worried
about soiling

Try this:

- Be prepared. An 'accidents happen' bag is helpful, including fresh incontinence products, clean underwear and clothes, wet wipes, cleaning cloths, gloves, barrier cream and plastic bag for soiled items.
 - Check penis position, ideally positioned upright towards nose so urine exits onto padded part of product.
 - Check the fit of the incontinence product in underwear.
 - Check product capacity, a new assessment may be necessary.
 - Full pull-up or wrap around products can help.
-
- Take furniture and bed protectors.
 - Take portable equipment, toilet seat, signage, low level lighting to aid finding and using the toilet.
 - Be aware of body language that may suggest the person living with dementia may need to use the toilet, e.g. fidgeting, searching, get up and down.



Personal continence products



Challenge:

Accessing a publicly funded supply

Maintaining supply

What if I have to buy my own?

Disposal of used products

Try this:

- You need a Continence Nurse assessment. See [slide 8](#).
- If you are not eligible for Te Whatu Ora Health New Zealand supply, you may be eligible for funding under Disability Allowance. See [slide 9](#).
- Continued public supply requires reordering.
- Anticipate delivery delay during public holidays.
- Use Continence Nurse Specialist as an information resource.
- Buy products for urine or faeces, not menstrual products.
- Shop around, try before you buy (ask for free samples):
 - At supermarkets, big brand chemists (e.g. Chemist Warehouse, Bargain Chemist) and large general retailers (e.g. The Warehouse, Kmart).
 - Online suppliers can be found on [Continence NZ](#).
 - Talk to your retailer about ongoing supply.
- Contact manufacturer for education and advice so that you buy the correct size (MoliCare® have [education videos](#), for example.)
- Full pull-up and wrap around products can be helpful as there is less positioning required.
- Generally, they go in domestic waste, check with your council.
- Consider your local circumstances for the best time to put these out for collection.

Directory of resources

- [Age Concern New Zealand](#)
- [Alzheimers New Zealand](#)
- [Carers New Zealand](#)
- [Can't Wait Card](#)
- [Continence New Zealand](#)
- [Dementia New Zealand](#)
- [Disability Allowance](#)
- [Disability Allowance Extra Help application form](#)
- [Eldernet service providers for older adults](#)
- [Mobility parking](#)
- [MoliCare® videos](#)
- [Red toilet seat example](#)
- [Te Whatu Ora Health New Zealand Health of older people organisations and websites](#)

Research team

We were privileged to listen to the stories of people living with dementia wareware and continence challenges and their care partners; the important people in their lives with whom they shared love, care and support. Their generosity in openly discussing this topic has made the creation of this resource possible.

We thank our co-creators for their contribution to the concept development and design of this this resource.

The “**Improving Continence Management for People With Dementia in the Community study**” was funded by the Health Research Council of New Zealand (21/117) .

Correspondence to Centre for Co-created Ageing Research ccreateage@auckland.ac.nz or Professor Vanessa (Ness) Burholt vanessa.burholt@auckland.ac.nz

We acknowledge the Investigators on the study: Vanessa Burholt, Julie Daltrey Yasmin Orton, Avinesh Pillai, Kathryn Peri, Sharon Awatere, Roni Nuku, Rosie Gibson, Ngaire Kerse, Gary Cheung, Erica Munro, Anna Lawrence, Deb Balmer, Lisa Williams. We are grateful to Arapera Riki for their assistance in recruiting participants; and in interviewing participants

Your guide to promoting and managing continence for people living with dementia mate wareware © 2024 by University of Auckland is licensed under [CC BY-NC-SA 4.0](https://creativecommons.org/licenses/by-nc-sa/4.0/)