

FACILITATOR'S GUIDE

CONTINENCE AND DEMENTIA

MODULE 5 IN THE DEMENTIA STARS SERIES

dementia STARs

NEW ZEALAND DEMENTIA FOUNDATION

CHT Healthcare Trust
WE TAKE GREAT CARE OF OLDER PEOPLE
Aged Care Fund



WELCOME!

Continence issues are common as dementia progresses, and can be particularly challenging to caregiving relationships. This training session focuses on enabling learners to confidently use a positive person-centred approach to promoting continence.

In this kit you will find all the resources you need to run an engaging 45-60 minute introductory staff education session on helping people living with dementia to promote continence. The Dementia STARs education is particularly suitable for direct care workers across a range of settings.

This Dementia STARs education kit is a partnership between the New Zealand Dementia Foundation and CHT Aged Care Fund.

You can find our other Dementia STARs kits at nzdementia.org/dementia_STARs

Ngā mihi nui from the Dementia STARs Team

Short Trainings in Awareness and Responsiveness

dementia STARs



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1. Getting started

Continence and dementia

CREATING A SHARED

CULTURE OF CARE

The Dementia STARs programme is an opportunity to effectively enhance the skills of individual learners and to reinforce a shared culture of person-centred dementia care: this is the heart of all we do at our place.

Research shows that face-to-face active learning is more effective for home-based and aged residential care staff than watching videos or reading written material [1,2]. Interactive training in a small group where teaching is interspersed with frequent discussion and opportunities to ask questions is not only more effective[3,4], it is preferred by learners [5,6]. Furthermore, this type of training can also help to strengthen team cohesiveness and shared values [1,2].

Congratulations on joining the Dementia STARs journey with your team to reinforce great person-centred dementia care at your place.



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TIPS FOR USING THIS KIT

If this is the first time you've used one of the Dementia STARs kits – welcome!
We're delighted that you are joining the Dementia STARs whānau.
We've put together some tips to help you know what to expect from the kit.

This guide

The facilitator's guide is just that. It's a guide and a starting point. Don't feel that you have to say things exactly the way that we have said them on the page. You can download the resources to print for the session from the Dementia STARs webpage.

The questions and activities

You will notice that we give lots of suggestions for places where you can ask the group for ideas or to engage in an activity, rather than just telling them the information. This is something you may well already do so you'll know that it is a helpful way to keep people engaged. Being interactive is a better way for adults to learn.

Audiovisual resources

We have provided a Powerpoint resource for each kit, which contains a variety of content to help run an engaging session. If you don't have access to audiovisual equipment, don't be put off from running the session. Check out the content provided and adapt.

> RELATIVELY FEW PEOPLE LEARN WELL FROM SITTING AND LISTENING TO LECTURES; IT IS IMPORTANT THAT TRAINING IS ENGAGING
>
> – BUZ LOVEDAY [7]

The PowerPoint slides

The PowerPoint slides generally have only a few key words on them, supported by compelling images. Having what you want to say written out in detail on PowerPoint slides can be reassuring for a presenter, but it is not so great for your audience:

- A lot of text can make it harder for the learners to really listen what you are saying when they are also paying attention to the words on the slide.
- A lot of text can be off-putting for people who don't read so well.
- A lot of text can be boring, especially if the presenter just reads out the text.

That is why we use images as much as we can and to only have a few words on each slide. The idea is that the PowerPoint slides complement what you say and makes it easier for the learners to understand, rather than just repeating what you say. This facilitator's guide is here for you to help you feel confident and remember what you want to cover. The PowerPoint slides themselves - they are for your audience!

The images in the slides are only licensed for use for Dementia STARs. Please do not use the images for any other purpose as this will violate copyright.

The expert video clips

There are video clips of people with professional and lived experience embedded in the PowerPoints. This is our way of giving you some company as you present. It means you can draw on experts and on different perspectives. It also means that you get to bring in some variety of faces and voices, which can help to give a little boost to engagement and interest. The videos can help to reinforce an aspect of the session.

As the video clips are embedded in the PowerPoint presentation, you do not need access to YouTube or the internet to show them. You can hover and click in the slide.

The animated stories

In some of the kits, there is an animated 'whiteboard' video embedded in the PowerPoint. These are a way of sharing case studies. Because cases studies tell a story, they often much better remembered than 'facts'.

The handout

Each kit has a summary handout to remind your learners about key messages.

The feedback form

You will find a one page feedback form in each kit. Feedback can help you make future education sessions better, and can provide evidence that the training has had an impact.

We may email you as follow-up to seek feedback on the Dementia STARs resources. If we do, we will ask you if you would be willing to share your learners' anonymous evaluation responses.

The going further list

We have included a list of five resources that provides some further detail on the topic for keen learners (or for yourself).

The certificate

We provide a certificate of attendance for you to give learners at the end of the session.

The webinar version

We have a version of each education session available as a video 'webinar'. This does not have exactly the same format as the in-person session you will run (there are no activities in the webinars), but you can use the webinar version to help a staff member 'catch up' if they have missed the in-person session, or to help orientate a new staff member.



MĀ TE HURUHURU, KA RERE TE MANU
FEATHERS ALLOW THE BIRD TO FLY

– MAORI PROVERB

WHAT'S IN THE FACILITATOR'S NOTES?



This is the PowerPoint slide you are showing

Many of our clients are in pain

We know that pain is common amongst older people. All sorts of things commonly cause pain or discomfort. [1]

This is our suggestion about what you might say for this slide

A number in brackets is a reference. You can find the list of references at the end of the guide

What are some of the common aches and pains we see?

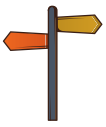
This is a suggestion about a question to ask the learners to increase engagement

Perhaps the most common types of pain they come across will be falls, back pain, arthritis, urinary tract infections, and pressure sores [8, 9] but the list can include almost any part of the body.

We also provide some examples of common responses



This symbol indicates that an audiovisual resource is embedded in the PowerPoint



This symbol indicates a choice



Activity

This symbol indicates a class activity



This symbol prompts you to add information about what happens 'at your place'

MEET THE EXPERTS

Here are some of the faces that you will meet in the Dementia STARs resources.



MATTHEW CROUCHER: MEDICAL

Matthew is the chair of the New Zealand Dementia Foundation. He is a Psychiatrist of Old Age, a Senior Clinical Lecturer, and leads the South Island Regional Dementia Initiative. Matthew is a prominent figure in teaching, training, research and service management advice in the older person's mental health sector.



MACKENZIE EBBETT: REGISTERED NURSE

Mackenzie is the Nurse Manager of a specialist cognitive impairment ward at Burwood Hospital. She is a passionate champion for person-centred care in this environment to optimise the level of functioning of older people with delirium and/or dementia by offering specialist assessment, treatment, care, support, and education.



ASHLEIGH FARR: SPEECH LANGUAGE THERAPY

Ashleigh is a Speech Language Therapist with decade of experience across a wide range of roles. Ashleigh has been active in expanding her skills in dysphagia and communication disorders in patients with more complex presentations including people living with dementia.



SUSAN GEE: CONTENT COODINATOR

Susan Gee has a background in psychology and gerontology. As a researcher and educator Susan is passionate about strengthening and embedding understanding and best-practice person-centred care to help amazing people provide great day-to-day support for people living with dementia.



TRACEY HAWKES: OCCUPATIONAL THERAPIST

Tracey is an Occupational Therapist with over two decades of clinical experience. She facilitates the 'Walking in Another's Shoes' dementia education programme for home-based support staff. Her focus is helping care staff to develop the confidence and person-centred tools to support older people to live more independent and fulfilled lives.



LARA HITCHCOCK: NURSE

Lara is a Registered Nurse in a Memory Assessment Clinic. Lara has specialised in the field of dementia care for over 20 years. In her current role she provides assessment, information, and support to those newly diagnosed with dementia and their care partners. She acts as a specialist resource to colleagues and is active in quality improvement to improve the care of those living with dementia.



HONEY MOHAN: CARE WORKER

Honey is a care worker in an aged residential care facility. She is a graduate of the Walking in Another's Shoes dementia education programme. Honey is passionate about getting to know each of the people she supports as a unique person, and she loves her job.



CHERYL NETTLETON: WHĀNAU / FAMILY SUPPORTER

Cheryl's introduction to dementia was when her husband started to display out-of-character behaviours around the age of 50. Cheryl has founded carers' support groups to bring cares together. Cheryl also helps to educate people about dementia through many different forums from her perspective as a wife and family member in the hope that it strengthens an emotional connection to the people living with dementia.



NICK UYS: WHĀNAU / FAMILY SUPPORTER

Nick worked in the pharmaceutical industry for many years. He was married to his beloved wife Anne for 44 years and became Anne's full-time care until Anne entered aged residential care. Nick is committed to sharing his perspective as a carer within dementia education programmes as a way to make a positive impact. .

2. Running the session

Continence and dementia





LEARNING OBJECTIVES: CONTINENCE AND DEMENTIA

When supporting a person living with dementia,

01 Learners are able to articulate their own perspective on what dignity in continence care involves.

02 Learners can identify the steps involved in successful toileting.

03 Learners are able to use prompts to promote continence.

04 Learners can identify a range of ways to help people to get to the toilet in time.

05 Learners are able to identify ways to adapt the environment to promote continence.

FACILITATOR'S NOTES FOR CONTINENCE AND DEMENTIA

Staying continent for a long as possible is something that we all want to do. People living with dementia may need extra help from you to make this possible.



Incontinence is very common as dementia progresses [8]. What do we mean by incontinence? We are thinking about situations when a person releases urine or faeces without meaning to, or when they urinate or defecate in a way that is not socially acceptable [8].

Once upon a time we probably tended to accept any continence difficulties as just part of the dementia illness, "oh well they are incontinent – we manage that with incontinence products". But now we realise that there is a lot of problem solving that we can do to help promote continence for many people.

Today we are going to look at three key messages to help us to promote continence:

- **The person comes first**
- **Understand the steps**
- **Problem-solve together**



The person comes first

Our first key message is that the person comes first. They always do in every situation when we are providing support but toilet issues can be especially challenging to relationships. One of the ways we can help put the person first is to think about the situation from their perspective.



Activity: What if it was you

Resources: Paper or whiteboard for collating answers, Powerpoint slides.



In this activity, the learners are asked to think about the perspective of a person experiencing continence issues and what they would want care to be like if this happened to them.

There is a scenario to discuss in two parts. Read the scenario aloud and collate the answers. As you write up the answers, separate them into

- a list of negative emotions/ responses (mainly from the first part of the scenario)
- and a list of positive emotions/responses (mainly from the second part of the scenario).

Scenario Part 1:

Imagine that you have been diagnosed with rapidly progressive younger onset Dementia of the Alzheimers type. Your family says your personality has changed. You have developed memory problems and also, to your surprise, continence problems. For the first time since you were a toddler you can't manage to stay continent and you are having to get help.

Q *How might it feel to have continence issues in your life?*

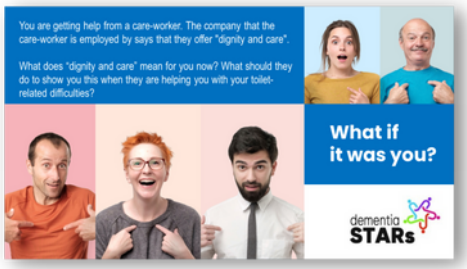
A Learners may give responses such as:

- Embarrassment
- Disgust
- Shame
- Strong emotions such as distress, frustration
- Inconvenience
- Self esteem
- Lack of control
- Stigma, wanting to hide it from people
- Wanting to deal with it themselves
- Privacy, taboos
- Worried what other people might think
- Some learners may share different responses around coping mechanisms such as being stoic, trying to use humour, accepting it's a medical condition etc

Discussion points: This discussion helps to make sense of some of the responses we might encounter when we are offering assistance with continence and incontinence - for example 'resisting' care, hiding soiled pads to try to conceal incontinence, low mood, or irritability [9]. We might respond the same way in that situation!

Scenario Part 2:

Continue to imagine that you have rapidly progressive younger onset dementia and you are struggling with incontinence. Now we introduce a care worker into our scenario:



You are getting help from a care-worker. The company that the care-worker is employed by says that they offer "dignity and care".

Q *What does "dignity and care" mean for you now? How could the care-worker show you this when they are helping you with your toilet-related difficulties?*

A Learners may give answers such as [9]

- Using humour
- Not making a song and dance of it. Being warmly business like and helping without a fuss
- Not telling me off
- Treating me like an adult
- Being mature and professional
- Being sensitive
- Being supportive, acknowledging the taboos and stigma and how I might be feeling, being aware of certain taboos in my culture
- Looking at things from my perspective
- Helping me be as independent as possible
- Working in partnership with me and my family
- Recognising me as person and not just a task
- Helping me feel safe and supported
- Being someone that I can trust and rely on, responding quickly
- Treating me with respect
- Being warm and compassionate
- Showing that they don't think less of me
- Not seeming disgusted
- Talking to me about what I want
- Trying to give me as much privacy as possible, being discreet if there are others around

Discussion points: We all want to be offering continence support that provides "dignity and care". What this looks like may be different for different people (you may be able to draw out some contrasts between learners). It's always about getting to know the person.

When we think about ourselves is this situation, we can see why it is so important that we do all that we can to help promote continence.

Going to the toilet is such a private part of our lives and it's horrible if things go wrong (There are a lot of negative emotions over here on this side of the board).

If problems do occur, we need to be very sensitive and understanding towards the person to maintain their dignity (all these wonderful things on this side of the board).

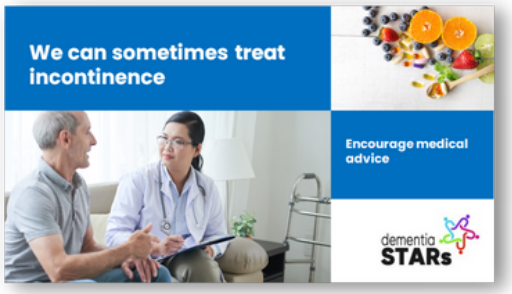
We are always getting to know the person – what is important to them, what they like and don't like, what their strengths are.

We also need to be committed to problem-solving possible barriers to help promote continence [10].

Our next key idea is going to be to consider possible causes of the problem and how they impact on the steps of going to the toilet.



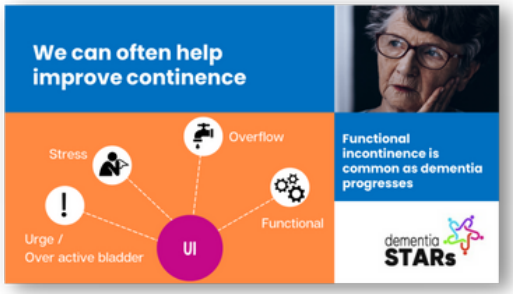
When we are thinking about possible causes, it is worth taking a step back and remembering that sometimes incontinence has a treatable cause.



It's always a good idea to encourage the person to seek medical advice.

Some common causes that a medical professional may be able to help with include urinary tract infections, constipation, prostate problems, and the side effects of medication [11].

We can often help improve continence where the persons dementia is making steps harder.



Continence isn't "all or nothing". Just because someone has continence problems doesn't mean that all hope is lost!

Some people who have advanced dementia may completely lose control of bladder or bowels. But this is far from the only reason that people living with dementia experience problems related to using the toilet [10]. There are four other common problems around urinary continence that we may encounter in the people that we support [11]:

1. Some people have urge incontinence which is caused by an overactive bladder. They have sudden bladder spasms that mean that they "gotta go now".
2. Some people, particularly women, can develop stress incontinence. They may experience leakage when their tummy muscles get a workout – things like sneezing, coughing, or lifting.
3. Some people have overflow incontinence, and they may leak urine when their bladder is full.
4. And some people have functional incontinence. Here the problem isn't with the bladder. This is where cognitive or physical impairments make it difficult to complete the steps of going to the toilet on time. This can be common as dementia progresses.

Activity: Steps of going to the toilet.

Resources: Powerpoint slide, paper or whiteboard to collate responses

Read the question out aloud.

If needed. prompt for smaller steps.



Q *You need to go to the loo to pee. Between you sitting here right now and you returning to your seat – what's involved? What are the steps?*

A Learners may give responses such as:

- Recognising the urge / remembering to go to the bathroom
- Deciding to do something about it

(Be sure to prompt learners for these earlier stages if needed)

- Getting up to go to the toilet
- Asking for assistance if required
- Controlling the urge until you get there
- Remembering where the toilet (room) is / finding the toilet (room)
- Recognising the toilet itself
- Pulling down / getting clothes ready
- For men deciding to sit or stand
- Sitting
- Peeing
- Wiping
- Disposing of paper/ wipe
- Standing up
- Flushing
- Pulling up / arranging clothes
- cleaning up any small messes

- Remembering to wash hands
- Turning on tap
- Washing hands
- Using soap
- Turning off tap
- Drying hands

- Leaving bathroom
- Finding way back

That's a lot of skill and steps involved in going to the toilet! No wonder it can be challenging.

Thinking about toileting this way can help us to see the person's strengths as well as the possible barriers- the things a person can do as well as the things they have difficulties with.

We start by thinking about the steps that they can do. We use that as our base and we make sure that we enable the person to keep doing these steps without taking over. Then we look at of the steps that might be an issue, and how we can problem-solve them together to help promote continence for an individual.

Let's see what problem-solving together to promote continence might look like by working through three case studies [10, 13]



For our first case study let's meet Mr Zwart. Mr Zwart's story focuses on "Get up and go" and the power of prompting.

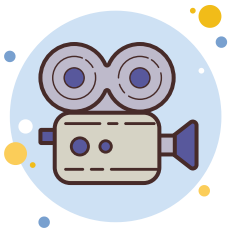


Pieter Zwart is a physically fit and healthy 58-year-old with frontal temporal dementia. Mr Zwart had to give up his job as his dementia progressed. He's also given up his hobbies of golf and gardening. He can't be bothered to clean his teeth or have a shower, and he doesn't seem to be interested in what's going on with the family or talking with people. He can certainly get up and go to the toilet when we prompt him, but he doesn't do it on his own which means that he sometimes wets himself. Mr Zwart doesn't show low mood or concern about these changes. His wife jokes that he's just got lazy.

This sounds a lot like depression, and that was something that Mr Zwart's GP checked out.

The GP says that while these changes do look a lot like depression Mr Zwart doesn't show any of the signs of sadness or negative thinking that we might expect.

The GP says that many people living with dementia, especially frontal lobe dementia, experience something called the "apathy syndrome". Lara Hitchcock is going to tell us about what this means:



Play Lara's video

If we think about strengths, Mr Zwart has retained many of the skills involved in toileting. The step that is difficult for Mr Zwartz is responding to the need to go to the toilet. His motivational "starter motor" is broken, so he can't get the process started himself – and we can help with that!

Prompting toileting can be really helpful to promote continence for many people living with dementia: it can help to overcome problems with memory and apathy.



One of the first things we can do is see if we can find the routine the person already has:

With Mr Zwartz and his wife we set out to find out if Mr Zwart has a predictable routine of when he wets his pad or needs to go the toilet, and we use this to know when to prompt.

The person may have had a lifetime routine, and sticking to the old routine may work particularly well.

- For example, we discover that Mr Zwart usually needs to go the toilet at about 20 past 10 after his morning tea coffee. Now we give a prompt about 10 past ten to ask Mr Zwartz if he needs to go to the toilet. This works really well as Mr Swartz is able to recognise that he does need to go the toilet, and with this assistance he maintains his continence.

What if we can't find a personal routine? Be regular

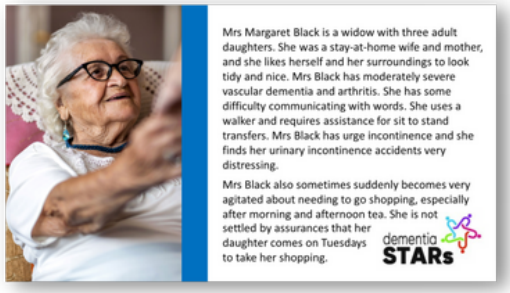
If we can't find a personal routine, the care-giving team could provide prompts every two hours during the day, and before and after meals.

For some people who have spent many decades knowing when they have to go to the toilet, having someone prompt them can seem a bit of nonsense, or it can feel quite insulting. Sometimes it can help to think about what makes sense for that person. For example, for one person washing their hands before a meal might make sense to them and we pair going to the toilet along with that. Another person may go for an after-lunch walk, and so it makes sense to them to go to the toilet before they go for their walk.

When Mr Zwartz is toileting we provide him with plenty of time. We don't rush him as it may take a little time to get started.

Sometimes the sound of running water can help. We also give him as much privacy as possible. If it's appropriate we might walk away and come back in a few minutes or stand just outside the door. We encourage Mr Zwatrto be as independent as possible. We provide simple step by step instructions if he needs them. We think about dignity and care, and we are really careful to avoid making any frustrated or belittling comments.[8]

For our second case study, meet Mrs Black. Mrs Black's story helps us to think about "Making it in time".



Mrs Margaret Black is a widow with three adult daughters. She was a stay-at-home wife and mother, and she likes herself and her surroundings to look tidy and nice. Mrs Black has moderately severe vascular dementia and arthritis. She has some difficulty communicating with words. She uses a walker and requires assistance for sit to stand transfers. Mrs Black has urge incontinence and she finds her urinary incontinence accidents very distressing. Mrs Black also sometimes suddenly becomes very agitated about needing to go shopping, especially after morning and afternoon tea. She is not settled by assurances that her daughter comes on Tuesdays to take her shopping.

If we think about strengths again, Mrs Black wants to stay continent and is able to tell the difference between being wet and dry: that's definitely a useful starting place.

We can see a number of challenges such as Mrs Black's verbal communication, her impaired mobility and physical abilities due to her arthritis, and her urge incontinence.

When we look more closely we can see that this means that the steps that are difficult for Mrs Black are asking for assistance, holding on until it is appropriate to go, getting to and from the bathroom, and getting clothes arranged to use the toilet properly.

Here are three things we can try:

1. Know the signs



Someone living with dementia may be reluctant to ask for assistance or, like Mrs Black, they may be struggling with words. We can look out signs and signals and get to know the ways that a person shows that they need to go to the toilet. For one person it might be pulling at their clothes, for another it might be getting restless.

As Mrs Black's care-worker we talk to one of her daughters.

It turns out that Mrs Black used to call going to the toilet 'I need to go spend a penny'. Now that Mrs Black has some difficulty with her words this has become "I need to go shopping". No wonder she didn't want to wait until Tuesday!

Now we know that saying that she wants to go shopping is a sign that Mrs Black wants to go to the toilet. We also notice that pulling her trousers or skirt up to her knees is another sign.

- We can make sure that we assist Mrs Black to the toilet straight after morning and afternoon tea to help prevent the need becoming urgent.
- We can keep an eye out for signs that Mrs Black is pulling her clothes or asking to go shopping and help her promptly.



How else might we help Mrs Black?

2. Reduce the urge

We could think about what Mrs Black is having to drink at morning and afternoon tea. Caffeinated drinks, fizzy drinks, and artificial sweeteners can irritate the bladder and make urge incontinence worse.

After some discussions we find that we can swap Mrs Black's coffee for decaffeinated coffee, still in the same mug and made just the way that she likes it. Mrs Black enjoys her decaffeinated coffee just as much, but the change seems to be helping with her urge incontinence.

We also check to see if Mrs Black is getting enough fluids. Being dehydrated can actually makes urge incontinence worse as the concentrated urine can irritate the bladder. We come up with some strategies to help Mrs Black keep her fluids up including providing more foods that help to hydrate, like juicy fruit, soup, or instant puddings, to help overcome her hesitance to drink.



3. Make it easy

We can also help people make it in time by making it easy.

We check to see if there are parts of toileting that are confusing or difficult for Mrs Black. Remember how many tasks there were involved in toileting. Knowing just which part of toileting is difficult allows us to help with provide assistance for just the parts that are difficult and encourage the person to still do the parts that they can. We can help the person to have as much privacy and independence as possible.

Sometime a simple clear prompt about the next step will help. Sometimes we can make the tricky part easier with equipment or adaptions. Sometimes we provide assistance with the tricky part.

For Mrs Black it turns out that getting her clothes undone in time was a problem. Some clothes are an absolute pain to get out of at the best of times, and desperately needing to go to the toilet while having arthritic fingers is definitely not the best of times. Swapping clothes with zips and buttons for elastic or velcro can be a time saver and help prevent accidents. Mrs Black's daughter helped find some elasticated pants to replace her button up ones, still in her favourite pink colour.

We also got some professional advice about Mrs Black's mobility issues. We worked out that the toilet was too low for her to get up easily and a raised toilet seat was helpful.

In some situations, a commode chair, or a urine bottle for men, may work when the toilet is too far away to get to in time, for example at night.

So, we tried a number of things, and we managed to reduce the frequency of accidents for Mrs Black. Mrs Black doesn't have the distress of feeling trapped when she can't get to the toilet without assistance.

Mrs Black still wears incontinence products that fit well to help her feel safe in case of accidents, but these are usually dry. If an accident does occur, we don't make a fuss and we reassure her after changing that she is looking very smart and nice.

Case study 3: Mr Pango. Mr Pangos's story helps us to think about knowing where to go and the environment



Read the third case study aloud.

Jack Pango is 74 years old. He's an ex-lorry driver with a great sense of humour. From early on in his dementia he has had visual and spatial problems, as well as memory problems. These have progressed. Jack has started going to the toilet in weird places like the hallway and the pot plant in the bathroom.

While Jack may have a wicked sense of humour, these problems related to going to the toilet are due to the changes in his brain, not from joking around.

If we think about strengths, Jack is actually trying to do the right thing and he's almost making it. However, his brain changes are getting in the way of the steps of finding the toilet and recognising the toilet.

Jack's growing problems with memory and spatial skills mean that he's now having trouble finding the toilet, so he ends up going in the hallway. Even though Jack's eyes are still working fine, the parts of the brain that process what he is seeing aren't working properly. When he gets to the bathroom he is having trouble recognising where the toilet is.

We want to think about how we can make it easier for Jack to find the bathroom and recognise the toilet.



Q *How do we do that? How can make it easier for Jack to find the bathroom and recognise the toilet?*

A Learners may suggest things such as:

- Making the toilet more obvious by using a contrast colour seat
- Putting a sign on the door
- Improving the lighting
- Keeping the toilet door ajar when the toilet is unoccupied so Jack can see the toilet
- Assisting Jack to the toilet

Discussion points:

There are two main things that can help in this situation: contrast and signage.



Contrast
If the bathroom has a white floor and white walls and white toilet and a nice bright pot-plant what catches your attention in the room? Perhaps it's no wonder that Jack was using the pot plant, particularly if he was used to sometimes relieving himself in the great outdoors while he was on long trips. We could try a coloured seat, to help make the toilet the focus of attention, and using a coloured cleaner block to tint the water [14]. This might help, or it might be confusing – Jack might never have had a coloured toilet seat! We would need to try it and see.

- Sometimes that white handbasin can be a trick for gentlemen too, as it can be interpreted as a urinal. You can see why. We could try keeping a facecloth in there to see if that helps signal that it is a handbasin while at the same time we make the toilet obvious with the coloured seat. If that doesn't work, we might just accept that a handbasin can actually make a pretty good urinal if we clean up and sanitise after the gentleman carefully [14].

- That mirror above the sink could also cause confusion for someone who doesn't recognise their own reflection. They might think the toilet is already occupied or that someone is trying to watch them. We might need to cover the mirror.

Signage
We want a sign that has good contrast so that it easy to see: black on a coloured background. We also want to use a picture and words that Jack recognises. Usually a realistic picture of a toilet is going to work better than a symbol that Jack has to interpret.

If Jack is still able to recognise words, we want to we could also label the toilet with whatever word Jack uses – whether that is dunny, loo, or toilet.

We don't make a fuss or tell Jack off for his use of different areas to go to the toilet, as we recognise that it is a genuine mistake.

Instead, we take positive action:

- **We take away the pot plant from the bathroom.**
- **We put in a black toilet seat.**
- **We attach a cleaner to tint the water blue.**
- **We stick a sign with picture of a toilet and the word dunny on the door, and another one with an arrow in the corridor.**

We show Jack these cues and have a few laughs. We drop reminders of these cues into conversations several time when we are going past or using the bathroom, like asking Jack if he likes the black dunny seat. Jack responds well to the new signage and the coloured toilet seat, and nearly always uses the toilet now.

So in summary we are taking a very positive approach to promoting continence: remembering that the person comes first: considering the steps of toileting and the persons strengths and difficulties, and proactively problem-solving.



With this approach we can often make a difference and help people to maintain comfort, dignity, and continence. It's a process of trial and error though and accidents will still happen. It doesn't mean that you failed or that they failed. Try to overcome any embarrassment or upset the person may feel: keep calm and carry on promoting continence!

Thank learners for their attention. Provide the summary handout, going further handout, and feedback form.

AT YOUR PLACE

Here are a few questions to reflect on before you facilitate the session, to help make the session relevant and effective in your organisaton.

CONTINENCE RESOURCES

Does your organisation have training or information about continence that you would like to refer to?

LINE OF COMMUNICATION:

Who should learners talk with for support around continence? Is there a designated staff member with a continence role?

SHARING:

How do care-workers document and share success full strategies? Are there opportunities to share and celebrate good news stories with supervisors or the team?

YOUR CHECKLIST FOR THE DAY

Here are some of the things you may want to take with you

- [ ] Audiovisual equipment with PowerPoint presentation loaded
- [ ] Whiteboard pens and either a whiteboard or large paper pad to record learners' responses for activities
- [ ] This facilitator's guide
- [ ] Handouts: Summary handout plus Going further handout
- [ ] Certificates of completion
- [ ] Feedback forms



3. Resources

Continence and dementia

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keep POSITIVE thinking

CONTINENCE AND DEMENTIA

1 The person comes first

Positive problem-solving together can help promote continence for many people living with dementia.

- We strive for dignity and privacy.
- We can think about the situation from the person's perspective. We get to know them.
- We can think about the steps involved in going to the toilet: what are their strengths? Then we can problem-solve together how we can support the steps that are difficult.
- Every person will be unique, and it's not a failure if something doesn't work: We're learning!

2 The power of prompting

Prompting can be really helpful to promote continence for many people living with dementia. It can help overcome problems with memory and apathy.

Find their routine: If we can predict when the person typically is incontinent we can prompt about 10 minutes earlier.

Establish a routine: We can provide prompts at regular times of the day around meals and snacks, and before bed.

Know the signs: We can get to know the signs that the individual wants to go to the toilet and act promptly.

Reduce the urge: Drinks with caffeine, fizz, or artificial sweeteners can irritate the bladder. So can being dehydrated.

Make it easy: Easy to remove trousers with velcro or elastic can often help. We can get advice about equipment like a raised toilet seat, grab bars, a commode, or a urine bottle

3 Making it in time

Sometimes we can help to make it easier to recognise the bathroom and toilet.

Signs: We can use a picture of a realistic toilet and the word that they use for toilet.

Contrast: We can use a coloured toilet seat to make the toilet the centre of attention. We can remove any containers that are being misinterpreted as a toilet.

4 Thinking about the environment

GOING FURTHER...
5 GREAT RESOURCES ON CONTINENCE

VIDEOS

1

The Australian Continence Foundation has a series of six brief videos on continence and dementia:

https://www.continence.org.au/who-it-affects/medical-conditions/dementia



2



HELP SHEET

Dementia Support Australia has a help sheet for staff about continence and toileting issues:

https://dementia.com.au/downloads/dementia/Resources-Library/Care-Support-Guides/J001025RB_DSA_Toilet.pdf

3



POCKET GUIDE

The Scottish Care Inspectorate offers an outstanding pocket guide about person-centred continence support that uses the voice of people living with dementia:

https://www.careinspectorate.com/index.php/news/9-professional/2613-promoting-continence-for-people-living-with-dementia-and-long-term-conditions



5

BOOKLET

Dementia UK offers a booklet about dementia and continence:

https://www.dementiauk.org/wp-content/uploads/2020/12/DUKFS08_continence_Online.pdf

4

WEBSITE

Continence New Zealand provides a website with information and advice:

https://www.continence.org.nz/pages/Dementia-and-incontinence/53/

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Feedback on EATING & CONTINENCE

	STRONGLY DISAGREE	DISAGREE	NEUTRAL	AGREE	STRONGLY DISAGREE
I understand more about promoting continence	○	○	○	○	○
I feel more motivated to encourage continence	○	○	○	○	○
I will be able to use what I learnt in my work	○	○	○	○	○
It was worthwhile coming	○	○	○	○	○

WHAT IS THE MOST IMPORANT THING YOU LEARNED TODAY?

WHAT IS YOUR GENERAL FEELING ABOUT THIS EDUCATION SESSION?

WHAT ARE YOU GOING TO DO DIFFERENTLY?

THANK-YOU FOR YOUR FEEDBACK, IT IS APPRECIATED

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CERTIFICATE

OF COMPLETION

_____

has completed the Dementia STARs Continence and Dementia Module

Date _____

Signed _____

Organisation _____

PROMOTING CONTINENCE

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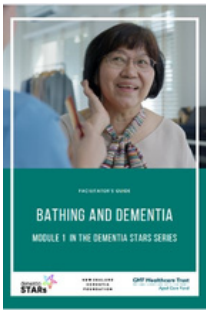
[13] Dementia Support Australia (2021) *Care staff help sheet: Continence and using the toilet*. https://dementia.com.au/downloads/dementia/Resources-Library/Care-Support-Guides/J001025RB_DSA_Toilet.pdf

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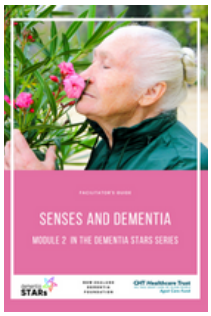
CONTINUE LEARNING WITH THE DEMENTIA STARS SERIES

We are delighted to offer eight Dementia STARs modules in this series. The Dementia STARs programme is an opportunity to reinforce a shared culture of person-centred care. Each kit offers all the tools needed to run an engaging introductory education session for direct care-workers and other staff.

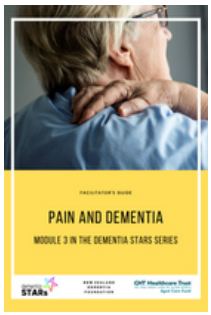
You can find the full series online at nzdementia.org/Dementia_STARs



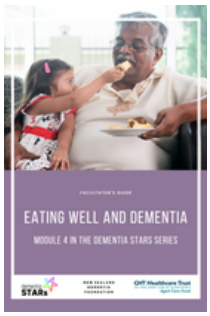
1: Bathing and dementia



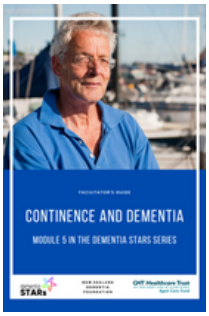
2: Senses and dementia



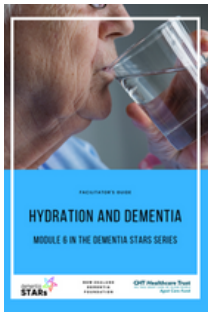
3: Pain and dementia



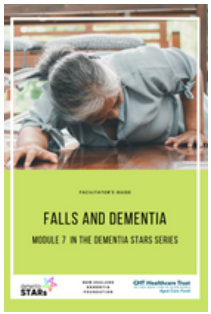
4: Eating well and dementia



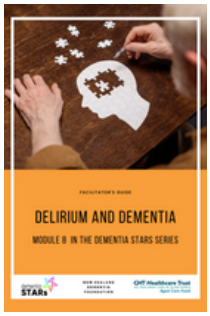
5: Continence and dementia



6: Hydration and dementia



7: Falls and dementia



8: Delirium and dementia

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