

FACILITATOR'S GUIDE

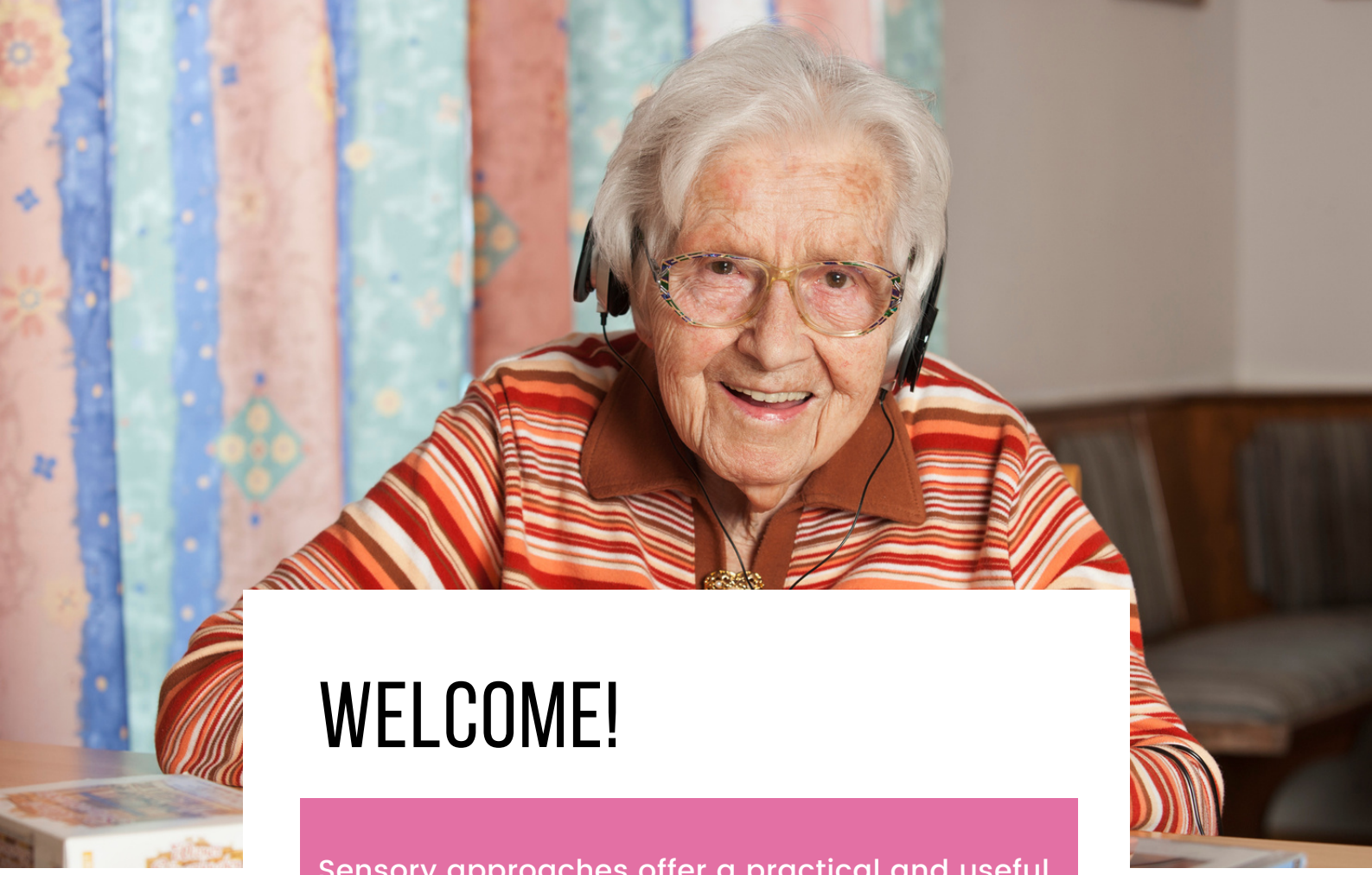
SENSES AND DEMENTIA

MODULE 2 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!

Sensory approaches offer a practical and useful way to help reduce distress and enrich the day-to-day life of people living with dementia that we support.

In this kit you will find all the resources you need to run an engaging 45-60 minute introductory staff education session on sensory approaches with people living with dementia. 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

Senses 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 to 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 a way of sharing case studies. Because cases studies tell a story, they are 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 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?

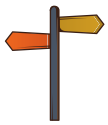
This is a suggestion about a question to ask the learners to increase engagement.

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 people and perspectives 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: NURSING

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



SUSAN GEE: ACADEMIC

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 THERAPY

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: NURSING

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. Lara 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 since founded carers' groups to bring whānau carers together for mutual support. Cheryl also helps to educate people about dementia from her perspective as a wife and family member in the hope that it strengthens an emotional connection to 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 carer 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

Senses and dementia





LEARNING OBJECTIVES: SENSES AND DEMENTIA

When supporting a person living with dementia

01

Learners are able to articulate the aims of sensory modulation.

02

Learners are aware of the value of understanding an individual client's sensory preferences, and able to articulate key questions to guide gathering this information.

03

Learners are able to identify common sensory changes associated with dementia and possible compensatory strategies.

04

Learners can develop a simple ideas tookit for sensory experiences for an individual client (alerting, just right, and calming).

05

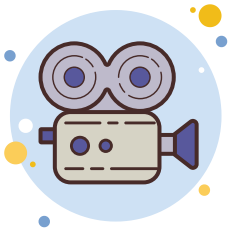
Learners understand that different individuals can vary in their response to the same sensory experience.

FACILITATOR'S NOTES FOR SENSES AND DEMENTIA

Providing support involves sensory experiences – whether it's the sound of cleaning, or the feel of personal cares, or even the sight of your cheery smile. Thinking about how we can make the most of sensory experiences can be an opportunity to add pleasure and joy into the day and to bring comfort and reduce stress.



Here's Nick and Cheryl who are family carers to give us their insight:



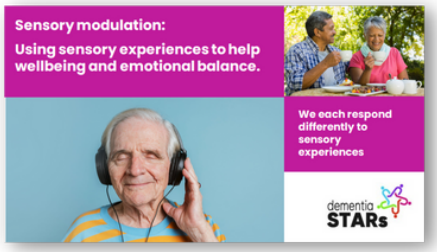
Play
video
with Nick and Cheryl

When we think about Nick's story, we can see how the sensory experience of the garden played a role in reducing distress.

Nick and Cheryl also remind us that the relationship is big a part of why sensory experiences are positive. There is a foundation of establishing trust and knowing the person as a whole person, and not just a disease or a task.

Today we are going to be talking about how we can work together with a person we are supporting to use sensory experiences to support their wellbeing and emotional balance.

This concept is known as sensory modulation.





We all do this without giving it a formal name [9].

For example, some people have a range of music playlists – they have a playlist that is good for when they want to chill, and they have another playlist for when they are doing a really intense workout [9]. Some people do this with herbal teas – they have a blend that they use when they want to unwind and relax and another that they use when they are feeling a bit jaded and want some get up and go [9]. These are examples of people using their senses of sound and taste to help them get into the "just right state" for that moment - whether they want to settle down or perk up.

We each respond differently to sensory experiences. My music playlist is probably different from your playlist. My favourite herbal teas might be totally different to yours – or I might not like herbal teas at all. So, we need to get to know a person's sensory preferences if we are going to make the most of the potential of sensory experiences.

As we go through the session today, we're going to use your own sensory preferences to explore how we can understand and use sensory experiences. These are great tools to have for your clients, and they are also great tools for own own self-care.

Today we'll be talking about what helps us to help people to feel "just right".
We want to know about people's sensory preferences.



We want to know if there are sensory challenges to be aware of.

And we want to develop a toolkit of ideas for sensory experiences for that unique individual.

First, let's take a little detour to talk about the seven senses.

There are the five senses that we all probably learnt at school – touch, sight, taste, smell, and hearing.



There are also two more senses that are related to body movement:

- Our vestibular system includes our inner ear. It helps us to sense balance, where our body is in space, and movement.
- Proprioception uses receptors in our joints, muscles, and tendons to sense movement and tell us where our body parts are.

For today we are going to group these two vestibular and proprioception sensory systems together as 'body movement' senses

Our first big idea is that we want to get to know people's preferences for sensory experiences.



How much is too much sensory stimulation? How much is just enough? That varies! So one question about preferences is:

How big is your "sensory" kete or basket?



People vary in how easy it is to stimulate their nervous system. We can think of this with the metaphor of a sensory kete. We need to keep our kete filled up with supplies to keep us going [10].

Some people have a small kete that can't hold very much. It's easy for the amount of sensory information to exceed the capacity of the kete.

Other people have a large sensory kete. They need lots of sensory input to fill up their kete, and it may need to be topped up frequently.

Some people are in between!



Noticing where a person fits on this continuum can be a big help in getting the sensory environment just right. Let's explore this for you.

Activity: How big is your sensory kete? Quiz and worksheets

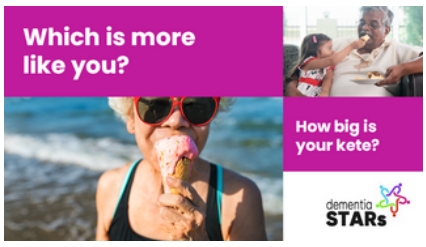
Needed: 'Getting to know my senses' side of worksheet (2 sides) for each learner, spare pens, Powerpoint

Step 1: Introduce the activity

To help us think about our sensory preferences we are going to start with a brief quiz. This isn't a formal sensory profile, it's a fun way to start us thinking about our sensory preferences [11].

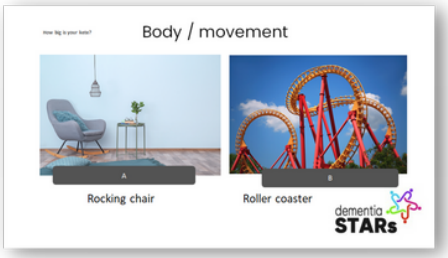
Step 2: Run the quiz

I have six quiz slides coming up. For each slide I'm going to give you two options,. I want you to choose the option that is most like you. You can call out your answers if you want to, or just think about your answer silently.



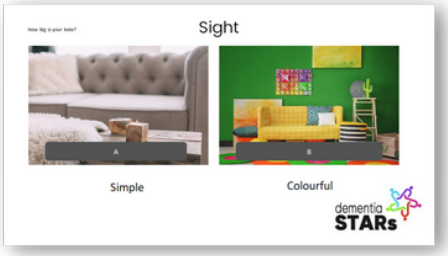
Which sounds more your style –

a. A rocking chair
or
b. a roller coaster?



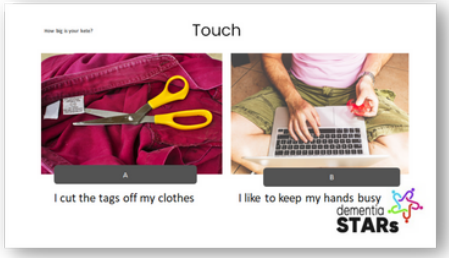
Which room would you be more comfortable spending time in –

a. The plain one
or
b. the colourful one?



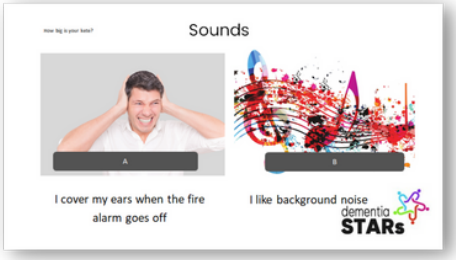
Which one sounds like you:

a. You cut the tags off your clothes so they don't scratch
or
b. you like to keep your hands busy



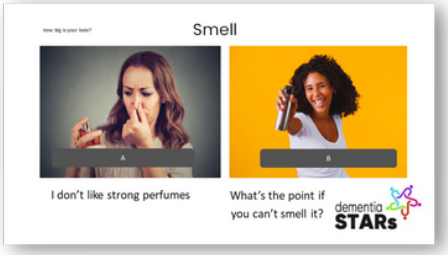
Which sounds like you:

a. You cover your ears when the fire alarm goes off
or
b. you like to have background noise like music



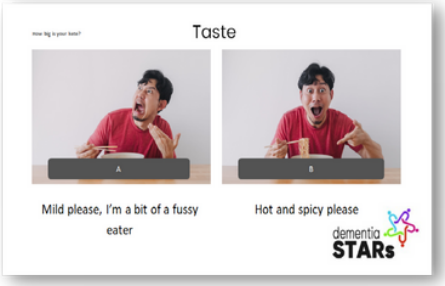
Which sounds more like you:

a. I don't don't like strong perfume
or
b. What's the point of perfume if you can't smell it?



Which sounds more like you:

a. Mild food please, I'm a bit of a fussy eater
or
b. Hot and spicy food please



Step 3: Group discussion

You may have found that you usually chose A. The responses marked with A were things that might be chosen by someone who is pretty sensitive to sensory input. [You can check whether there is someone with that pattern who is comfortable to talk about it. You might ask them if they were already aware of this preference.]

The choices marked with B were some examples of how someone with a bigger sensory kete might seek out more intense sensory experiences.
[Is there someone who is comfortable to talk about this pattern?]

You may have found that you picked A for some things but B for others. We can think of the different senses as a series of kete, and they don't all have to be the same size.
[Is there someone who is comfortable to speak about this pattern?]

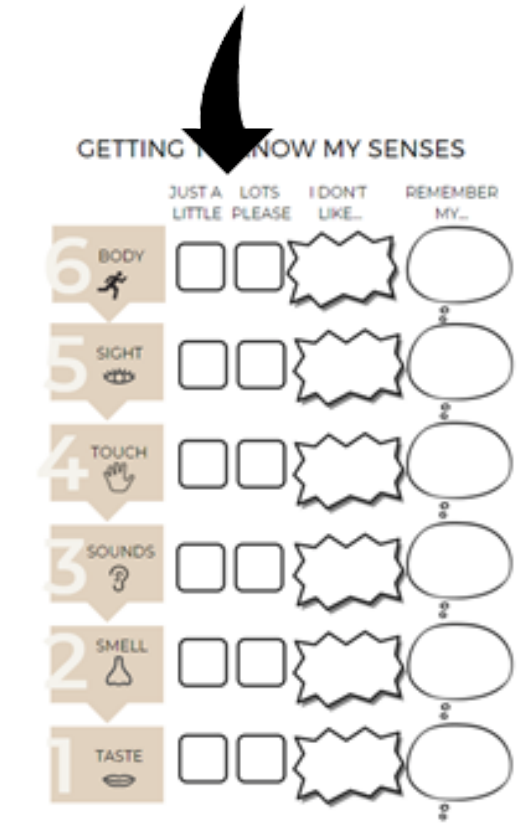
Step 4: Learners fill in their worksheet with own preferences.

Hand out the worksheets.

These were just some simple examples but hopefully they have got you thinking about your own preferences. Do you think that you have a preference for a little or a lot of sensory input? For what senses?

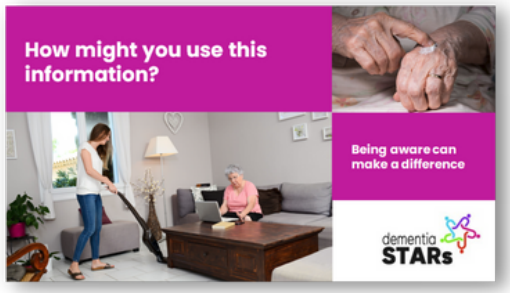
I want you to mark your own preferences on your worksheet in the first two columns. We will fill in the other columns later

Facilitator note: The picture to the right shows the handout. The arrow shows the columns that the learners fill in.



Step 5: Discussion in pairs

Ask the learners to form pairs.



Let's imagine now that you are all going to have a care-worker to help look after you, starting tomorrow. In pairs, look at your sheets so far and come up with some ways your care-worker could use this information.

The care-worker can be helping you with whatever care tasks you wish.

- So, for example, if I am sensitive to noise, my care-worker could help me to go to a quieter room when they vacuum. On the other hand if I really liked noise my care-worker might sing as she works!
- If I really like smells, my care-worker could use a scented hand-lotion after my shower. We might talk about how good lunch smells. We might take a moment to smell fresh fruit or flowers. We might even look over some old recipe books before lunch and sniff some cinnamon and vanilla. On the other hand, if I was really sensitive to my care-worker might use unscented products and make sure that the scents that they wear themselves aren't too overwhelming

Be creative and work together to come up with some ideas that might work for you.

Step 5: Group Discussion

Ask the learners to share their ideas.

The learners will hopefully have a diverse range of possibilities. Here are a few more examples:

- Rewa is sensitive to sounds, so the care-worker offers to fetch Rewa's noise cancelling headphones. Or some supermarkets offer a low noise quiet hour and the care-worker might arrange for their joint shopping expedition to take place during that quiet hour.
- Avi loves interesting smells and tastes so their care-worker tries taste-testing different teas at morning tea.

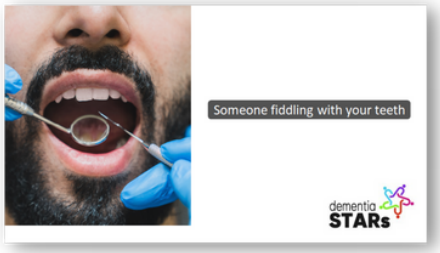
Discussion point: being aware of people's sensory preferences can make a difference.

Our second question about preferences is whether there are particular sensations that the person doesn't like. What do you dislike?



Here's some sensory experiences to get you started. Does the thought of this sensation make you squirm a bit?

A dentist working on your teeth ?



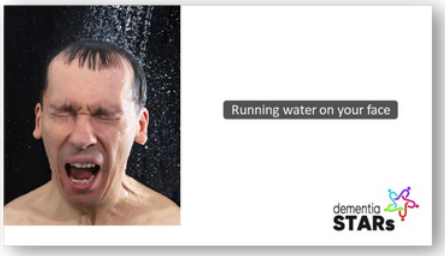
Seeing a spider?



Someone tickling your feet?



Running water on your face?



Sudden loud noises?

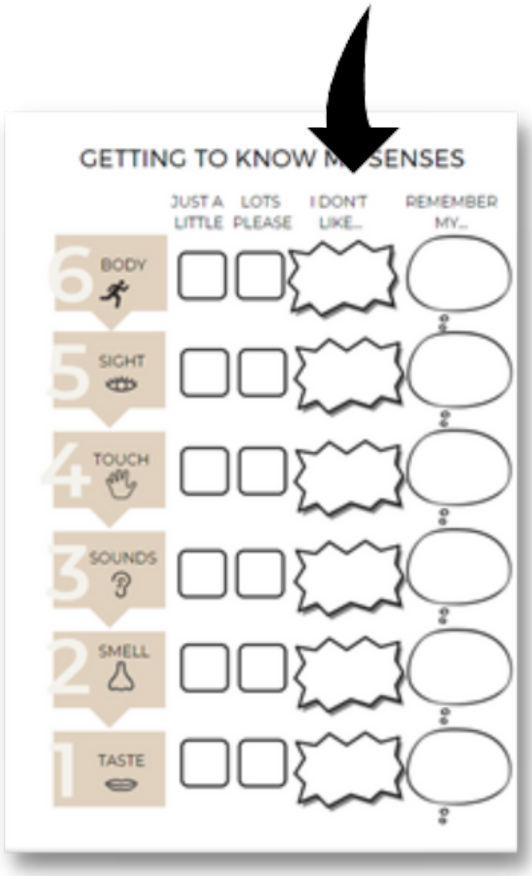


Seeing those slides might make you think of particular sensory experiences that you really hate.

If so, add them to your sheet. You'll see that there is a column with spiky boxes labelled "I don't like".

We'll fill in the last column later.

Facilitator note: The picture to the right shows the handout. The arrow shows the column that the learners fill in.



Knowing what a person dislikes can be really useful. Imagine if a person is afraid of dentists. If we know that, then we can adapt how we help them to clean their teeth.

Being aware and respectful of people's fears and dislikes around sensory experiences is a really important part of what is called trauma aware care [12]. People come into our care with a lifetime of experiences, and some of them may be traumatic. These can shape how a person responds to a particular sensory experience.

We can apologise and let them know that we understand that this sensation was horrible for them.

We can avoid that sensation if we can. We can try to do things differently to make the experience ok for them. We look for ways to make them feel safe.

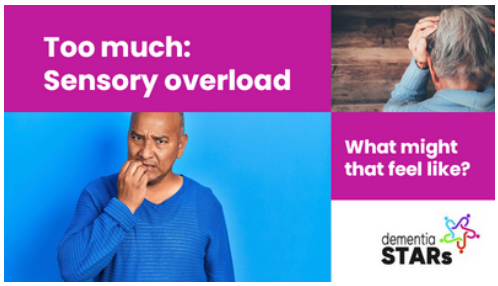
We also want to know if the person we're supporting has sensory challenges that are related to dementia and how we can help.

Let's look at some of the changes related to senses that are common for people living with dementia.

These change can make it harder for people living with dementia to keep their sensory kete filled to the just right level.



Sometimes we can receive more sensory information than our brain can process. We experience sensory overload.



Q

Let's imagine that we put your favourite TV programme on, that's pretty nice. Now let's put your favourite song on at the same time. And now let's put your favourite podcast on as well. And there's a car alarm going off next door. And now I come in and I want you to fill out a form for me right now.

What might that feel like?

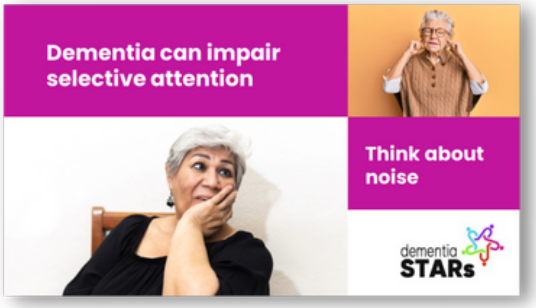
A

Learners may talk about:

- Can't concentrate, hard to focus
- Can't think
- Stressful
- Headache
- Discomfort, distress
- Irritable
- Anxious
- Overwhelmed
- Refuse to participate, withdraw
- Sensitive to any extra input

What we have described is a situation of sensory overload and it is pretty unpleasant. Many people living with dementia find that they get overwhelmed like this more easily.

When we think about our environment right now there are actually lots of different sources of sensory input. You can hear ….[e.g. other people in the room, wind, traffic], and you can see [e.g., outside the window, other people].



But your brain is able to focus on me talking to you and put the other things into the background. The part of the brain that manages this selective attention is the frontal lobe. When the frontal lobe is impaired by dementia, people can lose this ability to focus. For someone living with dementia, all those sounds and sights can be coming into their brain as if they are equally important. You can imagine how easy it is for that to be overwhelming.

How can we help compensate for this? A top tip here is to think about noise. Noise often contributes to sensory overload for people living with dementia

- Sometimes the environment has noise in the background like a television, radio, or music. The very idea of "background" noise takes it for granted that you can put that noise in the background and concentrate on something else. That's selective attention. Background noise can be stressful for a person living with dementia and makes it harder for them to concentrate.

- We can check with the person and turn the noise off before we talk with them. This can help the person to hear us, and also help them to process what we're saying [13]. There's more of their attention and brain power available.

- Using headphones for music can be pretty life-changing for some people living with dementia. Listening to music playing through noise-cancelling headphone feels like the music is 'inside your head' instead of out in the environment, and people often find this a very different experience than having music on in the room.

Another tip is that the changes in the brain with dementia can make people hypersensitive to touch too, and touch sensations like the feel of being dried with a towel can feel unpleasant or even painful. If this occurs we can do our best to make the sensations as gentle and soft as possible.

People living with dementia can experience sensory changes and losses because of the changes in their brains[14-17]. As some researchers have pointed out:



> "It's harder to live with dementia when you have sensory loss and it is harder to cope with sensory loss when you have dementia.'" [16]

The sensory changes related to dementia can mean that people are at risk of missing out on positive sensory experiences. A severe lack of sensory input is known as sensory deprivation, and this can be detrimental to our wellbeing and brain health.

Dementia can affect all the senses, in different ways. We are going to take a brief tour through each of the senses to look at some of the common dementia-related sensory losses.



Taste and smell

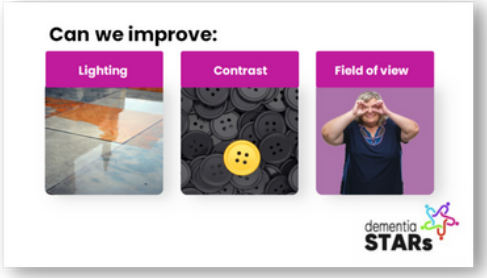
People often experience a decline in their sense of smell and taste with dementia. It seems as if the loss of smell may be a very early sign of dementia for some people, showing up even before they notice cognitive changes.



One of the big impacts from this change is that food is less appealing and so appetite can be affected. We often need to pay extra attention to helping encourage small appetites, for example by boosting flavour.

Sight

Dementia can affect the parts of the brain that process what we see. This means that people may have trouble interpreting what they see even though their eyes haven't changed. The brain may also struggle to process information from two different eyes so depth perception can be affected [15]. Visual processing issues mean a shiny floor can look like water or a dark mat can be perceived as a hole



Let's look at 3 tips:

Tip 1

Good, even lighting can sometimes help by removing tricky shadows. To see well, a person living with dementia may need the room to be lit more brightly than you would, especially in the evenings.

Tip 2

We can use contrast to make visual information easier to process. We can use this idea for everything from making food contrast with the plate, to using a coloured toilet-seat to contrast with a white bathroom.

Tip 3

As we get older we don't process information as well at the edges of our vision, and dementia can also narrows the field of useful vision. It's a bit like having blinkers on. We are going to try out what that is like.



Activity: Reduced field of useful vision

Needed: Sight Powerpoint slide (this activity reinforces Tip 3 "visual field" on the slide)

Step 1: Introduce the activity

Ask the learners cup their hands around their eyes like blinkers or binoculars [15] to simulate the reduced field of useful vision. [See the third picture in the 'Sight' Powerpoint slide above]

Step 2: Moving

Ask the learners to move around the room, while wearing their 'blinkers'. What do they notice?
Learners may notice that

- They look down
- They move slower
- They take shorter steps
- They feel less safe

Step 3: Seated

Ask the learners to return to their seat and put hands back into the 'blinkers' position.

Ask the learners to look ahead at you, and think about what they can see. Ask specific learners if they can see objects or people - e.g., Maia, can you see your water bottle at the moment? Tim, can you see Maamari beside you?

Discussion points: If we approach from the side we may be out of sight and startle people. If we put something like a drink or food out of the person's field of view it may be invisible.

Hearing

Dementia can make it difficult for some people to understand the words that they hear, particularly for people with a specific type of frontotemporal dementia called Primary Progressive Aphasia.



Dementia can also affect how people cope with hearing loss. Hearing loss is common among older people living with dementia, as you may well know from your own experience with clients. Over half of people in their 70s have hearing difficulties. Most older people with hearing difficulties have acquired hearing loss. This means that around 90% of people with hearing difficulties have spent most of their life hearing normally. Dementia can make it harder to adapt to this change. [20]

Dr Matthew Croucher is going to talk to us about hearing loss and dementia in this video.

Play Matthew's video

Clear communication is an absolute priority for people living with hearing loss and dementia.[20,21] We can use simple strategies to improve communication, such as reducing background noise, speaking directly face to face, and using visual cues like gestures or objects. For example, when we suggest that it's time to brush teeth we might gesture brushing teeth or show a toothbrush.

Touch

One of the losses for people living with dementia is changes in the opportunity for caring touch.



Caring touch is something that we are wired for from birth, and our brain responds differently to caring touch than it does to touch involved in tasks. Think about an infection control nurse briskly washing your hands compared to someone who cares about you giving you a hand massage. Caring touch helps us to relax and reduces anxiety.

Q

What are some signs that a person may be craving touch?

A

Examples might include
- grabbing people's hands as they walk past
- overfamiliar with hugs

A top tip for someone who is craving touch is to look for appropriate ways to help fill the sensory kete for caring touch like hand massages, foot massages, and petting animals.

Body

The body senses involved in balance and movement can also be affected by dementia, and people may find that they feel unsteady and clumsy, and they may tend to bump into furniture or fall.



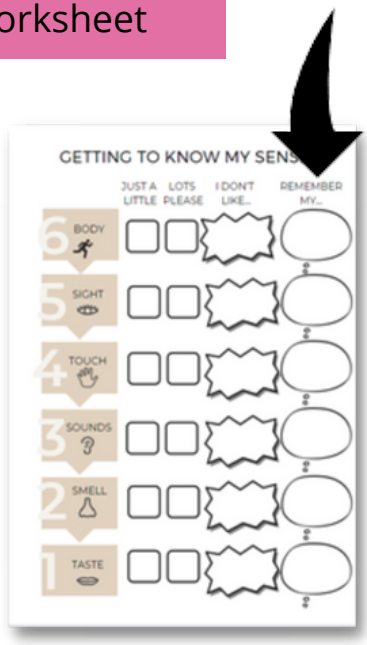
One top tip is that we can be aware of how unsettling these sensory losses can be. For some people it can be important to help them feel safe in tasks that involve their feet being off the ground like transfers using a hoist. For others it can be important to help boost confidence about keeping active on their feet.

Another top tip is that touch, movement, and balance are sometimes called the "powerhouse" senses. They can be very powerful in helping people to feel calmer: any type of 'heavy work' activity that involves resistance like pushing, pulling, or carrying, weighted modalities like weighted animals or lap pads, and even chewing and sucking can all tap into these powerhouse senses.

Activity: Add challenges to worksheet

Let's add our own challenges to our own sheets now: do you have a sensory challenge that a carer should know about? Put this in the last column in a speech bubble–for example:

remember my ...fear of heights
remember my....glasses for reading,
remember my ...skin hypersensitivity
remember my ...right ear hears better than my left
remember my ....sense of smell is very poor
remember my .... teeth hurt for chilled food

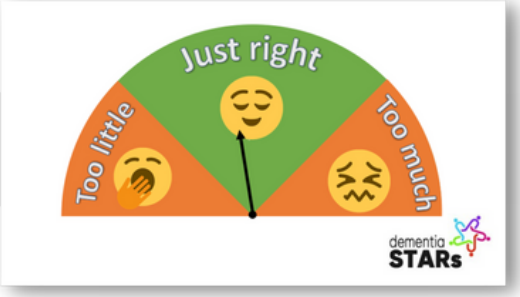


So now, we can put all our information together to create a sensory ideas toolkit.



Just right: the balanced kete

We are aiming "just right". It's a bit like the Goldilocks and the Three Bears story and the three bowls of porridge that are too hot, too cold, and "just right".



When we are feeling a bit out of balance we can use some ideas from our sensory toolkit to help shift that dial and get back into the just right zone.

- We can use sensory experiences to help to alert us when we feel bored and listless.
- We can use sensory experiences to help calm us when we are feeling overwhelmed, anxious, frustrated or jittery.

Before we head into looking at the kind of things that might be alerting or calming, a word of caution.

So far I've talked about situations where a person is a bit out of balance. Sometimes though, this dial can go right over into red and the person is really upset: they might be yelling or hitting for example. Generally, this isn't the time for sensory modulation. In these situations, where someone is really distressed, we want to pull out a different toolkit of de-escalation techniques.

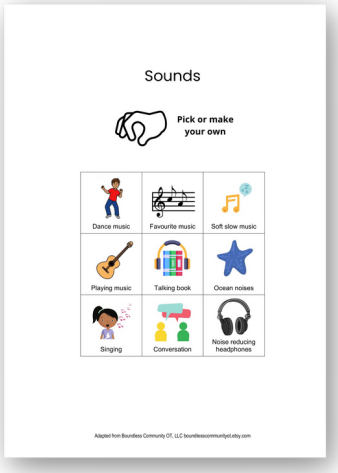
At your place: You may want to talk de-escalation training or resources that are available at your place.

Activity: Filling the toolkit

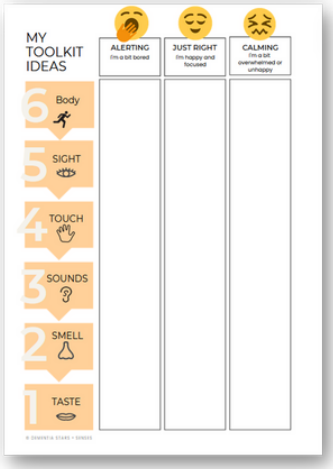
Needed:

- "My Toolkit Ideas" sheet for each learner,
- 1 copy each of 'body", "sight", "touch", "sound", and "smell and taste" ideas sheets (5 total),
- Spare pens

Spread the 5 inspriation sheets around the room, if possible. (See right for an example)



Give each learner a copy of the "My Toolkit Ideas" worksheet. (See right)



The aim is for the learners to go around the different inspiration sheets and gather ideas that they write on their own "My toolkit ideas" worksheet. This activity may take about 10- 15 minutes.

Step 1: Introduce the activity



This is a chance to develop your own toolkit of sensory experience ideas [show worksheet]. Your job is to go gather some inspiration.

We have some inspirations for the different senses around the room [point out the five sheets].

You can choose ideas from these inspiration or add ideas of your own.

You are going to fill up the three sections of your toolkit:

- Things that help you feel more alert
- Things that help you to keep feeling just right
- Things that help you feel more calm and relaxed

It's up to you where you put an idea, according to how you would respond to it. You can put the same idea in more than one place. This is your own list so choose things that you'd enjoy and be willing to try – don't put yoga as a calming activity if you hate yoga! Choose activities that are meaningful and appealing to you.

You might want to add some detail for some of the ideas– so if you choose music, what kind of music? If you chose physical activity, what kind of physical activity? If you put making, what kind of making: carpentry, baking, sewing?

Does anyone have any questions?..... OK, go fill your toolbox

Step 2: Filling the kete

Give the learners enough time to go around the five inspiration sheets.

Step 3: Discussion



Explore calming experiences for each senses, taking one at a time. Ask learners to share their chosen experiences, e.g.:

Q *Let's start with what kind of body and movement experiences people often find calming. We can think about slow repetitive movement, like a rocking in a chair, or winding up wool or but also activities that involve resistance, like pushing a trolley. What kind of things did you pick?*

A Learners share their responses. Draw attention to experiences that are popular. There may also be examples of how one person may find an experience calming while another person finds it alerting.

Q *What about sight – typical calming things include soft colours and pictures of family or favourite scenery..... What kind of things did you pick?*

A Learners share their responses.

Q *Now touch. Calming things often involve pressure and warmth – like massage or a warm blanket, or a weighted lap pad..... What kind of things did you pick?*

A Learners share their responses.

Q *How about sound? Calming things are generally soft and simple – maybe instrumental music or sounds of the ocean..... What kind of things did you pick?*

A Learners share their responses.

Q *Smell? Calming things might be mild and pleasant like rose or vanilla..... What kind of things did you pick?*

A Learners share their responses.

Q *And finally, what about taste? Calming things are again mild and pleasant, and for some people sweet – rice porridge, or a nice hot chocolate.... What kind of things did you pick?*

A Learners share their responses.

Step 3: Discussion continued



Now explore the alerting experiences for each senses. Once again ask learners to share their chosen experiences, e.g.:

Q *OK, we've explored the calming experiences, and we probably all use some of these already each day, to keep ourselves steady under pressure or wind down at the end of the day. But what about the opposite? Things that wake us up and get us going? Lets start with the body and movement. Here we can think about experiences that are a bit faster and more active, like clapping, stretching, or exercise. What kind of things did you pick?*

A Learners share their responses. As you go though, once again draw attention to experiences that are popular. There may also be examples of how one person may find an experience calming while another person finds it alerting.

Q *What about sight – we might have things that are brighter or have movement, like doing a jigsaw puzzle or watching sports..... What kind of things did you pick?*

A Learners share their responses.

Q *Now touch. Alerting activities might be having a cold face wash, or squeezing something squishy and spikey or fidgeting with something hard..... What kind of things did you pick?*

A Learners share their responses.

Q *How about sound? If we want a bit more alertness we may go for music that's a bit more upbeat, or we might make the music ourselves by singing out loud..... What kind of things did you pick?*

A Learners share their responses.

Q *Smell? Here I think of sharper smells like pine or citrus..... What kind of things did you pick?*

A Learners share their responses.

Q *And finally, what about taste? More intense tastes, maybe spicy or sour....or maybe something cold like an iceblock. What kind of things did you pick?*

A Learners share their responses.

Today we filled in our sensory toolbox for own selves, but you can see how we can use this process to develop an ideas toolkit for an individual that we support as we get to know them well.

We'll need to explore how the individual responds [22]. A great example is when a staff member introduced tai chi classes into a dementia environment. Most people responded to the gentle flowing movements as being calming. But a few of the men responded to the martial arts feel of some of the movements and so for them tai chi revved them up.

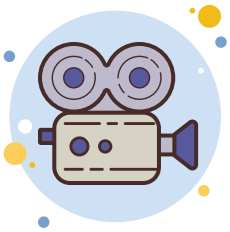
The more we know about the person the more we can make the sensory experiences meaningful for them. Family can be a great resource to help gather information about sensory preferences. What did the person love doing when they had a chance to relax? What helps them settle? Are there sensations that are likely to distress them?

Thinking about daily patterns can be useful too:

- You may find that you have a pattern during the day where you tend to use things from your calming toolkit to wind down for bed.
- You may notice that some people living with dementia have a bit of a predictable pattern across the day. About mid-morning once they have woken up their sensory kete is at its biggest and they are ready for something fun and a bit more challenging. So they may enjoy things from the "just right" to "alerting" parts of their toolkit.
- As the day goes on it can be pretty tiring dealing with the world when you're living with dementia. They are more tired, and their brain is more tired. Their sensory kete shrinks and it's easier to be overwhelmed. They may enjoy less demanding experiences from the "just right" to "calming" side of their toolkit.

Now that we have this way of thinking we can be looking for ways that we can engage senses in our everyday care.

Tracey Hawkes, occupational therapist is going to give you some examples in this video.



Play Tracey's video

So hopefully you are inspired to try some sensory modulation for yourself and for some of the people that you support. It's a great skill to have for your own self-care, and it's a great way to enrich the time that you spend with people.

A last question for the day:

What's one way that you might try some of these ideas?

It might be for yourself or it might be in your work.



Thank the learners for their participation and provide the summary handout, going further handout, and the feedback questionnaire.

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.

TRAUMA SUPPORT

Think through how you may respond if a learner feels triggered by the topic. For example, a non-judgemental empathetic response with the option for the learner to take a break, catching up with the student after class, informing them of available support etc.

LINE OF COMMUNICATION:

How can care-workers share / record what they learn about clients' sensory preferences?

SENSORY ASSESSMENT RESOURCES

Does your organisation have a sensory profile assessment protocol, sensory diet system or other resources about sensory modulation? Do you have de-escalation resources?

YOUR CHECKLIST FOR THE DAY

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

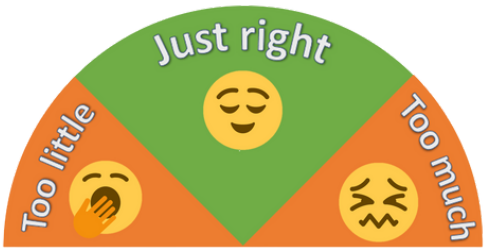
- [ ] Audiovisual equipment with PowerPoint presentation loaded
- [ ] Whiteboard pens and either a whiteboard or large paper pad to record learners' responses for activities
- [ ] This facilitator's guide
- [ ] For activities: pens or pencils,
  1 copy of each of the inspiration sheets (5 pages)
- [ ] For activities: one copy per learner of:
  "Getting to know my senses" worksheets (2 pages)
- [ ] Summary handout
- [ ] Going further handout
- [ ] Certificates of completion
- [ ] Feedback form



3. Resources

Senses and dementia

SENSES AND DEMENTIA



Sensory modulation is about using sensory experiences to support well-being and emotional balance. We can use sensory activities to help feel calmer or to help us feel more energised.

1



Sensory preferences

How much sensory stimulation is 'just right' depends on the person. We can think of this as 'how big is your sensory kete'? This can vary across senses and situations.

2



Dislikes

Knowing and respecting that some sensations make a person uncomfortable is important. Sometimes the discomfort may be linked to past trauma. We help the person to feel safe.

3



Dementia challenges

People living with dementia may be less able to filter out background sensory input. We can try to reduce sensory overload.
Dementia is also often associated with sensory losses. We are aware of challenges for the individual and how we can help compensate.

4



A sensory toolkit of ideas

We can develop a toolkit of ideas for sensory experiences to help a person to calm or alert. What works will depend on the person. We can look for opportunities to engage senses to enrich day-to-day care.

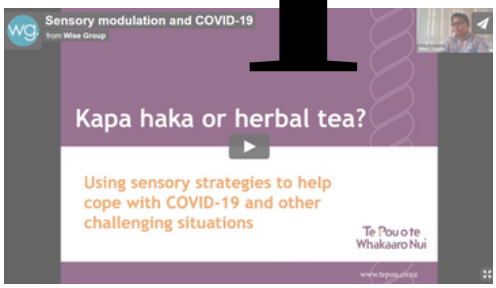
GOING FURTHER...
5 GREAT RESOURCES ON SENSES

1

WEBINAR

Te Pou has a webinar called “Kapa haka or herbal tea” that offers an introduction to sensory modulation.

https://www.tepou.co.nz/initiatives/reducing-seclusion-and-restraint/sensory-modulation



2

BOOK



Talking Sense is a free book about sensory changes in dementia co-written by someone living with dementia.

https://www.dementiacentre.com/resources?filter[tag][]=dementia-and-aged-care

3

ONLINE COURSE

The Australian course "Sensory modulation in mental health settings” is clear and useful.

https://rise.articulate.com/share/mn_W7PvScKEwI4Z8RxKPvs-i9WOyWX1R#/





5

VIDEO

A brief New Zealand video helps to explains sensory modulation to anyone.

https://www.healthnavigator.org.nz/videos/m/mental-wellbeing-videos/sensory-modulation/

WEBSITE

The Social Care Institute for Excellence (SCIE) in the UK has extensive information and videos about sensory loss and dementia.

https://www.scie.org.uk/dementia/living-with-dementia/sensory-loss/

4



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Feedback on SENSES & DEMENTIA

	STRONGLY DISAGREE	DISAGREE	NEUTRAL	AGREE	STRONGLY DISAGREE
I understand more about sensory experiences	○	○	○	○	○
I feel more motivated to use sensory modulation	○	○	○	○	○
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 Senses Module

Date _____

Signed _____

Organisation _____

SENSES

References

[1] Cunningham, N., Cowie, J., Watchman, K., & Methven, K. (2020). Understanding the training and education needs of homecare workers supporting people with dementia and cancer: A systematic review of reviews. *Dementia, 19*(8), 2780-2803.

[2] Surr, C. A., Gates, C., Irving, D., Oyebode, J., Smith, S. J., Parveen, S., ... & Dennison, A. (2017). Effective dementia education and training for the health and social care workforce: a systematic review of the literature. *Review of Educational Research, 87*(5), 966-1002.

[3] Kuske, B., Hanns, S., Luck, T., Angermeyer, M.C., Behrens, J., & Riedel-Heller, S.G. (2007). Nursing home staff training in dementia care: a systematic review of evaluated programs. *International Psychogeriatrics, 19*(5), 818-841.

[4] Mason, J., & Adeshina, A. (2011). The role of psychiatrists in developing the skills of dementia care workers. *Advances in Psychiatric Treatment, 17*, 372-380.

[5] Beer, C., Horner, B., Almeida, O.P., Scherer, S., Lautensclager, N.T., Bretland, N. et al., (2009). Current experiences and educational preferences of general practitioners and staff caring for people with dementia living in residential facilities. *BMC Geriatrics, 9*(36).

[6] Department of Health and Ageing (2006). *Stocktake of continence and dementia workforce curricula, education and training project*. Canberra, AU: Department of Health and Ageing.

[7] Loveday, B. (2013). *Leadership for person-centered dementia care*. Jessica Kingsley Publishers.

[8] Sutton, D., & Nicholson, E. (2011). *Sensory modulation in acute mental health wards: A qualitative study of staff and service user perspectives*. Auckland, New Zealand: Te Pou o Te Whakaaro Nui. https://www.tepou.co.nz/resources/sensory-modulation-in-acute-mental-health-wards-a-qualitative-study-of-staff-and-service-user-perspectives

[9] Te Pou o te Whakaaro Nui (2016). *Sensory modulation: 10 factsheet*. https://www.tepou.co.nz/resources/sensory-modulation-factsheet

[10] Note: The commonly used metaphor is of a petrol tank developed by the following authors Bialer, D., Miller, L. J. (2011). *No longer a secret: Unique and common sense strategies for children with sensory and motor challenges*. Arlington, Texas: Future Horizons.

[11] Jones, L. (2013). *When a rummage box is not enough: Exploring the need for assessment of sensory preferences in people living with dementia*. Aamana Living.

[12] Centre for Psychiatric Nursing, (2020). *Sensory modulation in mental health settings*. University of Melbourne. https://rise.articulate.com/share/mn_W7PvScKEwI4Z8RxKPvs-i9WOyWX1R#/lessons/kAxW3YTh81AfHUhVFaqOBP2tIvlMf48V

[13] Social Care Institute for Excellence (SCIE). (2020). Dementia-friendly environments: Noise levels. https://www.scie.org.uk/dementia/living-with-dementia/sensory-loss/

[14] Houston, A. (n.d.) *Dementia and sensory challenges*. Deal with Dementia.

[15] Houston A., & Christie, J. (2018). *Talking sense: Living with sensory changes and dementia*. Hammond Care.

[16] Social Care Institute for Excellence (SCIE). (2020). *Dementia and sensory loss: An introduction*. https://www.scie.org.uk/dementia/living-with-dementia/sensory-loss/

[17] Champagne, T. (2018). *Sensory modulation in dementia care: Assessment and activities for sensory-enriched care*. London: Jessica Kingsley Publishers.

[18] Snow, T. (2019). *Alzheimer's and vision loss*. Positive Approach to Care

[19] RNIB and Alzheimer Scotland (n.d.). *Dementia and sight loss*.

[20] Social Care Institute for Excellence (SCIE). (2020). *Dementia and sensory loss: Sight loss*. https://www.scie.org.uk/dementia/living-with-dementia/sensory-loss/

[21] Allan, K, McClean. F., & Gibson, L.S., (n.d.). *Dementia and deafness: What you need to know*. Deaf Action.

[22] Te Pou o te Whakaaro Nui (2020). What works for you? Using sensory challenges to help people cope with challenging situations.

Activity sheets

On the following pages you will find the activity sheets to use during the session:

- Worksheets (2 pages): each learner needs one of each worksheet
- Sensory inspiration sheets (5 pages): one copy of each inspiration sheet is needed for the group to use

GETTING TO KNOW MY SENSES

	JUST A LITTLE	LOTS PLEASE	I DON'T LIKE...	REMEMBER MY...
6 BODY	☐	☐		
5 SIGHT	☐	☐		
4 TOUCH	☐	☐		
3 SOUNDS	☐	☐		
2 SMELL	☐	☐		
1 TASTE	☐	☐		

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MY TOOLKIT IDEAS

6 Body

5 SIGHT

4 TOUCH

3 SOUNDS

2 SMELL

1 TASTE

 ALERTING I'm a bit bored	 JUST RIGHT I'm happy and focused	 CALMING I'm a bit overwhelmed or unhappy

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Movement



Pick or make your own

 Be active	 Rocking chair	 Pushing, lifting
 Clap	 Making	 Walking
 Gardening	 Cleaning, folding	 Repetitive movements

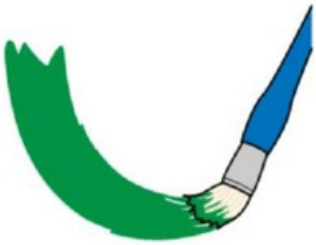
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Adapted from Boundless Community OT, LLC boundlesscommunityot.etsy.com

Sight



Pick or make your own

 Watch sports	 Sunlight	 Magazines of interests
 Puzzle	 Natural scenery	 Colouring in
 Art	 Movies / videos	 Pictures of family

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Adapted from Boundless Community OT, LLC boundlesscommunityot.etsy.com

Touch



Pick or make your own

 Cool facecloth	 Pat a pet	 Hand massage
 Hard or spikey fidget items	 Wash veggies	 Soft blanket
 Big hug	 Squash dough	 Weighted blanket

Adapted from Boundless Community OT, LLC boundlesscommunityot.etsy.com

Sounds



Pick or make your own

 Dance music	 Favourite music	 Soft slow music
 Playing music	 Talking book	 Ocean noises
 Singing	 Conversation	 Noise reducing headphones

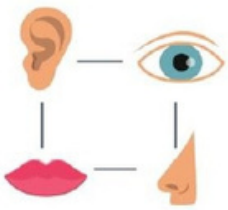
dementia STARs

Adapted from Boundless Community OT, LLC boundlesscommunityot.etsy.com

Taste and smell



Pick or make your own

 Movies or videos	 Favourite drink or food	 Hot chocolate or cup of tea
 Crunchy or chewy food	 Talk about food taste and smell	 Mild sweet food
 Citrus, pine, peppermint	 Sensory garden	 Lavender, rose, vanilla

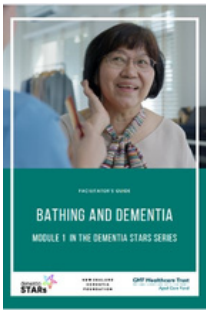
dementia STARs

Adapted from Boundless Community OT, LLC boundlesscommunityot.etsy.com

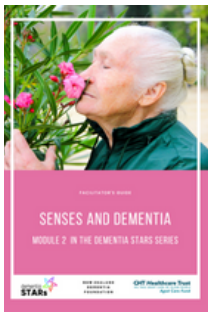
CONTINUE LEARNING WITH THE DEMENTIA STARS SERIES

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.

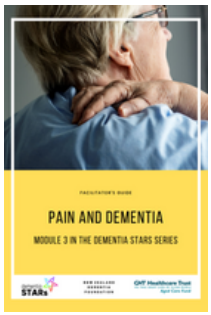
You can find the full series online at nzdementia.org/Dementia_STARs



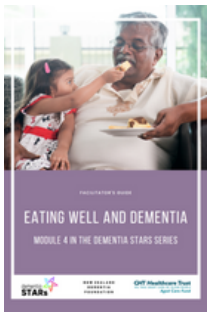
1: Bathing and dementia



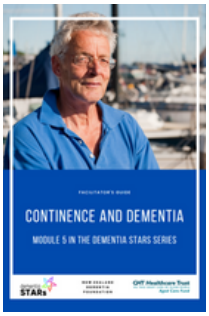
2: Senses and dementia



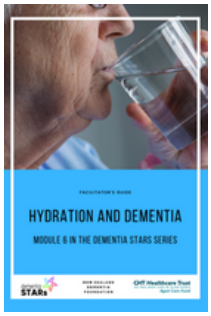
3: Pain and dementia



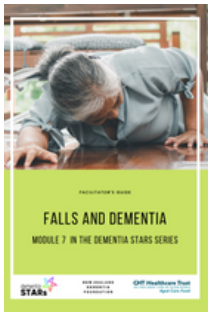
4: Eating well and dementia



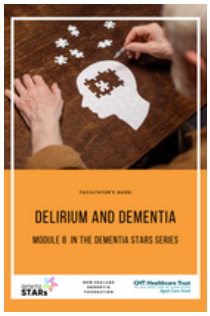
5: Continence and dementia



6: Hydration and dementia



7: Falls and dementia



8: Delirium and dementia

To cite this resource: Gee, S (2022). Bathing and dementia. Module 1 In the Dementia STARs series. New Zealand Dementia Foundation.