

Loss of motivation in dementia: **A guide for aged care workers**

TOOLKIT

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THE UNIVERSITY OF
SYDNEY

**Dementia Support
Australia**

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Loss of motivation is common in dementia. When someone is not motivated, they can seem disinterested in everyday activities. A lack of engagement is caused by biological changes in the brain, and is not under the person's control.

USING THIS TOOLKIT

Researchers at the University of Sydney in partnership with Dementia Support Australia developed this toolkit to help aged care workers to recognise changes in motivation that can occur in dementia. On the following pages, you will find a **Quick Guide** with simple strategies to help improve engagement in the aged care setting along with further information.

The toolkit will help you to:

- Recognise loss of motivation in dementia
- Understand the origin of these symptoms
- Use simple strategies to improve engagement based on your knowledge of the person
- Support the person living with dementia to stay engaged using an individualised approach.

We recommend printing this Quick Guide as a reference tool to use at work.

We also provide further information and resources about loss of motivation in dementia.

Quick Guide for Aged Care Workers



1.

KICKSTART AN ACTIVITY

Loss of motivation can reflect a problem with initiating or starting activities. **You can help to kickstart an activity using simple prompts:**

“Let’s finish this puzzle together.”

“I found this magazine and thought you might like it.”

“Let’s have a look outside at the garden.”

Or you can use visual prompts: Sit next to the person, start to colour in, then offer them the pen:

“you can have a go too if you like?”

2.

STIMULATE CONVERSATIONS

Well-chosen objects (e.g., games, books, scents, music) can help the person to reconnect with their past. Bring the object to the person and explore it together. Explain what it is and provide some context about its purpose or meaning, based on their personal history:

“I found this ball and remembered that you used to play in a team.”

“I heard this music and remembered how musical you are. Did you play an instrument?”

“I saw these flowers and thought of you. Didn’t you grow up in the country?”

3.

CREATE A SENSE OF PURPOSE

Support the person to feel useful and fulfilled. Draw on their past achievements and the roles they used to have (e.g., at work, family life, sports). Remind them that they have valuable skills and knowledge. This can be as simple as a request for help, followed by genuine praise:



“I hear you’re good at [.....], could you help me please?”
“I’d really like your help – you’re good at arranging things”
“While you’re here, could you help me with this?”

“That was a huge help to me. Thank you so much”
“I really like how you did [.....] – I never knew how to do that”
“I knew you were the best person to ask for help”

4.

TAILOR THE ACTIVITY

Some people enjoy a formal invitation to join an activity (e.g., “Would you like to join us for music time at 3pm?”). However, others may not respond well to planned activities or schedules. In such cases, activities can be brought to the person’s room and introduced casually. An individualised approach is key.

“This photograph is of [...]. Have you ever been?”

“I heard that you like cars. Do you want to have a look at this magazine together”

“I heard this music and I thought of you. Let’s listen to something together.”

5.

GET THE TIMING RIGHT

Try to time activities based on when the person has more energy and is more likely to be receptive to taking part.

For example, for people who prefer to come out of their rooms for meals, consider scheduling activities to start after the meal. This will ensure the person is already in attendance and may be more open to taking part.

“Now that you’re here, why don’t you join me in the garden.”

“Let’s go into the common room and listen to the music.”

“While I have you here, would you like to....?”

6.

STAYING POSITIVE

Our own demeanour and attitude can strongly influence the engagement and mood of others. Enthusiasm is contagious and a relaxed, positive attitude can go a long way in helping others to feel uplifted.



By fostering a sense of purpose and engagement in residents, you can decrease anxiety and improve rapport between staff and residents, making the setting more pleasant for everyone.

Understanding changes in motivation

Here we provide some additional information that might help you to recognise and understand changes in motivation in dementia.

This information can be used in parallel with the tips presented in the **Quick Guide**.

What can cause a loss of motivation?

- This is often caused by biological changes in the brain - it is not under the person's control.
- Loss of motivation can present in different ways depending on the personality of the person, their social background, and their interests.
- Symptoms may vary depending on the context or level of stimulation in the care environment.
- Loss of motivation can co-occur with depression. This should always be explored further to determine underlying or treatable factors.

Common signs of loss of motivation in dementia

- Loss of interest in former hobbies and activities
- Lack of engagement in social situations
- An inability to look forward to events
- Loss of pleasure from enjoyable activities
- Loss of intimacy and warmth towards others
- Decreased ability to start new activities
- Unwillingness to try new things
- Reduced effort/satisfaction in completing tasks
- Overall lack of energy and enthusiasm.

Effects on the person with dementia

Reduced motivation can have negative effects on the person living with dementia. They may seem unwilling to engage in new activities or particularly set in their ways. They may show a restricted set of interests and seem focused on just one or two activities (e.g., watching television, doing word searches).

Even simple activities can become challenging. A loss of drive can prevent the person from initiating or completing basic acts of daily living (e.g., getting dressed, attending to personal hygiene) and they may decline assistance from staff or seem unwilling to engage in social activities (e.g., group time).

Over time, the person living with dementia may become increasingly focused on their immediate surroundings. They may develop a set of narrow interests or almost compulsive behaviours. The effort required to deviate from an established routine may be too much and the person may be unable to think of ways to pass the time. They may develop rigid behaviours or strong routines. Deviating from an established routine may cause agitation or anxiety.



Effects on the care team

Changes in motivation can be difficult to manage, particularly if the person living with dementia seems disinterested in activities that they once found enjoyable. Engaging someone to participate in activities can feel demoralising when the person declines or shows an apparent lack of interest. It is normal to feel frustrated, but we need to remember that these behaviours are not deliberate or intended to be hurtful.

Care staff might feel a loss of rapport with the person with dementia and may feel that their energy might be better spent elsewhere. As a result, the person with dementia may become increasingly isolated or disengaged from their fellow residents and care staff.

By supporting the person living with dementia to remain engaged we can help to:

Improve rapport between the staff and person with dementia. Increased social participation can also improve **positive interactions** with other residents.

Foster independence by enabling the person to maintain some autonomy in basic daily activities (e.g., feeding, getting dressed, personal hygiene).

Understanding the individual's unique needs can reduce agitation and anxiety, and ultimately promote **wellbeing for residents and their care partners**.



Using the Quick Guide

Further information

Here we provide further information to accompany the Quick Guide to help you to incorporate the strategies into your practice. These strategies are designed to support the person living with dementia to overcome barriers associated with a loss of motivation and to engage in positive and enjoyable interactions.

It is important to note that not all strategies will work for all people, and it may take trial and error to find what works best for the individual in your care. Every person living with dementia is different and will experience different challenges at different points in their dementia journey as well as variability over the course of the day.

The toolkit draws on the below scientific research:

- Shaw et al. (2021). **Uncovering the prevalence and nature of anhedonia in frontotemporal dementia.** *Brain*, 144: 1551-64.
- Strikwerda-Brown et al. (2019). **All is not lost - Rethinking the nature of memory and the self in dementia.** *Ageing Research Reviews*, 54: 100932.
- O'Callaghan et al. (2019). **Hippocampal atrophy and intrinsic brain network dysfunction relate to alterations in mind wandering in neurodegeneration.** *Proceedings of the National Academy of Sciences*, 116(8): 3316-21.

1.

REFRAME THE BEHAVIOUR

Loss of motivation is a complex clinical feature. While a loss of interest can be difficult to manage, sometimes it can help to view the symptoms in a different way. This can result in practical solutions with immediate benefit:



“She refuses to join in group activities”



“Let’s remind her how much she usually enjoys this”



“All he does is sit in his room and watch TV”

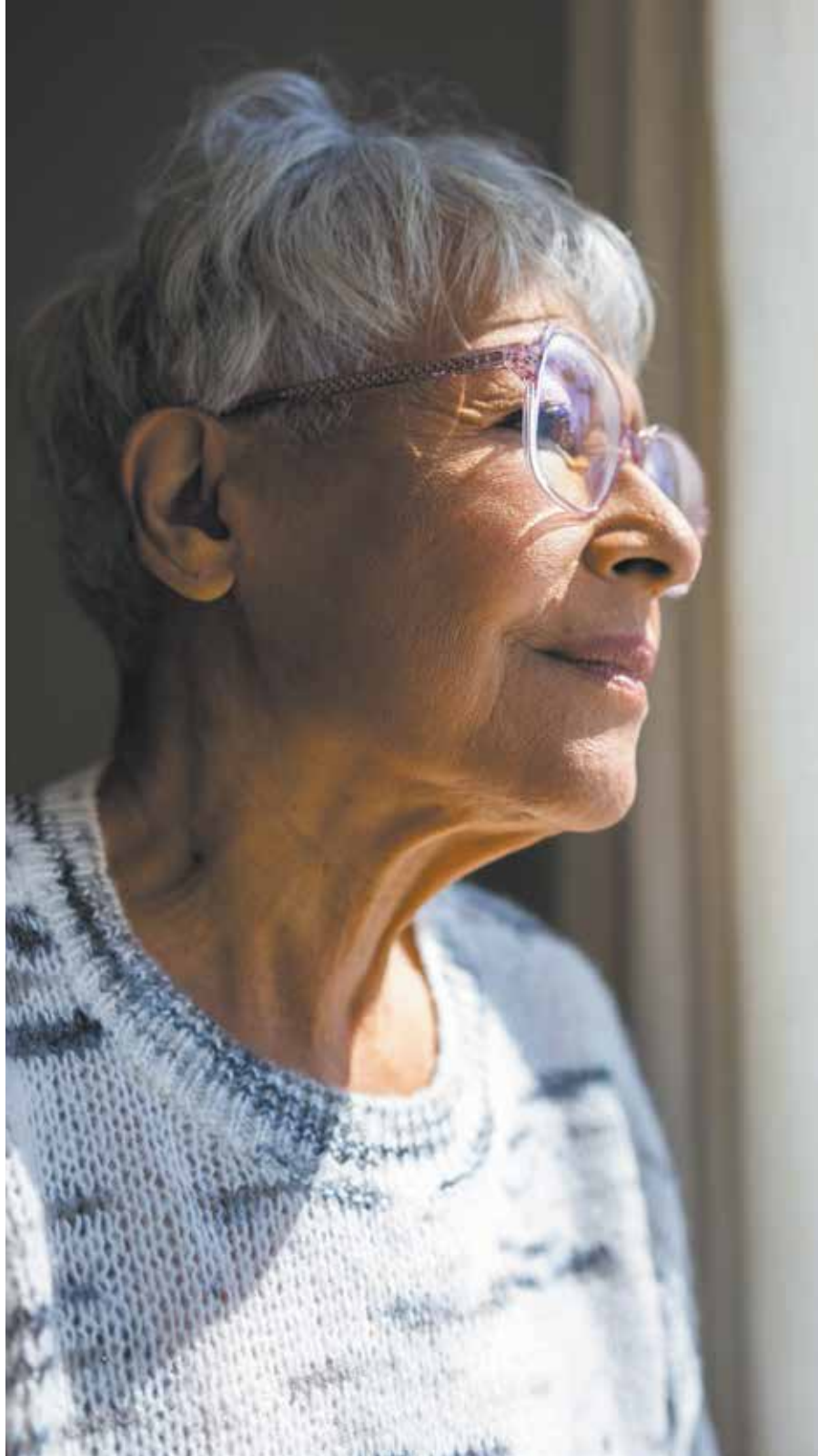


“Let’s suggest some activities and help him get started”

2.

STIMULATE MEANINGFUL CONVERSATIONS

Changes in memory may lead the person with dementia to rely on memories from childhood or early adulthood. In this case, activities, objects, and music from these time periods may evoke a strong sense of nostalgia and can motivate and energise the person. Some trial and error may be needed to find the appropriate triggers for action. Ask friends, former colleagues, family members for ideas, and build new activities around these suggestions. Try to keep the person’s life story and social background in mind.



CASE STUDY:

A former midwife living with Alzheimer's disease found great pleasure in assisting with simple tasks in her residential care home.

Staff members recognised her strong work ethic and her need to feel useful and busy.

By engaging her in various tasks during the day (e.g., rolling bandages, assisting with morning tea), staff members noted a reduction in agitation, improved sleep quality, and fewer requests to go home.

3.

CREATE A SENSE OF PURPOSE

We can encourage people living with dementia to engage meaningfully by creating a sense of purpose. This is often related to the person's past achievements, background, or roles (e.g., career, hobbies, sport, cooking, caring, children). Find out what the person used to enjoy doing and use simple phrases that appeal to their sense of self (e.g., "I really need your help with this today" or "Could you please help me with this?").

Encourage participation in tasks that contribute to the home environment and are familiar to the person (e.g., setting the table, sorting items, folding towels, rolling bandages, collecting the post). Comments such as, "I hear you're really good at..." can boost confidence and put the person with dementia in a positive space to engage. Following each activity, remember to give genuine praise for a job well done (see point 5).



CASE STUDY:

A former tradesman living with dementia was often withdrawn and disengaged, and would become visibly distressed in the afternoons.

Care staff structured the environment to create a clear path from where he usually sat in the garden, to a paintbrush and pot of paint near the main fence. The gentleman recognised these items from his past and immediately set about painting the fence.

Staff noticed an increase in his mood and engagement and a clear reduction in agitation and outbursts.



4.

ENCOURAGE AND PRAISE

Positive feedback is important to acknowledge someone's effort and to build their sense of confidence and wellbeing. This can be as simple as providing a personalised thank you for helping with a task, or genuine praise for a job well done.

Providing positive feedback can further help to motivate the person with dementia to engage in similar activities in the future.

5.

OPTIMISE THE ENVIRONMENT

A cluttered environment is distracting and can obscure items that the person living with dementia enjoys using, or relies on to feel psychologically safe.

Ensure that meaningful items are visible and easily accessible. For people who enjoy structured activities, schedules, checklists and clocks/calendars can help the person to feel more in control of their daily life.



6.

HELP TO VISUALISE

Our research shows that many people living with dementia find it difficult to envisage future events or to imagine pleasurable experiences. This can contribute to a loss of motivation. However, we can overcome this difficulty by describing the activity to the person and helping them to imagine it. Try to set the scene by describing what will happen, who will be there, and how much the person with dementia enjoyed the last time they engaged in this activity.

For example: Instead of asking “would you like to go outside?”, try to set the scene in more detail for the person.

Describe the visual aspects of the garden, the warmth of the sun on your skin, the colours of the flowers, the sound of the birds, the smell of freshly cut grass, and how nice it will feel to be outdoors...

Using these techniques, we can overcome the difficulties that people with dementia sometimes experience in imagining or anticipating pleasure. By bringing the experience to the person, we can help them to reconnect with the pleasure of the activity. This can help to motivate them to re-engage in activities that they previously found enjoyable and hopefully inspire them to try new things.

Contact Us

This toolkit was co-developed and designed by Professor Muireann Irish at the FRONTIER research group, University of Sydney, in collaboration with Dementia Support Australia.

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FRONTIER website: <https://frontierftd.org>

Dementia Support Australia

Phone: 1800 699 799

www.dementia.com.au/who-we-help/dementia-healthcare-professionals

Sources of support:

National Dementia Helpline: 1800 100 500

Carer Gateway: 1800 422 737

Lifeline (24 hours): 13 11 14



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