

Module Overview

Leader's Guide

Aims

This module is for all congregations and faith communities who are seeking to welcome, include and nurture people who have dementia and those who share their journey. The module includes information, advice and resources to explore in more depth.

This module builds on other DIY modules in Congregational Leadership, including:

- E5 The Ministry of Elder: Pastoral Visitor
- E11 Pastoral care with older people
- E12 Dementia and pastoral care

Participant outcomes

After completing this module, participants will be able to discuss the issues and opportunities, implement some effective strategies for a congregation to become more 'dementia friendly', and source further information.

Leader's role

This module involves participants in a discussion on the local congregation's support and nurture of people who have dementia and those who share their journey. It aims to encourage a process for open and helpful conversation and reflection on the nature of dementia, the related challenges and tasks, and to help the group begin to develop guidelines and action steps for becoming more 'dementia friendly'.

Note: learning is a life-long activity, best practised by individuals within their regular context and relationships, hosted by capable leaders, and formed within concrete experience.

- If space permits, arrange chairs in a circle so all participants can see each other.
- Ensure all participants know each other's names.
- Encourage respect and active listening skills among participants in discussion times.
- Note that in sharing experiences participants should still maintain confidentiality of pastoral interactions.

Encourage participants to draw on their own experiences and that of others in the group in a process of self-reflection and collaborative exploration for this aspect of pastoral care in the congregation.

The process is critical for the participants' learning. Some participants may experience uncertainty, fear or grief for themselves or for others. The leader can provide a relaxed, friendly and open environment. Remember to offer a brief break, where appropriate.

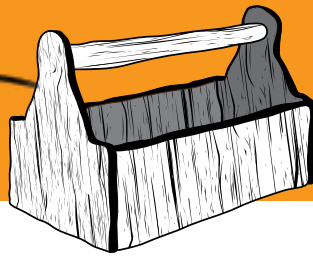
Resources required

For plenary activities the leader may choose to use a whiteboard and pens to record contributions and reflections (or newsprint sheets and felt pens, or computer and data projector, or overhead projector and transparencies).

The participants will each need:

- Copies of the Handouts – these may be distributed beforehand to enable people to read the content at their own pace before the session.
- A whiteboard or butchers paper and markers

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- Individual pens and highlighters
- A lined exercise book to use as a journal

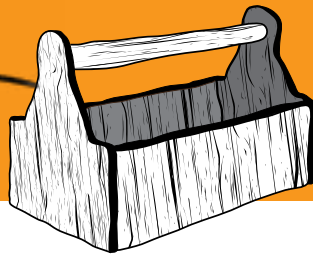
Session outline (times are approximate)

Total 130 mins

1. Introduction	10 mins
2. Small group activity: Handout E13.H1	30 mins
3. Small group activity: Handout E13.H2	20 mins
4. Small group activity: Handout E13.H3	20 mins
5. Plenary conversation	10 mins
6. Small group activity: Handout E13.H4	30 mins
7. Individual activity: Handout E13.H5	5 mins
8. Close	5 mins

This DIY module was collaboratively developed by Uniting Church people in the Presbytery of Yarra Yarra including Joan Waters and Lionell Parrott, Uniting AgeWell, and the Centre for Theology and Ministry (CTM).





1. Introduction

Tell the group: *Dementia is an illness of the brain that is increasingly common amongst people after the age of 65. Although it is not a normal part of ageing for the majority of people, the older people get the greater the likelihood of dementia being part of their life in some way.*

Dementia affects thoughts, behaviours and the ability to perform everyday tasks. The brain is impaired sufficiently to affect people's social and spiritual life but God continues to love and cherish each person. The Church through each local congregation can do much to support and enrich people with dementia and their carers, to become more 'dementia friendly'.

Ask the group: *With just a simple indication of your hand, how many of us know people with some level of dementia in our congregation? (pause to acknowledge this)*

How many are confident that this congregation is doing all it can to support and enhance the participation of people with dementia and their carers? (pause to acknowledge this)

Tell the group: *This module aims to raise awareness and understanding of ways that a congregation can become more 'dementia friendly'. Although most older people will never get dementia themselves, the Church can actually be a place of safety, care and affirmation for those who do.*

Another DIY module in this series focusses on dementia and pastoral care at a more personal level. This DIY module explores the ways that the congregation can be more friendly to everyone with dementia and those who care for them.

Open with a brief prayer:

(10 mins)

2. Small group activity

Invite participants to form small groups and with one or two others to read through Handout E13.H1: *Awareness and reflection*, then to discuss the questions and to note any concerns or new ideas for contribution to the larger group.

After 20 minutes invite the small groups into a single larger group and ask participants to share any concerns or new ideas they have noted.

(30 mins)

3. Small group activity

Invite participants to form small groups of 3-4 and to work through Handout E13.H2: *Becoming 'dementia friendly' – part 1.*

(20 mins)

4. Small group activity

Invite participants to form different small groups of 3-4 and to work through Handout E13.H3: *Becoming 'dementia friendly' – part 2*

(20 mins)

5. Plenary conversation

Invite some participants to share responses to the questions from Handouts E13.H2 and E13.H3.

(10 mins)

6. Small group activity

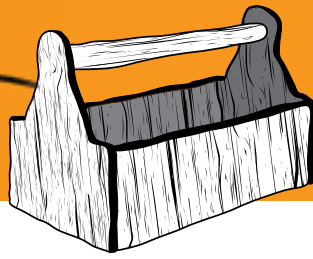
Tell the group: *Becoming more dementia friendly is a goal for the whole congregation, not just a few interested or committed individuals. The checklist in Handout E13.H4 includes a wide range of ways in which a congregation can enhance the experience of those people with dementia and their carers, and add your own for further ideas.*

Invite participants to spend 15 minutes in pairs working through Handout E13.H4: *Dementia friendly congregation checklist*. Ask participants to note actions or responses that could be applied in the local congregation. The focus is less on whether 'Yes' or 'No' is the right answer, and more on what could be done to (further) improve in each of these areas.

After 15 minutes, ask one participant to act as recorder for the whole group, and invite responses to each item on the checklist. In addition to suggested actions, seek ideas about who in particular might be well-placed or well-suited to help that action come to fruition.

(30 mins)

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7. Individual activity

Invite participants to read through Handout E13.H5: *Resources for further understanding & action*, and to note at least a couple of resources they could explore further.

(5 mins)

8. Close

Thank people for participating in the session.

Close the time with prayer, perhaps the following:

Loving God, in whose image each person is created:

give us courage and strength

to face the challenges of dementia together;

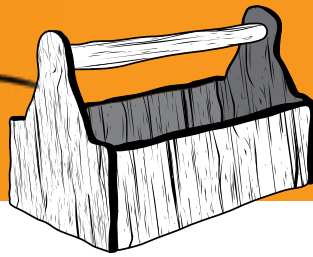
and give us love and understanding

to share with those whose memories fail,

but whose faith remains in you. Amen.

(5 mins)

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Handout #1 Awareness and reflection

The task

With one or two others, read through the information and discuss the questions below. Note any concerns or new ideas for later contribution to the larger group.

Dementia

Dementia is a life limiting illness associated with a collection of symptoms that are caused by disorders affecting the brain. It affects thoughts, behaviours and the ability to perform everyday tasks. The brain is impaired sufficiently, and progressively, to affect people's social and working life. Dementia can affect anyone and is more common after the age of 65, but it is not a normal part of ageing.

There are over 100 diseases that may cause dementia. The most common forms are Alzheimer's disease, vascular dementia and dementia with Lewy bodies. Each person's experience of dementia will be unique, but we commonly notice memory loss, confusion, withdrawal and diminished ability to carry out normal tasks of daily living. Not everyone with these symptoms will have dementia; it needs to be confirmed by first consulting with a GP and undergoing tests and further assessments. Becoming a member of Alzheimer's Australia will keep you in touch with the latest resources, courses and research.

Theological Reflection

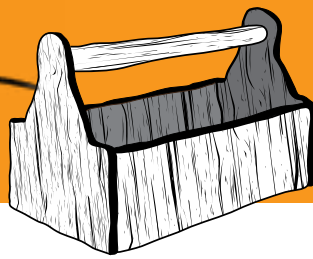
God welcomes, respects, listens to, understands, appreciates and loves us, and expects that we offer the same to people with dementia. Despite their terminal diagnosis, a person with dementia retains their personhood, being made in the image of God. Their ability to experience and express their sense of spirituality is likely to change, but their need for meaning and purpose and connection remains, even if they are unable to recall past encounters with us or with the divine.

Questions for discussion

1. With one or two others, discuss your own awareness of or connection to someone with dementia. Note their continuing needs and the ways these are fulfilled, as well as the evident challenges. Ensure each person has a chance to share. (10 mins)
2. Reflect on the ways that a person with dementia is (still) created in the image of God. We speak of a person with dementia, rather than a demented person or a dementia sufferer. This theological idea moves beyond cognitive capacity (rational thinking skills) to a deeper sense of personhood, identity, and human worth. This change in perspective is itself often a theological challenge for any Christian whose abilities or capacities are changing. (10 mins)



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Handout #2 Becoming 'dementia friendly'

The task

Worship and pastoral care are two central aspects in the life of a local congregation or community of faith that can become more 'dementia friendly'. There are many more aspects which are explored in handout E13.H3.

In a small group with 3-4 others (or as a whole group), read one paragraph each around the group, noting any questions of clarification as you go. Then respond to the discussion questions at the end.

Worship

As memory and ability to cope with new situations diminishes, a person with dementia will appreciate a predictable order of worship with detailed data projection if used. Encourage their participation and roster them for familiar tasks that are still achievable, but keep this under constant review. Small tasks such as folding the bulletin or taking up the offering might provide a sense of accomplishment and contribution. Having a weekly church notice sheet can be a reminder of location and context, but they don't need too much paper or information given all at once. Large print might help as would a summary of the sermon to read. Using all the senses in worship is likely to assist participation. With a supportive companion they can often cope with spontaneity.

It helps to adapt the liturgy to suit a person with dementia if you are able to put yourself in the place of someone with no short term memory. For instance, halfway through passing the peace, they may forget where their seat was or start heading home. If using data projection it is best if every verse, refrain, chorus and prayer response are included in order, as shuffling back up to the top of a screen is likely to confuse. Familiar hymns and rituals such as Holy Communion are usually appreciated long after other abilities diminish. With a trusted familiar companion worship can remain a significant part of their life.

Creating a special mid-week service for those unable to attend on Sundays allows the service to be specifically tailored to the needs of those with dementia. While this service might be shorter in length than the usual Sunday

worship, it needs to follow the same predictable pattern and include all the elements including refreshments.

Continuing to include a person with dementia in our conversations after worship in the hall or fellowship space reinforces their inclusion in the "church family" and their sense of belonging. If you approach them openly, stating your name and use statements based in the present moment, it will help them to feel included and appreciated. Conversation about what can be immediately seen, heard or tasted will be more helpful than theological discussions about the sermon they may have already forgotten or the list of forthcoming events. As they leave, the person will remember feeling your warmth and the community's love long after they have forgotten the details.

Pastoral Care

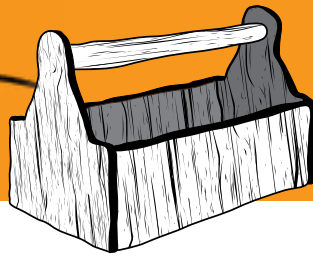
Visiting and pastorally supporting someone with dementia is just as significant as for any other person, even if the conversation's details will be soon forgotten. As dementia is a terminal illness, these times of connection and love are especially valuable so regular pastoral care is appreciated even if the person moves to an aged care community. As well as their minister and elder, the regular visits from a "church friend" expresses the congregation's ongoing pastoral care, as do news from the congregation, audio from Sunday's worship, phone calls, emails, texts and cards.

Using active listening skills, you can follow the person's lead, affirm their comments even if they are confusing to you, and respond to the underlying emotions. Conversations are often facilitated if something is happening around you, such as sitting beside a busy street or going on a walk (even with the assistance of a wheelchair), as each person can comment on what is being seen instantaneously and enjoy the interaction. Companionable silences are also helpful.

Where a person with dementia gets life details confused, it is usually best just to go along with this as this validates their reality. A person with dementia will often enjoy recounting events from long past and if familiar you



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can initiate this reminiscence. Their prized photos and mementos may assist your pastoral conversation. Familiar hymns, Bible readings and prayers may continue to resonate with their spirituality. As part of a pastoral visit, they will probably appreciate a simple prayer and join in reciting the Lord's Prayer with you.

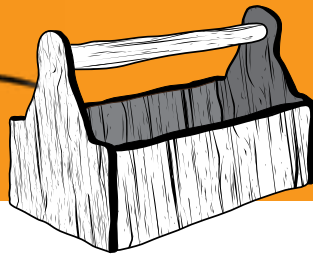
The carer of someone with dementia will also have significant pastoral needs such as exhaustion, guilt, martyrdom, violence, poor advice, judgement, family conflict and non-recognition. Focussing the congregation's pastoral resources on the carer to offer understanding, respite or providing practical assistance will support both the carer and the person with dementia.

Questions for discussion

1. What are the most obvious or easiest ways this congregation can become more 'dementia friendly' in worship and pastoral care? Who might help those changes to occur?

2. What are the challenges or hurdles you can foresee? How might those challenges be addressed, and whose assistance will make the difference?

3. What change are you most passionate to personally commit to? What are the next steps?



Handout #3 Broadening 'dementia friendly'

The task

There are many more aspects in the life of a local congregation or community of faith that can become more 'dementia friendly', in addition to worship and pastoral care as explored in handout E13.H2.

In a small group with 3-4 others (or as a whole group), read one paragraph each around the group, noting any questions of clarification as you go. Then respond to the discussion questions at the end.

Routines

People with dementia are usually assisted if familiar routines are maintained or adapted so that they can feel safe and still experience a level of independence. Quick changes, loud noises, or tasks that require several consecutive actions can each challenge and confuse. A person with dementia may enjoy new challenges if they have a companion who can explain each next step.

Welcoming

It is best to approach a person with dementia front on, so they have time to process who you are and the circumstances of your meeting. Wearing a name tag and saying their name and your name or connection will cue their memory and limit any likely confusion. For example, "Hello [name], welcome to worship at St John's this morning. I'm Chris Rogers. I'm pleased to see you. This is the order of service."

Details often escape a person with dementia, but they may well be highly attuned to the tone, emotion and body language of your greeting, since emotions are heightened as cognitive function fails.

Physical Environment

As perception of colour, space and proportions can change, it helps people with dementia to have even, bright colours where seats, floors, doors and crockery are easily distinguished. Someone may be needed to guide them to formerly familiar places including the rest rooms. The usual aids for older people such as well-lit rooms, ramps,

handrails, chairs with tables for conversation and cups, and easy access to places for conversation and gardens all assist mobility and continued engagement.

Entering an Aged Care Community

Having their affairs in order (a will, powers of attorney, guardianship and financial matters) and knowing their preferred aged care community well ahead of time will help ensure that a person's care can continue according to their best interests, and make the way clearer and simpler for their carers.

Moving to an aged care community may be stressful for both the person with dementia and their carers, so the congregation's ongoing support and pastoral care is vital. The need for continual connection with their "church family" is undiminished. If the aged care community has a chaplain and includes worship services within their lifestyle program, you may ask to attend with them to assist them to participate.

Contributing to outreach and mission

Outreach, service and doing something useful are often still important to a person with dementia. As with anyone who ages, we just need to keep adapting what is reasonably achievable with current abilities or support them as they carry them out.

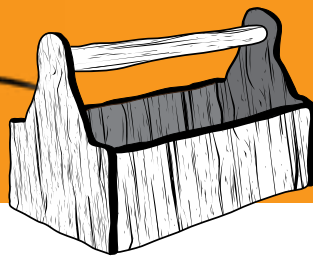
Someone with dementia may enjoy washing the dishes even with the commercial dishwasher bright and shining in the kitchen corner. By contributing within their capacity their personhood is affirmed.

Advocacy

There are many ways to advocate for the inclusion and support of people with dementia, including the following:

- i. Find out what other congregations are doing in your presbytery, Synod, Assembly. Share ideas.
- ii. Subscribe to Uniting AgeWell's monthly prayer letter
- iii. Advocate for a specialist Synod Dementia Inclusion officer

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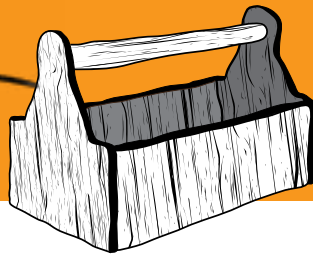
Handout #4 Dementia friendly congregation checklist

1. Work through the following checklist, noting actions that could be taken to make this congregation more 'dementia friendly', and who holds responsibility for these activities.
2. Select one activity or strategy for becoming more dementia friendly and spend a few minutes brainstorming ideas to plan how this can be achieved.

Aspects of a dementia friendly congregation	Yes	No	Partly	Action proposed
Expression of Uniting Church Values				
We publicly proclaim our dementia friendliness				
We have a designated person or group who actively oversees our dementia friendliness				
Our preaching provides a theological context and understanding of dementia				
We annually assess and improve our dementia friendliness				
Our vision includes being welcoming to the disadvantaged and providing a voice for the voiceless				
Awareness				
Our congregation members have good knowledge of dementia				
Dementia education has been offered for our congregation members				
We intentionally include people with dementia in the life of our congregation				
We feel confident that our congregation members will welcome a person with dementia appropriately				
A group of us regularly monitor and update our dementia friendly status				
Physical Environment				
We have assessed our property from a dementia friendly perspective				
Our property is dementia friendly				
Nametags are used by most people				
Pastoral Care				
We promptly identify those needing support				
People with dementia are offered pastoral care by our congregation both at home and when in aged care including holy communion				



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<i>Our congregation has conducted the learning module CTM DIY E12 "Dementia and Pastoral Care."</i>				
<i>Carers of people with dementia are offered pastoral care by our congregation</i>				
<i>We have identified pastoral carers with dementia specific skills</i>				
<i>We can refer people to external dementia resources and networks</i>				
Worship Resources				
<i>Our orders of worship and liturgy present material in order, linearly with prompts to explain what is expected</i>				
<i>People with dementia are rostered to assist with worship within their capacity</i>				
<i>Our congregation tolerates unusual behaviour during worship</i>				
<i>Our worship often uses all the senses, sight, hearing, touch, taste and smell</i>				
Mission Opportunities				
<i>Our congregation encourages people with dementia to participate in outreach and service opportunities</i>				
<i>Our congregation adapts tasks to enable people with dementia to contribute</i>				
<i>Our congregation offers worship and pastoral care to our local aged care communities, including memory support units</i>				

2. Select one activity or strategy for becoming more dementia friendly and spend a few minutes brainstorming ideas to plan how this can be achieved:

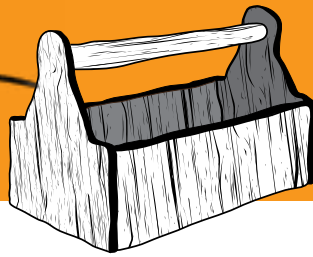
Some potential first steps:

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Other people or groups to collaborate with, recruit or advocate to:

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-
-
-
-





Handout #5 Further Resources

There are a wide range of options for increased understanding and active response to the challenges and opportunities of becoming a dementia friendly congregation.

Read through the following list, and tick or circle two options you are interested to explore further. Think about what your next step might be, and when you will take that action. Committing to action with a trusted friend or as a small group will increase your likelihood of following through. (5 mins)

Note: the underlined items below are embedded web links in the electronic version of this handout.

Read a book:

- More than body, brain and breath: a guide to the spiritual dimension of care for people with Alzheimer's disease and related dementia, Eileen Shamy (published by Jessica Kingsley Publishers, 2013).
- Dementia: Living in the memories of God, John Swinton (Eerdmans, 2012)
- Dementia: Pathways to Hope: Spiritual Insights and Practical Advice, Louise Morse (Monarch Books, 2016)

Explore further Uniting Church resources:

- DIY Module E12: "Dementia and Pastoral Care", Uniting Church Centre for Theology and Ministry (<http://ctm.uca.edu.au/lay-ministries/diy/>)
- Uniting AgeWell Dementia-friendly social support checklist (<https://unitingagewell.org/>)

Explore further online resources:

- Alzheimer's Australia (<https://vic.fightdementia.org.au/>)
- Livability UK, a national Christian disability and community engagement charity.
- Growing Dementia-Friendly Churches, Methodist Homes (MHA) and Christians on Ageing (CCOA), UK.
- The Dementia-Friendly Church, United Methodist Church, USA.
- Dementia Friendly Faith Community, ACT on Alzheimer's, Minnesota USA.
- How to Become a Dementia-Friendly Congregation, Minnesota Council of Churches, USA.

Watch an online video:

- Alzheimer's Society Youtube channel.
- Graceful Journey, Minnesota Council of Churches, Twin Cities Medical Society and Bush Foundation.
- Interview with John Swinton on Dementia and spiritual care.