

Module Overview

Leader's Guide

Aims

This module will explore some of the basics of dementia in general and pastoral care of older people in relation to dementia. Participants will work together to develop guidelines for effective pastoral contact with people experiencing dementia, and those caring for them.

Elders in particular will benefit from this module, but also others in the Congregation who are recognised as pastoral visitors. A Church Council has oversight of pastoral care for all members of a congregation, and responsibility for relevant policies and guidelines.

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

- E3 Communication Issues for Elders
- E4 Grief Care
- E5 The Ministry of Elder: Pastoral Visitor
- E6 The Ministry of Elder: Crisis care
- E11 Pastoral care with older people

Participant outcomes

After completing this module, participants will be able to discuss the issues and concerns for pastoral care related to dementia, some effective strategies for pastoral care and pastoral visiting, and sources of further information.

Leader's role

This module involves participants in a discussion on dementia and pastoral care, particularly with older people. It aims to encourage a process for open and helpful conversation and reflection on the nature of dementia, what supports those who experience dementia and their family and friends, and to help the group to develop guidelines for visiting.

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

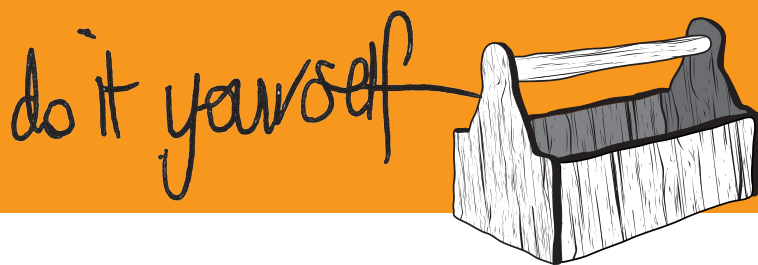
- If space permits, arrange chairs in a circle so all participants can see each other.
- Ensure all participants know each other's names.
- Pause for quiet reflection before beginning
- Encourage respect and active listening skills among participants in discussion time.

Encourage participants to draw on their own experiences and that of others in the group in a process of self-reflection and training for this ministry of pastoral care. Note that in sharing experiences participants should still maintain confidentiality of pastoral interactions.

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.

This DIY module was developed as a collaborative project between **Uniting AgeWell** and the **Centre for Theology and Ministry**





Resources required

This session includes a role play of a pastoral conversation using a script provided in Handout E12.H4. Ask two participants who are willing to take the roles to prepare a little beforehand. Dramatic acting skills are not required, but it will be helpful if the participant taking the role of Noelene has experience with dementia in order to portray that role with some authenticity as well as sensitively.

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

The participants will each need:

- Copies of the Handouts (you may consider distributing Handouts ahead of the session)
- Individual pens and highlighters
- A lined exercise book to use as a journal

Session outline

(times are approximate)

	Total 120mins
1. Introduction	5 min
2. Whole group activity: Handout E12.H1	10 min
3. Individual and small group activity: Handout E12.H2	10 min
4. Small group and plenary activity: Handout E12.H3	25 min
5. Whole group activity: Handout E12.H4	35 min
6. Small group activity: Handout E12.H5	25 min
7. Individual activity: Handout E12.H6	5 min
8. Close	5 min

Session flexibility

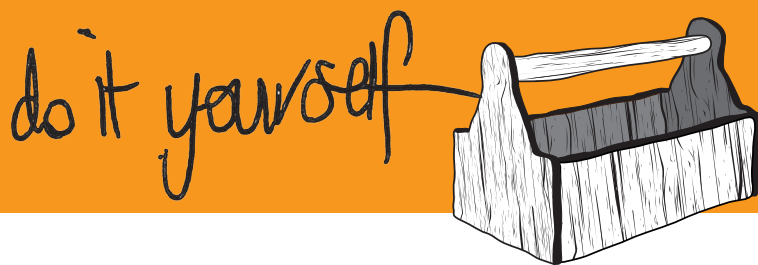
The leader may choose to modify the module in any of several ways, including:

- changing the session timing to suit the group, or the Leader's words ("Tell the group") to your own words,
- distributing the handouts to participants before the session so they have more time to read the background information,
- running the module over two sessions to provide more time for discussion and reflection.

The suggested time for handout activities provides time for participants to begin the task, but to comprehensively complete the task additional time may be required outside the session.

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1. Introduction

Tell the group: *Dementia is an increasing health challenge in Australia and around the world. The pastoral care of people experiencing dementia, and their family and friends, is a significant ministry challenge and opportunity for the Church.*

Ask the group: *With just a simple indication of your hand, how many of us have some experience of dementia amongst our family or friends? (pause to acknowledge this)*

How many are currently caring for someone with dementia? (pause to acknowledge this)

Two passages that relate to dementia and pastoral care are Matthew 10 and Psalm 31.

Invite one or two participants to read Matthew 10:40-42 and Psalm 31:19-22.

Open with a brief prayer:

*Pour your grace, O loving God,
upon all suffering with dementia.
It is frustrating
not to find a word;
it is fearful
to lose one's memories.
Bless them with patience,
a loving and supporting family,
and days of hope and accomplishment.
In Christ's name we pray.
Amen.*

(Anderson, 1991)

(5 min)

2. Introducing dementia

Invite members of the group to locate Handout E12.H1, and to take turns to read one paragraph each.

Tell the group: *This module aims to raise awareness and understanding of pastoral care with older people and dementia. A majority of older people will never get dementia, but their networks of family and friends are likely to include some with dementia, and the older they get the greater the likelihood of dementia. (10 min)*

3. Individual and small group activity: Understanding dementia

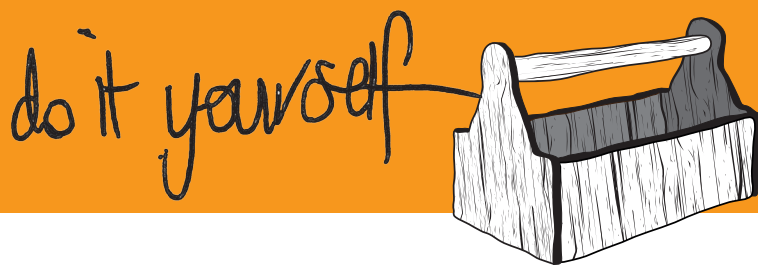
Tell the group: *The first learning activity looks at some of the facts around dementia. Read through Handout E12.H2 individually, and then form groups of three to discuss which particular facts stand out for you, and perhaps why. Ensure that each person has a chance to share for a couple of minutes. (10 min)*

4. Small group and plenary activity: Types of dementia

The intention of this activity is to have small groups of participants learn a little about one of the various types of dementia, consider what might be relevant to a church context, and share something with the whole group, so that overall each type of dementia is mentioned and participants have some basic information about each of the major types they can read later.

Estimate small group sizes to distribute the first six or all eight types of dementia described on Handout E12.H3 amongst small groups of participants: each group may be allocated one, or perhaps two, types of dementia. If there are 8 participants, groups of 2 can explore two types of dementia each. If there are 12 participants, groups of 3 can explore two types each. If there are 16 participants, groups of 2 can explore one type each, or groups of 4 can explore two types each.

Tell the group: *The next activity focusses on some of the different types of dementia, including their common names, their causes, signs and symptoms. The different types of dementia have much in common, which is why they have that common label, and they are often difficult to distinguish without specialist medical diagnosis. Uncertainty about different forms of dementia can lead to confusion or fear, such as how fast it may progress, or the requirements for or duration of care. Pastoral care that takes account of each personal situation is the goal.*



In small groups spend 10 minutes on Handout E12.H3, looking at the particular type(s) of dementia I will allocate to you. After 10 minutes I will invite each group to share two characteristics of their particular type of dementia that might be noted in a church context. (10 min)

Invite small groups to share their reflections in plenary discussion. (10 min)

5. Whole group activity: A pastoral conversation

Before the session, arrange for two willing participants to role play a pastoral conversation using the script provided in Handout E12.H4. Dramatic acting skills are not required, but it will be helpful if the participant taking the role of Noelene has experience with dementia. Ask the two participants to portray their roles with some authenticity as well as being sensitive to other group participants who may have their own experiences with dementia.

Tell the group: *Dementia affects memory and other cognitive abilities, but the person still uses all their senses to engage with the world around them. The next activity briefly focusses on a pastoral conversation with a person with dementia, and their visitor.*

Invite the two to share the role play. Other participants may read along using E12.H4 or simply watch and listen.

Tell the group: *For people with dementia, experiences and feelings are much more immediate, and are influenced by what they can see, hear, taste, touch and smell right now. Pleasure and enjoyment become more focussed on the present moment, rather than the past or the future.*

6. Small group activity: Engaging in the present moment

Tell the group: *Dementia affects memory and other cognitive abilities, but the person still uses all their senses to engage with the world around them. Experiences and feelings are much more immediate, and are influenced by what they can see, hear, taste, touch and smell right now. Pleasure and enjoyment become more focussed on the present moment, rather than the past or the future. The*

next activity briefly focusses on engaging with a person with dementia, and their carer.

Think for a moment about what it would be like without your memory: you would have little sense of time, no past or future, just the present moment. In that moment you can still enjoy experiences and communicate with others about what is going on right now.

In small groups of three people, allocate one person to engage in informal pastoral care, one person to represent dementia, and one person to be their carer.

The pastoral carer is invited to engage in a brief conversation with the other two. Imagine a church-related context, and talk about whatever comes to mind – but be aware that past and future are a bit blurry, and focus on the present moment. Use attentive listening, follow conversation leads offered by this moment and these surroundings, attend to body language and eye contact. Pay attention to stress or anxiety in both the person representing dementia and their carer.

You will have only a few minutes in each role, and then will exchange roles so each person takes a turn in the role of pastorally caring for the others. (3 mins)

After the small groups have formed, encourage the conversations to begin.

After about three minutes, encourage the participants to change roles.

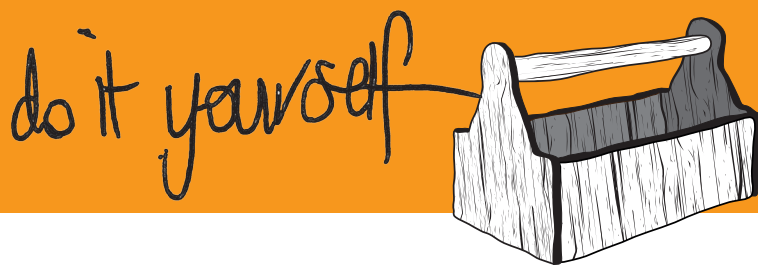
After another three minutes, encourage participants to change roles again. (9 mins)

Once each person has had a turn in each role, encourage the small groups to reflect on what they might learn from the activity.

Ask the groups:

1. *What helped to engage the person with dementia in conversation?*
2. *How can you include and attend to the carer as well?*
3. *What might you do if you noted stress or anxiety in the person or their carer?*

You may need to repeat those questions, or write them up for visibility. Give small groups five minutes to reflect on those questions. (5 mins)



Invite people to move back into a large group to include everyone. Tell the group: *Let's briefly share in the larger group what will be most helpful in our care of people with dementia and their carers.*

Invite responses to the three questions:

1. *What helped to engage the person with dementia in conversation or activity?*
2. *How can you include and attend to the carer as well?*
3. *What might you do if you noted stress or anxiety in the person or their carer?* (10 mins)

Tell the group: *Engaging in the present moment is a challenge when so much of our culture focusses on time, either past or future events, and on the results rather than the process. Being 'mindful' of the present moment is a significant spiritual practice in itself, and an effective way to connect with people with dementia and their carers. Dementia may affect a person's short-term memory, but some of their rich life experience including favourite foods, songs,*

If we note significant stress or anxiety it is important to both respond in that moment, and to refer for appropriate care. We may be able to relieve present stress or anxiety by sharing information, providing company, or making adjustments to what is going on. Appropriate referrals should be directed through the local minister, pastoral care coordinator or the local pastoral leader. Pastoral sensitivity and confidentiality are always important; offer to help but let the person involved choose what will happen next. (3 mins)

7. Optional plenary activity: Comfort in, debrief out

If participants have not completed other DIY modules exploring pastoral care, it may be valuable to include this activity in order to set a basic level of understanding of providing appropriate comfort and support. If time is limited, this activity could be skipped.

Ask all participants to locate Handout E12.H4, and invite several participants to read aloud one paragraph each in turn. (10 min)

Invite participant to form groups of three to briefly share with each other any personal reflections on the concept of 'comfort in, debrief out'. (10 min)

Invite any brief comments or reflections from the whole group on what they have read and heard. (5 min)

8. Small group activity: Planning for pastoral care

Tell the group: *The final activity draws together insights into dementia and strategies for the inclusion of people with dementia in Church life, and briefly explores a variety of ways the Church can intentionally plan to provide pastoral care around dementia.*

Remember the foundations for pastoral care explored in DIY Module E5. Pastoral care expressed has several core attributes, including:

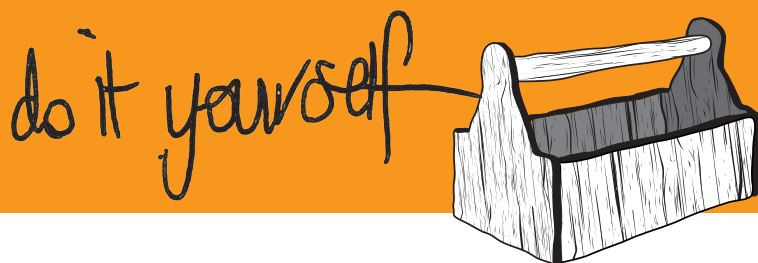
- *being open to those visited – responding to their interests and concerns*
- *mutuality as a companion traveller – rather than directing or instructing*
- *a non-judgemental attitude about their conversation with you*
- *confidentiality about the contents of the conversation or visit*
- *encouragement for their faith and prayer life*
- *exploration of options the person may choose to consider*

In small groups of two to four participants use Handout E12.H5 to identify and plan to meet the needs of various people associated with dementia. Plan to include the three major principles of enablement, dignity and individual choice. Completing this activity comprehensively would take a lot longer than this session allows, but making a start will begin to get our ideas flowing. (10 min)

Allow 10 minutes for small group work on Handout E12.H5, and then invite all participants to form a larger group again.

Ask the group: *Did this planning process help you to identify aspects of pastoral care that could be provided by the Church? What further information would be*





required? How might you obtain such information? Who would take responsibility for comprehensively completing the table in handout E12.H5, and making it all happen? (10 min)

Tell the group: Remember that it is important for the Church community to also help support each other as together we provide pastoral care for all those in need.

9. Individual activity: Resources for further understanding & action

Tell the group: Have a look at Handout E12.H6, which includes a list of various resources for further information and action for pastoral care with older people. Spend a few minutes reading through the list of options, and mark a couple of items which you might find interesting or helpful in order to learn more. You are more likely to follow-through if you also note when you will take this action, or if you commit to take action with another person. (5 min)

10. Close

Thank people for participating in the session.

Each participant could be invited to write two brief prayers and record these in their journal over the next few days. One prayer might be offering thanks to God for the shared nature of a pastoral visit. The second prayer could be seeking God's presence in a difficult situation that a person is encountering.

Close the time with prayer, perhaps the following:

Lord,
thank you for your presence this moment,
holding us in your love.
Help us to share your love
with those who live among us with dementia,
that we may see your beauty in them.
Amen.

(Association of Catholic Women Bloggers, 2012)

(5 min)

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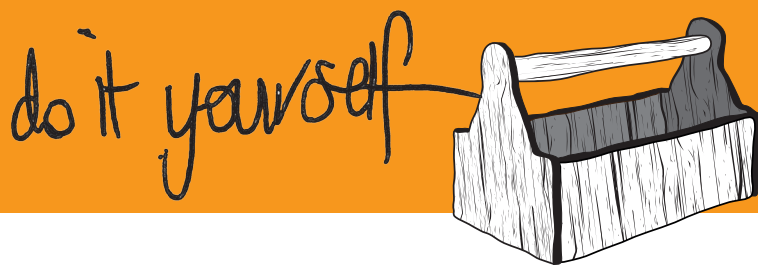
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Handout #1 Introducing Dementia

The Alzheimer's Disease organisation in the United Kingdom calculates that there are currently 46 million people with dementia in the world, with 4.6 million new cases annually (that is, one new case every 7 seconds). The estimated number of people affected will be over 130 million by 2050. These estimates were derived from detailed population-based studies of the prevalence of dementia in different world regions (Alzheimer's Disease International, 2015).

Estimates in Australia are that by the year 2050 dementia prevalence will triple to around 900,000 people. The graph below shows the likely increase in the number of people with dementia by year. This increase is due largely to the growth and ageing of Australia's population, and assumes that prevalence rates remain stable (Australian Institute of Health and Welfare, 2012). Dementia is one of the biggest health challenges for Australia society, hence the need for coordinated and effective pastoral care.

Dementia is a broad term that describes different effects related to changes in the brain functions and cognitive capability. The most obvious characteristics is impairment of memory, which affects thinking and behaviour. Alzheimer's disease is the most common form of dementia, but most are progressive and permanent.

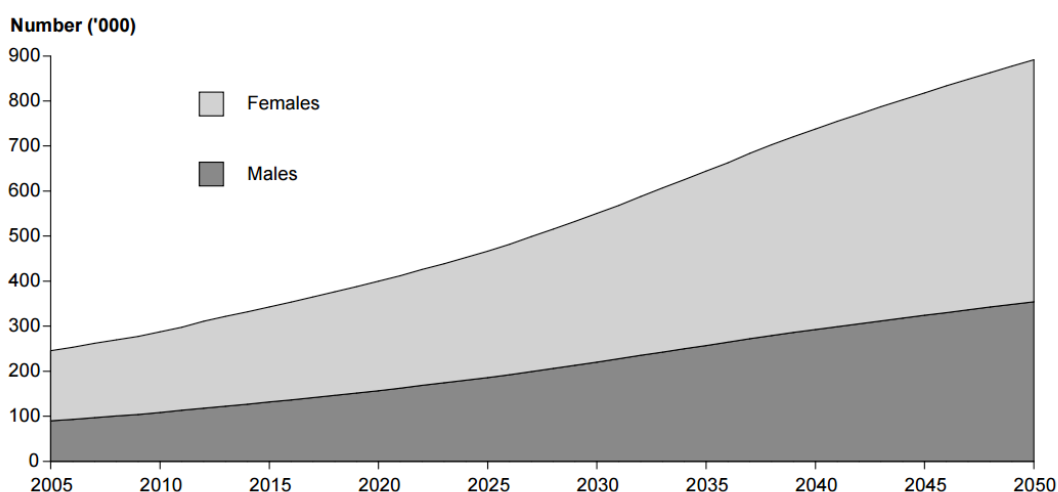
For people with dementia, and for their family and friends, the changes in cognitive capability make their physical

and social environments more and more challenging. Dementia significantly changes not only how people think but how they interpret their senses and feelings.

Anyone trying to create a dementia-friendly environment must first ask how people living with dementia experience their world. From their own perspective (that is, in their own words), people with dementia say that it:

- impairs our memories
- impairs our reasoning
- impairs our ability to learn
- raises our levels of stress
- makes us very sensitive to built and social environments
- makes us more and more dependent on all our senses. (Uniting AgeWell, 2015)

Dementia progressively affects every area of a person's life, including their physical and mental capabilities, community connections, and personal identity – and these vary significantly in different cultural groups. Pastoral care is one area of the ministry of the Church in which everyone is engaged every day, in their everyday life as well as in connection with Church activities. More formally, pastoral care within and on behalf of the Church is supported through specific focus and oversight by the Church Council and Elders.



Note: Data for this figure are shown in Appendix Table A2.2.

Sources: Calculations by AIHW using rates based on ADI (2009) and Harvey et al. (2003) and applied to population data for 2005 to 2011 (ABS 2012a) and population projections for 2012 to 2050 (ABS 2008a).

AIHW 2012, Dementia in Australia, Fig 2.2 people with dementia 2005-2050.PNG (Australian Institute of Health and Welfare, 2012)



do it yourself



Handout #2 Understanding Dementia

1. By yourself initially, read through the facts listed below and circle the three that grab your attention or stand out most for you. (4 mins)

More than 300,000 Australians have dementia, and the number keeps rising.

Where English is learned as a second or subsequent language, the language most recently acquired is lost first for people with dementia

Dementia is a general term to describe problems with memory and thinking, caused by various disorders affecting the brain.

It is possible to grow new nerve connections, or maintain the connections you have, by exercising your mind.

Regular routines to help minimise confusion and assist communication.

Dementia is not a normal part of ageing, but is more common after the age of 65 years.

Forgetting where you left the car keys is normal. A person with dementia may lose the car keys and then forget what they are used for.

If people feel they have control over their lives, their brain chemistry actually improves.

Dementia is the inability to carry out everyday activities as a consequence of diminished cognitive (thinking) ability.

Dementia is a collection of symptoms, not one specific disease, with physical, psychological, personal and social impacts.

Dementia is the second leading cause of death in Australia and at present there is no cure.

People with dementia are much more immediately influenced by feelings or emotions.

Family and friends continue to play an important part in the lives of people with dementia.

2. Form a group with two others and briefly share which facts stand out particularly for each of you, and why. Ensure each person has an opportunity to share. (6 mins)

These facts are drawn from the huge number of Help Sheets by Alzheimer's Australia: (Alzheimer's Australia) (Alzheimer's Australia)



do it yourself



Handout #3 Types of dementia: names, causes, signs & symptoms

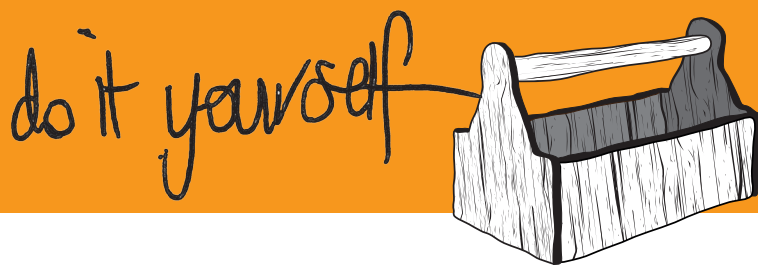
In a small group, focus on one type of dementia and read the description aloud together: each take a paragraph in turn, or select one person. If you have mobile Internet access you could quickly find more information about the particular type of dementia.

Discuss and decide on two key characteristics of this type of dementia that would be relevant to a church context, in preparation for reporting back to the whole group.

Note also the diagram below the table which indicates the approximate proportions of different types of dementia.

<p>Alzheimer's disease is the most common form of dementia, affecting up to 70% of all people with dementia. Alzheimer's disease damages the brain, resulting in impaired memory, thinking and behaviour. The biggest risk factor for having Alzheimer's disease is increasing age, with 1 in 4 people over 85 having dementia. A variety of suspected causes are being investigated including factors in the environment, biochemical disturbances and immune processes. The cause may vary from person to person and may be due to one factor or a number of factors.</p> <p>In the early stages the symptoms of Alzheimer's disease can be very subtle. However, it often begins with lapses in memory and difficulty in finding the right words for everyday objects. Symptoms vary and the disease progresses at a different pace according to the individual and the areas of the brain affected. A person's abilities may fluctuate from day to day, or even within the one day, becoming worse in times of stress, fatigue or ill-health.</p> <p>The rate of progression of the disease varies from person to person. However, the disease does lead eventually to complete dependence and finally death, usually from another illness such as pneumonia. A person may live from three to twenty years with Alzheimer's disease, with the average being seven to ten years.</p>	<p>Lewy body disease is caused by the degeneration and death of nerve cells in the brain. The name comes from the presence of abnormal structures, called Lewy bodies, which develop inside nerve cells. Lewy body disease is a common form of dementia, sharing many similarities with Alzheimer's disease.</p> <p>The symptoms of dementia with Lewy body disease include:</p> <ul style="list-style-type: none">• Difficulty with concentration and attention• Extreme confusion• Difficulties judging distances, often resulting in falls. <p>There are also three cardinal symptoms, two of which must be present in order to make the diagnosis:</p> <ul style="list-style-type: none">• Visual hallucinations• Parkinsonism (tremors and stiffness similar to that seen in Parkinson's disease)• Fluctuation in mental state so that the person may be lucid and clear at one time and confused, disoriented and bewildered at other times. Typically this fluctuation occurs over a period of hours or even minutes and is not due to any underlying acute physical illness. <p>Some people who have Lewy body disease may also experience delusions and/or depression.</p> <p>Lewy body disease differs from Alzheimer's disease in that the progression of the disease is usually more rapid. However, like Alzheimer's disease it is a degenerative condition, eventually leading to complete dependence. Death is usually a result of another illness, such as pneumonia or an infection. The average lifespan after the onset of symptoms is about seven years.</p>
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Vascular dementia is the broad term for dementia associated with problems of circulation of blood to the brain, and is the second most common cause of dementia after Alzheimer's disease. Vascular dementia can be very difficult to distinguish from other forms of dementia. Some people have both Alzheimer's disease and Vascular dementia.

Vascular dementia usually progresses gradually in a step-wise fashion in which a person's abilities deteriorate after a stroke, and then stabilise until the next stroke. If further strokes do not occur, the abilities of people with Vascular dementia may not continue to decline, or in some cases, may improve. However, these improvements may not last. Sometimes the steps are so small that the decline appears gradual. On average though, people with Vascular dementia decline more rapidly than people with Alzheimer's disease. Often they die from a heart attack or major stroke.

Alcohol-related dementia arises from consumption of too much alcohol, particularly if associated with a diet deficient in thiamine (vitamin B1), and can lead to irreversible brain damage. Many doctors prefer the terms 'alcohol-related brain injury' or 'alcohol-related brain impairment', rather than alcohol-related dementia, because alcohol abuse can cause impairments in many different brain functions.

The most vulnerable parts of the brain are those used for memory and for planning, organising and judgement, social skills and balance. This type of dementia is preventable.

Fronto Temporal Lobar Degeneration or FTLD is the name given to dementia when there is degeneration in one or both of the frontal or temporal lobes of the brain.

Early symptoms can affect behaviour, and sometimes language. People may show a change in their character and in their social behaviour. For example, they may show insensitivity when they have previously been very considerate of others. A person with FTLD may become obsessive and repeat the same action over and over again. Language problems often occur early in the disease and may range from limited speech to total loss of speech. Repeating phrases over and over, or echoing what others have said are also common symptoms. Instead of being able to find the right word to describe an object, a person with FTLD may give a description of it instead. For instance, instead of naming a watch, the person may refer to something you tell the time with.

Although it can affect people at any age, it usually begins between 40 to 65 years of age. The course of FTLD is one of inevitable progressive deterioration. From the onset of the disease, life expectancy is two to fifteen years, with an average of six to twelve years. Death usually comes from another illness such as infection.

HIV-associated dementia (HAD) is a complication that affects some people with HIV and acquired immune deficiency syndrome (AIDS). This condition was known as AIDS-related dementia or AIDS dementia complex (ADC).

HAD is associated with severe cognitive, motor and behavioural problems that impair day-to-day functioning, and reduce independence and quality of life. It is uncommon in people in the early stages of HIV/AIDS, but may increase as the disease advances.

In Australia, where most people who are HIV-positive receive treatment with combination antiretroviral therapy, HAD is fortunately uncommon. However, despite effective treatment, the milder forms of HAD affect many HIV-positive people.



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Parkinson's disease causes tremors, stiffness in limbs and joints, speech problems and difficulty in starting physical movements. Most people with Parkinson's disease will develop symptoms of dementia. If the symptoms affecting movement appear first and are followed by symptoms affecting thinking and behaviour, the diagnosis will be Parkinson's disease dementia.

Huntington's disease is an inherited, degenerative brain disease that affects both the mind and body. Other symptoms include personality change, memory disturbance, slurred speech, impaired judgement and psychiatric problems.

There is no treatment available to stop the progression of this disease, but medication can control movement disorders and psychiatric symptoms. Dementia occurs in the majority of people with Huntington's disease.

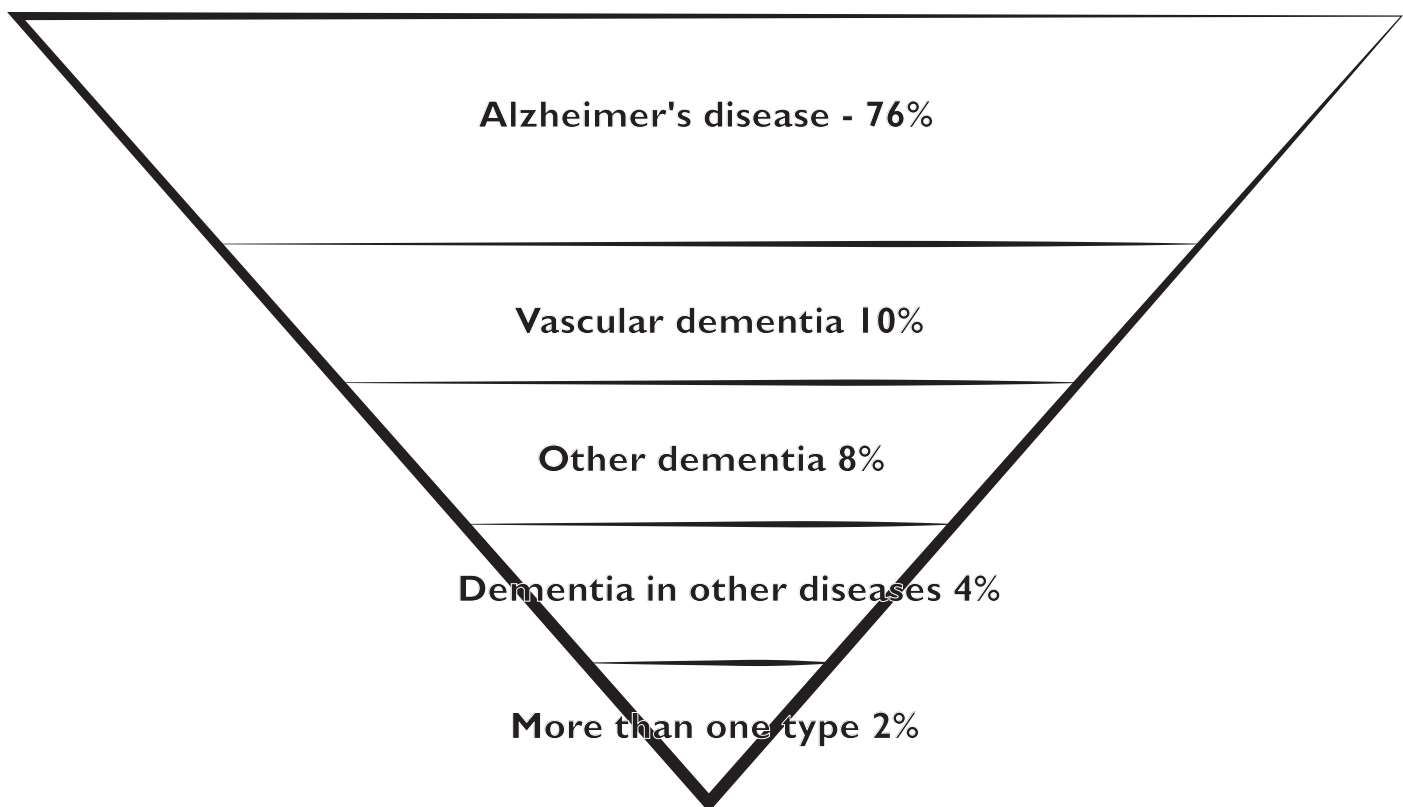
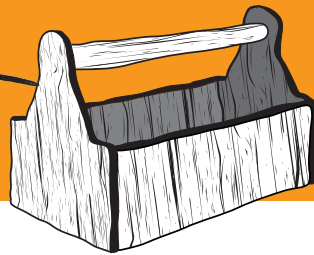


Figure 1. Types of dementia in Australian Government subsidised aged care facilities 2009-2010 (Australian Institute of Health and Welfare, 2012, p. 42).



do it yourself



Reporting back

Note two key characteristics of the selected type of dementia that would be noted in a church context, in preparation for a very brief report back to the whole group of 2-3 minutes.

These characteristics might include the physical environment, the type of activity and participation expected, the individual attention and care needed, or other aspects of dementia in church contexts.

Characteristic 1:

Characteristic 2:

Does the frequency of this type of dementia, as illustrated in the diagram, affect the Church's response?

Sources: (Alzheimer's Australia), (Department of Health & Human Services, State Government of Victoria, Australia, 2014)



Handout #4 A Pastoral Conversation

Pastoral care is about coming alongside others in order to help them to address their own needs through sharing empathy, listening actively, encouraging and supporting the other. It involves maintaining relational connections and respecting confidentiality, and may also include referring as needed.

Pastoral care is not about telling another person what to do or feel, what to think or believe, nor even really about feeling good that we have helped the other person. Pastoral care is guided by the needs and wishes of the person being cared for, and their family and close friends.

The following conversation transcript is a hypothetical but real-life pastoral conversation between Chris and Nolene.

Chris is visiting Nolene who now lives in the memory support unit of a residential aged care facility near the church they both go to. Nolene's three children have been keeping in touch really well since her husband Nick died two years ago.

Chris sees Nolene sitting in a chair facing the window. Knocking on the door, Chris gives Nolene time to turn before approaching her.

- C 1** Hi, it's Chris from the church, is it a good time to drop in?
- N 1** Oh ... Chris ... yes ... sure, it is lovely to see you. *(Smiling enthusiastically)*
- C 2** How are things going?
- N 2** Not good. It's a disaster really, we never get fed, life is dull, nothing ever happens here.
- C 3** *(Trying to cheer her up)* Always look on the bright side of life, I always say!
- N 3** Bright side, what bright side? No one ever comes to see me here. I never get out either.
- C 4** But Nolene, I saw you and your daughter Bekky at church last Sunday, didn't I?

N 4 Last Sunday. At church? But I haven't been to church in years. And Bekky never comes to see me.

C 5 *(Picking up a nearby photo frame.)* But isn't this a photo of you at Bekky's when your grandson turned one last month?

N 5 Is that who it is, I was wondering? He's cute, what is the baby's name?

C 6 Nicholas, named after your husband, Nick.

N 6 Nick will be pleased, I must remember to tell him when he gets home.

C 7 Ummm, he is a lovely baby, curly hair like you.

N 7 And he is ... Bekky's?

C 8 Yes, see that's you and there's Bekky, Hamish, and Ruby is holding Nicholas. Don't you all look so happy!

N 8 Is that me? I didn't think I looked that old. Pity Nick couldn't be there. ... I guess he took the photo, silly me.

C 9 Yes, he was so proud when Ruby was born, wasn't he?

N 9 If only he would get home, he could set things straight and I could get out of here.

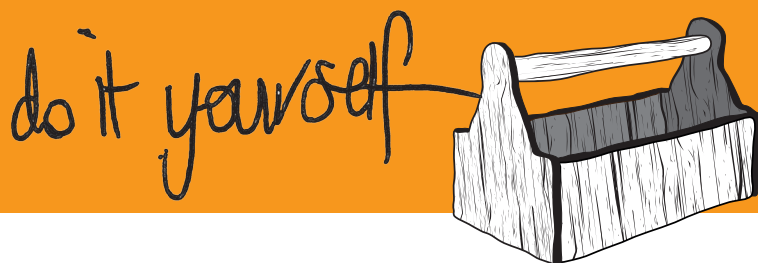
C 10 Ummm. *(Not sure what to say, just waits a little)*

N 10 But gee they look after me well here. Meals and everything. I just have to put my clothes in that basket and within a few minutes they are back clean and folded. And they all seem to know my name, so friendly.

C 11 Sounds like you feel loved and safe here.

N 11 Yes, if you have to be somewhere, you may as well be here. But sometimes some of the children misbehave.

C 12 How so?



N 12 Oh you know, things disappear, little hands, that sort of thing.

C 13 I guess these things happen.

N 13 Yes, but I keep a good eye on them all. Gave one a tongue lashing the other day, nicely mind. He bounced back, understood he was wrong. It won't happen again.

C 14 You seem to be on top of things.

N 14 Yes, just like when I ... you know, ... stood in front of ...

C 15 You were a great teacher, they said.

N 15 That's it, teacher, yes kept good control. The ... those in charge of the children at home, the ... guardians, were very pleased when their children were in my class.

C 16 You have lived a long rich life.

N 16 It seems so long ago now ... I can hardly remember it all.

C 17 Time I got home. It has been lovely to catch up.

N 17 I don't 'spose I will see you again soon?

C 18 Yes, on Sunday, remember, we sit at the same table having a coffee most Sundays.

N 18 Do we? Of course, we do. I look forward to it. It will be nice to get out. I better tidy up here for when Nick comes home from work soon.

C 19 See you Sunday. *(Gets up and leaves)*

N 19 *(Turns away and starts fiddling and sorting some things out)*

Ask the group each of the following questions, using a whiteboard or butcher's paper to record participant responses where useful. Take note of responses that differ from each other, and ask the participants for a little more information about their experiences and perspectives.

Group discussion questions:

1. Did this sound like a realistic conversation? Why or why not?

2. Was there any aspect that puzzled you?

3. How did Chris demonstrate good listening and a good understanding of dementia and Nolene's situation?

do it yourself

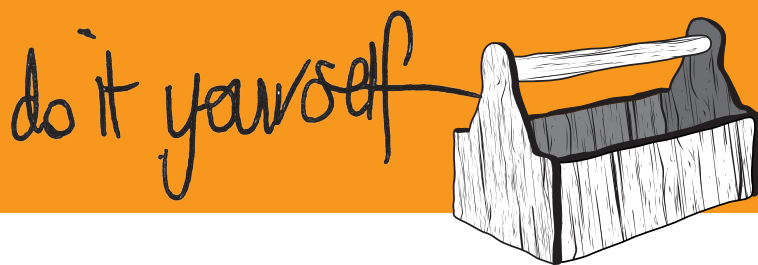


4. Were there some responses or actions of Chris that were less helpful?

If the following points do not surface in discussion, contribute them where appropriate:

- Note the way the pastoral visitor assists the person with a brief reminder of their name and context / connection (“Hi, it’s Chris from the church...”)
- Note how even the usually helpful open question “How are things going?” challenges Nolene’s memory. Remarking on today’s weather or some flowers in the room may be an easier opening for Nolene to respond to.
- Note the way the pastoral visitor clearly knows the key members of the person’s family networks, and can assist them to remember without pointing out memory lapses.
- Note the way the visitor responds to mention of getting out of the residential aged care facility, or of the impending return from work of the deceased partner.
- Note how each time the visitor says “But” it unhelpfully corrects Nolene’s faulty memory.
- Note the way the visitor follows conversational leads in an affirming way, and then winds up the conversation with a positive forward-looking connection.
- Note how positive the conversation was for Nolene, yet within five minutes she may have forgotten it happened. Regardless, Nolene has felt valued and experienced a loving conversation.

5. What are some of the key learnings from this conversation for you?



Handout #5 Planning for pastoral care and inclusion

Church activities and networks can play a very important pastoral role in the lives of people who live with the effects of dementia. These effects are individual and variable, but commonly result in various forms of exclusion, often unconscious, as dementia changes cognitive abilities and requirements for care.

The major needs of people with dementia include:

- **Comfort:** People living with dementia may have a sense of loss, causing anxiety and insecurity. They need an environment of comfort and empowerment.
- **Attachment:** The need for attachment is strong in each of us, more than ever when we feel like a stranger in someone else's environment. People with dementia need to feel a sense of belonging, and to contribute what they are still able to do.
- **Inclusion:** People with dementia can find it hard to be included in situations where others do not have the same impairment. Individualised care and physical settings help people feel they are part of a group.
- **Occupation:** Being occupied means being involved in everyday life. Carers and their supporters need to create conditions that support social involvement, drawing on people's experiences, strengths and abilities.
- **Identity:** A person with dementia is unique. A person's life-story should be built into all interactions in the care setting.

How can the Church include people regardless of cognitive abilities, and provide pastoral care through all the stages of the illness? How can the strengths and abilities of a person with dementia still contribute to participation in church contexts and activities?

A local Church can do several key things in providing pastoral care around dementia:

1. **Include the person** with dementia in the community's life.
2. **Use the active listening skills** of pastoral care to follow with their interests and agenda.
3. **Seek to comfort, never confront.**

4. **Provide pastoral care for those caring** for the one with dementia.
5. **Intentionally plan to provide coordinated pastoral care**, in addition to the informal care that Church members may individually provide.

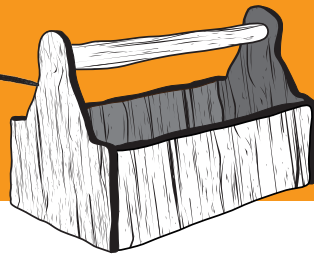
A well designed pastoral care program supports the three major principles of **enablement, dignity** and **individual choice** – and applies these to each part of the network of care that centres on the person needing the most care:

- **Enablement** encourages participants to engage in their social and physical environment on their own terms.
- **Dignity** focusses on the capacity and aspirations of each person, to identify and respond to those parts of our lives we value most.
- **Individual choice** is life affirming and provides opportunities for involvement: when, how and where to participate in activities available. (Uniting AgeWell, 2015)

Each pastoral visit or Church activity is part of a wider web of pastoral care for the person and their network of family and friends. A church-related social or support group may be a highly significant program in the life of a person. It can provide an opportunity to enjoy a familiar, engaging and interactive environment whilst spending time with other people of similar backgrounds and values, and sharing or re-discovering skills, memories, ideas and experiences.

In addition, church networks and support programs can assist carers by providing additional information on caring, a change in the routine of caring and direct support of the carer; and the knowledge that their loved one is engaged in a meaningful social program and a wider network of support.

do it yourself



Small group task – basic planning

In a small group use this worksheet to identify and plan to meet the needs of various people associated with dementia, and ways to include their strengths and

abilities. Plan to include the three major principles of **enablement, dignity** and **individual choice**. (10 min)

	What will help a person to navigate the changes dementia brings? <i>(if we don't know, how will we find out?)</i>	How can we plan to meet their needs? <i>(not our own)</i> How is care shown, and felt?	What strengths and abilities can they contribute?
An older person wondering about dementia	• • •	• • •	• •
A person experiencing early stages of dementia	• • •	• • •	• •
A spouse / partner / significant other	• • •	• • •	• •
Church friends	• • •	• • •	• •

Extension task – further planning

The basic framework above can be extended by a pastoral community or congregation to provide more comprehensive planning for support around dementia.

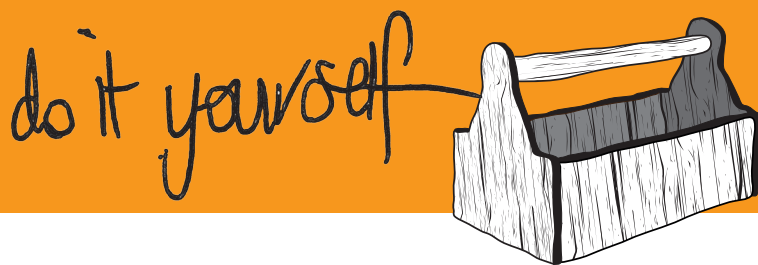
- Additional columns could be added in order to consider:
- What activities would better enable participation with fewer challenges?
- What support and encouragement is needed for each person to feel included?
- What are some short-term and long-term goals for each person or group?

- A person experiencing more advanced stages of dementia
- Other family members
- Close friends and social networks
- Wider support structures (e.g. Church volunteers, aged care staff)

Comprehensive planning for pastoral care and inclusion, and assessment of the effectiveness of the care provided, enrich the lives of those involved and enhance the ministry of the Church.

Additional rows could be added in order to include the needs of:





Handout #6 Resources for further understanding & action

There are a wide range of options for increased understanding and active response to the challenges and opportunities of pastoral care around dementia.

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

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

Read more information:

- [Alzheimer's Australia](#) free resources, including in [many languages](#)
- [Uniting AgeWell's "Dementia-friendly social support checklist"](#), Uniting AgeWell
- [Dementia in Australia](#), Australian Institute of Health and Welfare
- [Dementia Centre](#) and [Dogs4Dementia](#)
- [Dementia Training Study Centres](#) and [Dementia Research](#)
- [Ministering to People with Dementia: A Pastoral Guide](#), Catholic Health Australia and Alzheimer's Australia
- [Ministering to people with dementia: a pastoral guide and related books](#)
- [World Alzheimer Report 2015, The Global Impact of Dementia](#), Alzheimer's Disease International
- [Australian Government Department of Social Services](#)
- [Centre for Cultural Diversity in Ageing](#)
- [Seeing the Hidden Grace of Alzheimer's](#), by Colleen Carroll Campbell in *Christianity Today*
- An infographic on [Dementia - A global epidemic](#), and [The prevalence of dementia worldwide](#), both by *Alzheimer's Disease International UK*

Read a novel:

- *Elizabeth is Missing*, Emma Healey (2014)
- *The Night Guest*, Fiona McFarlane (2013)
- *The Wilderness*, Samantha Harvey (2008)
- *We Are Not Ourselves*, Matthew Thomas (2014)
- *Still Alice*, Lisa Genova (2009)

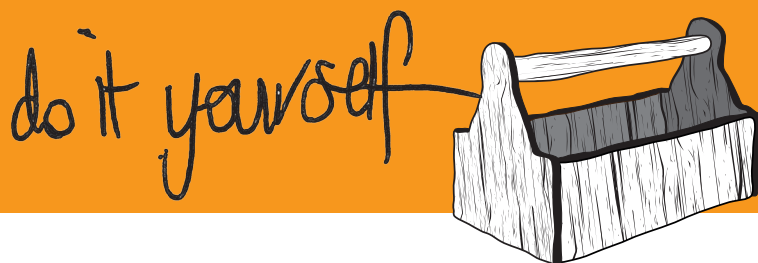
Watch an online video:

- [What is Alzheimer's disease?](#), Ivan Seah Yu Jun, 4 minute TED-Ed talk, 2014
- [How I'm preparing to get Alzheimer's](#), Alanna Shaikh, 6 minute TED talk, 2012
- [The coming neurological epidemic](#), Gregory Petsko, 4 minute TED talk, 2008
- [10 TED Talks That Will Change the Way You Think About Aging](#), Sarah Stevenson, 2012
- [Parkinson's, depression and the switch that might turn them off](#), Andres Lozano, 15 minute TED talk, 2013
- [One more reason to get a good night's sleep](#), Jeff Iliff, 12 minute TED talk, 2014
- [A New Shot at Life](#), 60 Minutes Australia segment from 4 Nov 2011 and [Alzheimer's Australia response](#) on 7 Nov 2011.

Watch a movie:

- [The Notebook](#) (2004): about dementia and the strength of love
- [Still Alice](#) (2014): about early-onset dementia; see review by [The Guardian UK](#).
- [6 Alzheimer's Movies from 2014](#)
- [Eight Movies About Dementia You Shouldn't Miss](#)
- [5 Movies About Memory Loss, Dementia, and Alzheimer's](#)
- [Movies featuring depictions of dementia](#)





Donate some time or money:

- Consider becoming a Uniting AgeWell volunteer or donor.
- Consider involvement with the national and state Carers associations.

Take a free online course:

These online courses are free and anyone can enrol: each course website indicates when the next course will start.

- Understanding Dementia is a 9-week online course that builds upon the latest in international research on dementia, from the University of Tasmania's Massive Open Online Courses (MOOC). The curriculum draws upon the expertise of neuroscientists, clinicians and dementia care professionals in the Wicking Dementia Research and Education Centre.
- Dementia Education Online is a 6-module course by the University of Wollongong and Dementia Training Study Centres, which also offer various eLearning resources for health professionals supported by the Australian Government.
- Living with Dementia: Impact on Individuals, Caregivers, Communities and Societies is a 5-week online course by Johns Hopkins School of Nursing, USA.
- Alzheimer's Disease or Other Dementias is a 5-module interactive course by Home Instead Senior Care, USA.

‘Do-it-yourself’ (DIY) educational modules for the Uniting Church

DIYs are single-session educational modules intended for small-group (or individual) learning, including notes for group leaders, of about 90-120 minutes in duration. No assessment tasks are included.

Foundations of faith (6 modules)			
No.	Module name/topic	Resources supplied	Time (mins)
F1	How to read and understand the Bible	MO + LG + 4H	85
F2	Old Testament perspectives	MO + LG + 2H	90
F3	New Testament perspectives	MO + LG + 4H	90
F4	Major themes in the Bible	MO + LG + 3H	75
F5	A short foray into theology (A)	MO + LG + 2H	80
F6	A short foray into theology (B)	MO + LG + 4H	90
Congregational life (6 modules)			
C1	The changing face of the church	MO + LG + 3H	90
C2	The call to faithfulness in these changing times	MO + LG + 2H	90
C3	Being the church today	MO + LG + 3H	90
C4	Resourcing our Ministry and Mission	MO + LG + 2H	90
C5	Understanding the UCA regulations	MO + LG + 2H	90
C6	Creative Diversity	MO + LG + 4H	90
Day-to-day ministry (6 modules)			
M1	Theology of lay ministry	MO + LG + 3H	90
M2	Discerning our gifts	MO + LG + 3H	90
M3	Ministry in the workplace	MO + LG + 2H	95
M4	Ministry in the community	MO + LG + 3H	90
M5	Understanding conflict	MO + LG + 3H	90
M6	Becoming a public church	MO + LG + 2H	85
Leadership skills (9 modules)			
L1	Basic leadership skills	MO + LG + 4H	85
L2	Communication: a basic leadership skill	MO + LG + 3H	85
L3	Presentation: a basic leadership skill	MO + LG + 3H	90
L4	Encouragement: a basic leadership skill	MO + LG + 4H	90
L5	Leading a discussion	MO + LG + 3H	90
L6	Resolving conflict	MO + LG + 4H	90
L7	Understanding group dynamics	MO + LG + 4H	90
L8	Decision making	MO + LG + 2H	90
L9	Creative chairing	MO + LG + 3H	90
Congregational leadership (10 modules)			
E1	The Ministry of the Church Council	MO + LG + 6H	120
E2	The Ministry of Elder in the Congregation	MO + LG + 4H + Sum + FR	120
E3	Communication Issues for Elders	MO + LG + 4H	90
E4	Grief Care	MO + LG + 3H	90
E5	The Ministry of Elder: Pastoral Visitor	MO + LG + 3H + Sum + FR	120
E6	The Ministry of Elder: Crisis care	MO + LG + 2H + FR	120
E7	Leading Worship: Intercessory Prayer (UiW)	MO + LG + 3H	90
E8	Lay Presidency at Baptism	MO/LG + 2H	85
E9	Lay Presidency at Holy Communion	MO + LG + 2H	70
E10	Communion beyond the gathered congregation	MO + LG + 2H	70
E11	Pastoral care with older people	MO + LG + 4H	120
E12	Dementia and pastoral care	MO + LG + 6H	120

Key: MO: Module Outline LG: Leader's Guide nH: n Handouts

FR: Further reading

Sum: Summary