

1495



UNIVERSITY OF
ABERDEEN

Educating for Inclusive, Caring Communities

What kind of education do clergy and ordinands require in order to include and care for people living with dementia and their carers and supporters?

Authors:

Jennifer Riley, Trevor Wight,
Peter Archer, Steve Calder,
Lois Haultain, Sarah Oakey,
Jennifer Thompson, and
John Swinton

December 2023

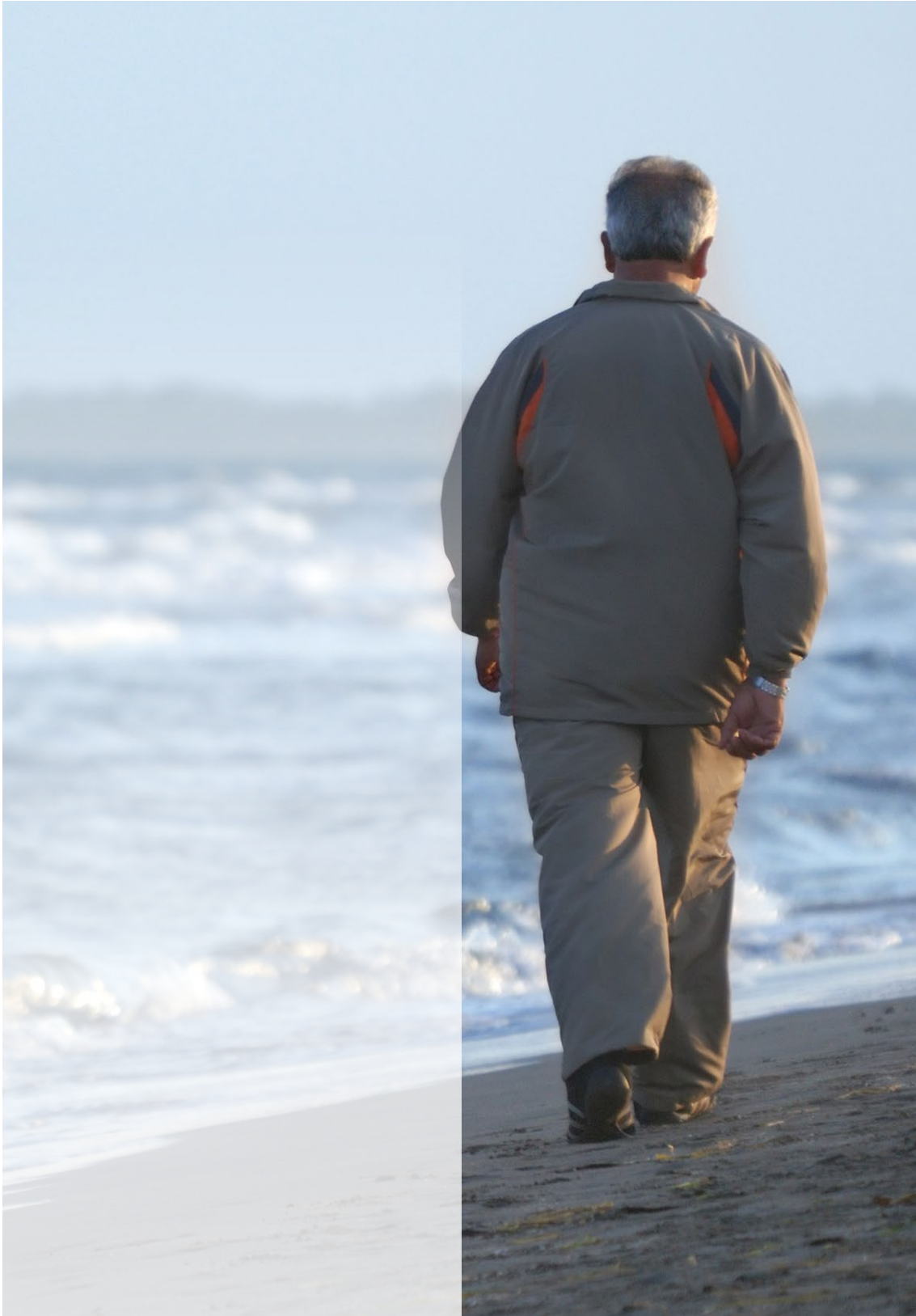
Sir Halley
Stewart Trust


Laing Family Trusts

HammondCare 

Educating for Inclusive, Caring Communities: Report © 2023 by Jennifer Riley, Trevor Wight, Peter Archer, Steve Calder, Lois Haultain, Sarah Oakey, Jennifer Thompson and John Swinton is licensed under CC BY-NC 4.0

Citation for published version (APA): Riley, J., Wight, T., Archer, P., Calder, S., Haultain, L., Oakey, S., Thompson, J., & Swinton, J. (2023). *Educating for Inclusive, Caring Communities: What kind of education do clergy and ordinands require in order to include and care for people living with dementia and their carers and supporters?* University of Aberdeen. <https://doi.org/10.57064/2164/22617>



Contents

Acknowledgements	5
Executive Summary	6
How to read this report	6
Section Summaries	7
Background to the project	8
Introduction	8
Methodology	9
Rationale	9
Ethics	10
Recruitment, selection and sampling	10
Interviews	12
Analysis	12
Dementia, Faith and the Church	14
Overview	14
God, faith and dementia	14
Physical and Material Accessibility	17
Worship, Liturgy and Sacraments	18
Communion	21
Visiting and Community Ministry	22
Gifts and Service	23
Fellowship	23
Ethos, Attitudes and Understanding	25
Section summary	27
Case Studies	28
Using the case studies	28
Doris and Dave	28
Jim	29
Dementia in Theological Education	31
Leadership	31
Clergy with dementia?	32
Trends	33
Excluding the margins	33
Outsourcing	33

Contents (continued)

Assumption of cognitive norms	34
Goal-orientation and production-orientation	34
Ageism	35
Theological Breadth	35
What ministers need	37
Forming dispositions, building knowledge	37
Top-down pressure	41
Continuing Ministerial Education.....	41
Mechanisms for training and education	42
Modular teaching.....	42
Placements and reflection	45
Allusion across the curriculum.....	47
Extra-curricular spaces	48
Barriers and Concerns.....	49
A Way Forward	51
Option 1 - Curriculum Time and Assessment.....	51
Option 2 – An Integrated Approach.....	52
Option 3 - Placements and theological reflection.....	52
Option 4 – Extra-curricular spaces.....	53
Option 5 – Befriender Scheme.....	53
An Exercise.....	54
Concluding Statement.....	55
Recommendations	57
For Theological Education Institutions.....	57
For further research and exploration.....	58
For churches	59
Resources	61
References.....	64
Glossary	66
Appendices	73

Acknowledgements

The authors would like to thank everybody who passed on and answered our calls for participants.

This research has been generously supported by HammondCare, The Sir Halley Stewart Trust, and the Kirby Laing Foundation.



Executive Summary

The Educating for Inclusive, Caring Communities report delves into the critical role that clergy and church leaders play in fostering inclusivity and support for individuals living with dementia and their carers within Christian communities.

Through the *Educating for Inclusive, Caring Communities* project, we have explored how Theological Education Institutions (TEIs) in the UK and Australia currently prepare their students for dementia ministry and identified strategies for enhancing this aspect of their training.

Key Findings:

- There is a growing need for clergy and church leaders to be well-equipped to support the dementia community.
- Dementia shines a critical light upon many aspects of spiritual and church life, making it a key indicator of the inclusivity and accessibility of church practices.
- Current theological training on dementia varies widely and often lacks depth or practical application.

Recommendations:

- TEIs should integrate dementia education into their curricula to better prepare future clergy for inclusive ministry.
- A multi-faceted approach to training is necessary, combining modular teaching, placements, reflection, and extracurricular learning.
- Churches should engage in continuous dialogue and education to foster environments that are welcoming to those living with dementia.

Actionable Steps:

- Evaluate Current Programs: TEIs to conduct self-assessments on current dementia-related content in their courses.
- Curricular Integration: Incorporate dementia-specific taught and/or assessed content and embed cross-curricular references to dementia-related issues.
- Practical Placements: Provide hands-on learning experiences for ordinands in settings that support individuals with dementia.
- Continuing Education: Encourage ongoing training for ordained clergy to keep abreast of best practices in dementia care.
- Community Engagement: Facilitate workshops and create resources to help church communities become more inclusive.

Future Direction:

The report concludes with a call to action for TEIs to consider a range of options for enhancing their approach to dementia education. We recommend prioritising two of the five proposed options for immediate implementation, alongside a list of resources to support these initiatives. Additionally, the report outlines areas for further research and proposes a series of recommendations for both TEIs and church bodies to consider as they work toward creating more caring and inclusive communities.

How to read this report

This report has three main sections: *Dementia, Faith and the Church*; *Dementia in Theological Education*; and *A Way Forward*. These are followed by summary recommendations, a list of resources, and a glossary.

We anticipate that *Dementia in Theological Education* and *A Way Forward* will primarily be of interest to those involved in ministerial training and theological education. These can be read in isolation, or in addition to the opening two sections.

Church leaders – lay or ordained – might find *Dementia, Faith and the Church* useful in isolation, accompanied by the specific recommendations for churches on page 57.

Section Summaries

Dementia, Faith and the Church explores people's experiences of living with dementia, or caring for someone living with it, in a number of different areas of spiritual and church life: one's relationship with God; aspects of physical and material accessibility; worship, liturgy and sacraments; visiting and community ministry; gifts and service; fellowship; and ethos, attitudes, and understanding. This section of the report illustrates varied experiences in each of these domains. It also shows that, in several senses, participants saw dementia as an indicative issue, pointing to broader ways in which churches needed to examine and consider their inclusion and accessibility. This section of the report ends with a reflection exercise based upon two illustrative case studies.

Dementia in Theological Education first builds a case for giving dementia focused attention in the context of ministerial training and formation. It examines the role of a church leader, and their power to respond correctively to norms, cultures and trends which can tend towards exclusion. Again, in this respect, dementia emerges as an indicative issue. Relatedly, it highlights the breadth of dementia's

theological significance, particularly its capacity to serve as an 'acid test' for normative theological constructions.

This section of the report then examines what TEIs currently do - or could do - to prepare prospective ministers to support people living with dementia and their carers. It advocates and assumes that most TEIs already take an approach which strongly emphasises the importance of formation and developing transferable skills to nurture 'theological improvisation.' It specifically considers where dementia might be incorporated within modular teaching structures, placements and reflection, and extra-curricular spaces, as well as examining the possibility of integrating dementia across trainees' courses through cross-curricular allusion. While drawing attention to existing good practice, this section acknowledges throughout that none of these options are without associated concerns and potential limitations.

In view of such concerns, and the diverse approaches currently taken to dementia education, the final main section – *A Way Forward* – eschews any one-size-fits-all solution. Instead, it proposes five 'options' which, when used in combination with one another, might see TEIs take realistic, incremental steps towards increasing their dementia provision. An exercise is included which encourages each TEI to evaluate their existing work in this area and prioritise two 'options.'

By way of end-matter, the report closes with a series of recommendations – respectively for TEIs, for future research, and for churches - a list of resources, and a glossary.

Background to the project

Introduction

Dementia is ‘an umbrella term for several diseases affecting memory, other cognitive abilities and behaviour that interfere significantly with a person’s ability to maintain their activities of daily living’ (World Health Organisation [WHO], 2023) including Alzheimer’s Disease.

Incidences are increasing rapidly in the UK and globally (WHO, 2023; Alzheimer’s Society, n.d.) The World Health Organization (WHO) predicts that by 2030, 75 million people worldwide will be living with dementia, rising to 139 million by 2050 (WHO, ‘World Failing to Address Dementia Challenge’ n.d.)

Caring for people living with dementia – and, in turn, for their carers and supporters - is therefore a significant current social concern (Farrow et al. 2018) spanning multiple social domains, including: home, residential and hospice care (Fahey-McCarthy et al. 2009; Goh et al. 2022); healthcare (Cashin et al. 2019); law enforcement (Powers et al. 2020); and social work (Collins et al. 2007). Such care has many forms and sources, including organisations – not least religious communities such as Christian churches (Kevern and Walker, 2013; Friedrich, Woods and Williams, 2021; Gore et al., 2022).

Research has indicated that well-informed religious communities can be valuable resources that support people living with dementia, and their carers, to manage, flourish, and grow (Kevern and Walker, 2013; Foster and Epps 2020). However, this rich potential is not always realised, and can result in such communities causing harm (Epps et al. 2021). Religious leaders have a key role in such communities, and in shaping the care they can provide (Carter 2021; Plunkett and Chen 2016; Kevern and Walker

2013) but little is known about how prepared or equipped they feel for this task.

To care well, leaders need training and support. With respect to Christianity, anecdotal evidence suggests that UK churches vary widely in their capacity for such care. Strategic, top-down encouragement to build such capacity is often limited: regional and national church strategies typically award care of the elderly very low priority compared to, for example, engaging children and young people (see, for example, the Church of England Vision and Strategy for the 2020s, which includes the aim of making churches ‘younger and more diverse’ but makes no specific mention of the elderly) (Church of England, ‘Vision and Strategy’ n.d.) We might reasonably assume, therefore, that a great deal of responsibility falls on church leaders at local level, who may feel under-prepared to lead churches which care well for people living with dementia. For example, while parachurch networks and ecumenical resources are available to offer local leaders support, and some work has been done to measure the effectiveness of such interventions (Kevern and Primrose 2020) very little is known about how easy these are to operationalise in diverse local contexts, and whether further steps might be taken to alleviate the church leaders electing to use them.

With that in mind, the *Educating for Inclusive, Caring Communities* project set out to ascertain the space currently awarded to dementia within Christian ministerial training programmes at Theological Education Institutes (henceforth TEIs) and to find realistic and meaningful ways to enhance it. It has been funded by the Sir Halley Stewart Trust, The Kirby Laing Foundation, and HammondCare Australia.

Participants agreed that consideration of the implications of dementia for the church was important, not least since its growing incidences were especially concentrated in churches with typically ageing congregations. For example, Geoff (UK TEI) called dementia an ‘increasing need [...] given the generational makeup of most of our churches.’ As Rebecca (UK TEI) pointed out, this was likely to mean that ministers would encounter both those diagnosed with dementia ‘and potentially quite a lot of undiagnosed dementia in those early stages.’ Eleanor (UK TEI) described working with people living with dementia as ‘an essential part of ministry for the 21st century [...] We couldn’t, we couldn’t not [teach it] [...] Because this is so much part of life.’ Mike (UK TEI) stated:

[As] education providers we not only need to meet the current needs but we need to at least be on the lookout for trends, for the current trajectory. And certainly this is part of the current trajectory, this is – we’re going to be seeing more and more people who have dementia issues [...] We would be very unwise to ignore that.

Following a brief methodology, this report offers a summary of the project’s key findings. It first explores the lived experience of dementia, personal faith and church, and second, the current space awarded to dementia at TEIs, and possible means of expanding this. It then sets out recommendations, aimed primarily at TEIs. It is important to emphasise that we do not expect any one of these recommendations to work universally, nor without troubleshooting, consultation and refinement. Indeed, we hope some of those reading this report might be willing to support this initiative by aiding us in precisely these next stages.

Methodology

Rationale

The *Educating* project set out to ascertain the space currently awarded to dementia within Christian ministerial training programmes at TEIs and propose realistic, meaningful, and non-problem-centred ways to enhance it (Kevern 2010; Friedrich, Woods, and Williams 2021). While theological education is only one route by which theologies, cultures, and practices of dementia inclusion in churches will change, it is nevertheless an important aspect which has received only limited consideration to date.

To do so, we identified and interviewed: TEI management, teaching and/or research staff; and people living with a diagnosis of dementia or recent or present carers for one or more people living with dementia. TEI employees are uniquely positioned to offer insights about the practical realities and mechanisms of Christian ministerial training. They could additionally offer insights concerning dementia care and inclusion in churches, aspirations in these areas, and ways of achieving them. In this latter regard, it was also vitally important to include people with direct lived experience of dementia in the context of Christian communities and care provision (Mason 2020).

The project ran in parallel in the UK and in Australia from 2021-2023. In the UK, the project was run by the University of Aberdeen, a public research university based in Scotland. In Australia, the project was coordinated by HammondCare, a non-denominational Christian charity providing aged care, specialist Dementia care and health care across Australia. These two sites were selected to identify both common threads and differences between these settings, allowing us to offer conclusions and recommendations which might, with suitable adaptation and sensitivity, apply to more than one national context.

Ethics

In the UK, ethical approval for the project was granted by the University of Aberdeen's Committee for Research Ethics and Governance in Arts, Social Sciences and Business.

In Australia, ethical approval for the project was granted by the St Vincent's Hospital Human Research Ethics Committee (application reference 2023/ETH00166).

Recruitment, selection and sampling

Across the two sites, we interviewed 55 individuals, 31 of whom were TEI employees (see Table 1).

Australia (n)		United Kingdom (n)	
TEI staff	16	TEI staff	15
PLWD	7	PLWD	5
Dementia carers	7	Dementia carers	5

Table 1. Study sample with breakdown by recruitment category

In both the UK and Australia, we aimed to interview 15 TEI staff whose roles covered diverse aspects of TEI curricula, development and management, and who represented TEIs of varying denominations and locations.

TEI staff were recruited following an initial email by researchers (JR, SC, TW) inviting relevant staff to consider participating and/or advertising the study at their organisation.

In the UK, the resulting sample included 15 individuals, representing 14 different TEIs (some staff were employed at several institutions, and at some institutions we interviewed more than one member of staff). The UK TEIs' denominational affiliations and locations are detailed in Tables 2 and 3.

Denomination	n
Anglican	6
Baptist	2
Church of Scotland	1
Free Church of Scotland	1
Methodist	1
Roman Catholic	2
United Reformed Church	1

Table 2. Frequency of denominations of UK TEIs at which participants worked

TEI location	n
England	10
Scotland	3
Northern Ireland	1

Table 3. Frequency of locations of UK TEIs at which participants worked

In Australia, the resulting sample included 16 individuals, representing 15 different TEIs. The Australian TEIs' denominational affiliations and locations are detailed in Tables 4 and 5.



Denomination	n
Anglican	3
Australian Christian Churches	1
Baptist	3
Catholic	1
Churches of Christ	1
Greek Orthodox	1
Interdenominational	2
Presbyterian	2
Seventh Day Adventist	1
Uniting	1

Table 4 Australian TEI participants' denominational affiliations

TEI Location	n
ACT - Australian Capital Territory	1
NSW - New South Wales	9
QLD - Queensland	1
VIC - Victoria	4
WA - Western Australia	1

Table 5 Frequency of locations of Australian TEIs at which participants worked

In both the UK and Australia, we aimed to interview 10–15 people with lived experience of dementia – either those living with a diagnosis of dementia, or recent or present carers for one or more people living with dementia. We considered it important to directly hear the voices of people living with dementia (Hudson 2016) and recognised that many people living with dementia can provide informed consent.

However, to safeguard those unable to consent, we restricted participation to those who retained both legal and cognitive capacity to do so, determined through conversations with gatekeepers, carers and the people living with dementia themselves. We also gave participants living with dementia the option of having a friend, relative or carer present or nearby throughout the interview, whether or not they were also being interviewed. We did not need to exclude anybody on such bases; informed consent was given verbally or in writing in every case. The relevant interviewers (JR, SO, LH) had training in conducting sensitive interviews with dementia patients.

We were open to interviewing anyone who had experience of seeking dementia support from a religious organisation, irrespective of whether they considered themselves 'Christians' (see Appendix 2). However, in all but three cases, the participants did consider themselves Christians, albeit belonging to diverse denominations, and with varied involvement in churches and Christian organisations both at the time of their interview and at other times in their lives. The exceptions were two people living with dementia in Australia, and one UK carer participant (who had instead worked with local churches within her role in residential care.)

In Australia, recruitment of people living with dementia and carers took place through HammondCare. As HammondCare employees, the interviewers (LH; SO) could use their own and colleagues' knowledge of residents and clients to identify prospective participants, inviting them to consider taking part. This meant that the participants living with dementia in Australia typically had more advanced memory loss symptoms than those in the UK, resulting in shorter interviews, shorter and less detailed answers, more repetition of questions, and more frequent long breaks during interviews.

In the UK, we reached people living with dementia and their carers by sharing an advert (Appendix 2) via specific churches, dementia charities and social media. The resulting sample of 10 individuals included three couples – each made up of a person living with dementia and their spouse-carer – who elected to be interviewed together. Conducting interviews with couples results in a different quality of interview: for example, some of the couples disagreed at points, and at other points one partner would speak as if for both individuals. This was borne in mind throughout: the interviewer (JR) was careful to ensure that both people had equal opportunity to have their voices and opinions heard; they were expressly asked to agree or disagree with what the other person said (though it is impossible to know if they were truthful!) Analysis of these interviews included noting those areas where the mood or answers had been, or seemed to have been, affected by the 1-to-2 set up.

Interviews

We designed the interview schedules to be used conversationally. In the UK, topic guides were used flexibly, while in Australia, topic guides were considered more prescriptive due to local ethical requirements. However in both countries, it was important to follow interviewees' leads in discussion. Participants shared insights, opinions, experiences and feelings in depth in both contexts.

We used the same interview questions in both Australia and the UK. The topic guide for TEI interviews concerned: the theological questions and challenges associated with dementia; churches' roles and capacities with respect to dementia care; educational strategies and mechanisms for incorporating dementia within TEI programmes; and the practical considerations and implications relating to

these. Importantly, many TEI participants also shared personal stories of their encounters with dementia among family members or within their church congregations. The topic guide for participants living with dementia and their carers concerned: what it means to live well, including in light of a dementia diagnosis; the role of faith and religion in their lives; the relationship between faith and dementia; future hopes and fears; experiences seeking support from churches; and how churches might better support people living with dementia and their carers.

The UK interviews were all conducted by one researcher (JR) whereas the Australian interviews were divided between four researchers, who interviewed people living with dementia and their carers (SO; LH) and TEI staff (SC, TW) respectively. Interviews were conducted via video-conferencing, telephone or in-person (per participant preference and feasibility) lasting between 12 minutes and 2 hours, then transcribed verbatim, initially using Microsoft automatic transcription facilities, before being checked twice (first by the interviewer, then by JR). Because the Australian interviews were divided between four individuals, for comparison's sake the interviewers stuck more closely to the questions suggested in the interview schedules and the order in which they appeared than the UK interviewer did. Nevertheless, using the same interview schedules in both countries generated a dataset highly amenable to direct comparative analysis.

Analysis

All checked transcripts were uploaded to NVivo 12. The TEI interviews and interviews with people living with dementia and/or their carers were analysed separately using different coding frameworks. The UK and Australian data for each recruitment category were stored

separately, but analysed using the same coding framework. The coding utilised thematic analysis principles (Braun and Clarke 2006). Table 6 summarises the stages of thematic analysis proposed by Braun and Clarke. For this project, familiarisation was achieved by reviewing and close reading of interview transcripts. Code generation was based on a random sample of transcripts taken from both international contexts, and closely informed by the themes which underpinned interview questions. A draft coding framework was piloted on a further random sample and tweaked in light of this. It was then organised into a tree structure, whereby the most significant themes had nested 'sub-themes'. The full dataset was coded using the 'top level,' significant themes first, before the data coded to each of those top level themes was coded again using the sub-themes. One researcher (JR) coded the whole dataset for consistency, and to gain oversight. All names used throughout this report are pseudonyms (Appendix 1, p.71).

Stage Number	Stage Description
1	Familiarisation
2	Generate codes
3	Combine codes to create themes
4	Review themes
5	Determine theme significance
6	Report findings

Table 6



Dementia, Faith and the Church

Overview

Conversations about faith and engaging with churches with people living with dementia and their carers and supporters were central to this project's design. And participants were clear that both parties deserved consideration: as Bernie (Australia) phrased it, 'really – it's both of them. You can't focus on one without remembering the other.' These conversations covered wide-ranging aspects of church life and personal faith. Participants were quick to point out that dementia, faith and church were difficult topics about which to generalise. Participants' observations ranged in scope and purview from the individual to 'the church' as a whole, and often related to specific local settings and congregations.

The subsections below illustrate the breadth of aspects of church life and ministry upon which dementia has a bearing. They are organised under heuristic headings, each illustrating a facet of church life – though the reader might note that their contents are often interrelated. While a degree removed from the TEI settings into which we primarily expect this report to speak, it is important to include these conversations because they inform and steer the aims and character of its proposals. We also hope that the observations made in this part of the report – which explores several aspects of church life and faith – will prove useful to those engaged in local church settings with a heart for inclusion. To this end, this section ends with a guided reflection exercise based upon constructed case studies.

God, faith and dementia

The topic guides for interviews with people living with dementia and their carers asked where participants felt God was in their experiences of dementia, and how dementia

had affected their personal faith. These questions elicited varied, rich and often candid responses.

Many retained firm faith and a sense of God's presence with them as they journeyed with dementia. For example, Heather (Australia) explained, 'I don't worry about my faith because I know God's backing me all the way along the line.' Edie (Australia) whose husband has dementia, similarly felt God was:

right there with us. [...] [My faith's] still as strong [...] you know, it's all part of God's plan [...] we know that it's going to work out. And that He's going to be there [...] [And my husband's] faith is strong as well [...] God's there with him.

Indeed, Elizabeth (UK) explained that her encounter with dementia had:

made my faith stronger [...] simply because I do have conversations with God every morning. Yeah. So yes, I think it's made me more in contact if you like [...] [And] If I'm having a bad day he tends to get blamed for it. {Chuckles} But yeah, I do have good conversations and sometimes not quite so good conversations. But yeah – but I just feel he's always there, and have that conversation, whether I'm in a good mood or a bad mood.

Some felt their faith had changed. Since Isobel's diagnosis, she and her husband Ian (both UK) had discovered newfound joy and a sense of God's direction. Through their church community, they felt God had surrounded them with 'love and kindness' (Isobel) and 'people that care' (Ian). Ian concluded, 'It's so nice knowing that God is leading us on this path.' Isobel explained: 'I thank God. Every single day. That we are having a wonderful life

[...] God showed us that road. And it was meant to be. And it's been life changing.'

Others depicted subtler changes to how they expressed their faith. For example, Marian (Australia) explained:

when I was caring from my parents there was very little time so God got lots of arrow prayers and I tended to read my Bible on the go, when I was waiting, things like that. But I also feel like God understands that because He's put me in this [situation].

However, Marian did not feel as though '[dementia's] affected my faith as in detrimentally. It certainly made me ask God a lot of serious questions. When things were getting really tough, it [...] led me to [...] ask him to help me more.' In addition to finding her own faith became more questioning, Marian also described her mother's faith continuing, suggesting dementia 'gave me the opportunity when my mum was unsettled to read the Bible to her [...]. And because she had a faith, even if she didn't say it, I could tell that she understood what I was saying.' She mused that there were still 'discipleship opportunities, but not in the same way that we imagine them for most people,' and that it would require 'trusting that God's word will be just what they need to hear.'

Charlotte (Australia) described reassuring her mother of God's purposes:

[Sometimes] the reality of her losing her short-term memory really grabs hold of her [...] she says 'Why do I have to keep living? Why can't I just die?' [...] I just say to her 'Because it's just God's plan for you, and you just have to be patient and trust in him' [...] [I find that] just helps you to have that acceptance [...] that that God has got a plan for you, and if you can be patient and trusting, you will see that plan even through the tough times.

As her mother's carer, Charlotte felt that her journey with dementia had 'deepened it [my faith] [...] I have prayed for support and guidance in supporting [Mum] through the dementia and sometimes for having patience myself.' In a similar vein, carer Bernie described herself as 'hugely blessed because God has, in the whole process, given me a massive ministry in pastoral care [...] with many people [to] encourage them in their walk with God.' She felt God was 'continually focusing me more and more to what's important and what's permanent, what's eternal [...]. And I love it.' By being forced to learn about dementia, she saw God 'teaching me. I was learning and sometimes it was frightening.' But she nevertheless described a 'real feeling of peace' that God had a 'perfect plan.' She tried to embody 'acceptance of God's will with joy.'

Melissa (UK) spoke rapturously about the ways in which her faith was 'enriched [...] better and deeper' through journeying with dementia. When I asked if she had concerns about her faith as dementia progressed, she replied confidently that she did not. She gave two reasons. The first was that her father had 'had dementia and he still knew who God was. He didn't know who I was or didn't know where the bathroom was, and he could still pray to God and he could still talk about God even then.' The second was that she believed God could work through her in this new context: 'God filled me up with his love and care and grace and mercy [...] making me more beautiful because of the fact that I've been broken.' Convicted of her own ongoing spiritual vitality, she was determined that churches 'need to believe that we [people living with dementia] can still be spiritually alive. That's so important because the spiritual never dies - never dies.'

Similarly finding purpose, Amy (Australia) explained that

[M]y sister and I still see her [our Mum] having some form of witness [...] her language skills are very good still and they often get her reading the Bible for the chapel service [...] and we've had reports from [people about] how much they enjoy her reading. She's a great encouragement to the staff. She's always tells them 'thank you' and 'you're beautiful' and compliments them.

She thus felt that 'despite all the angst and everything, [Mum's] still showing God's love to people.' This was not to say Amy had not 'struggled at times.' For example, she described a time when her Mum:

was in hospital and she was in a lot of pain and she would just lie there and cry out 'Jesus, Jesus, Jesus, Jesus, Jesus, Jesus.' And at that point I was going, 'Look, God, she's been faithful to you all her life. What are you doing? Why is she in this much pain for so long? Why is she so distressed?' [...] I don't know. I question that. I think it's all part of our fallen world [...] I think it is a cruel disease and I do question... the question, 'Why?' But I see it as, you know, God's obviously got it figured out. [But] I wonder why she has to go through the prolonged deterioration [...] At the moment, while I can see her as God's instrument, that's fine. But I don't understand. But he's obviously got his ideas.

Amy's repetition and uncertainty suggest no easy answers had been forthcoming.

Others struggled to see divine purpose in dementia. Carer Arthur (Australia) explained 'I've heard people - and I've probably said it myself - you think, "Well, why did [this] happen to them?" [...] But apparently there's a purpose

for all that [...] There definitely has to be a higher hand there controlling things.' Elizabeth explained, 'I guess for me, my question to God would always be "Why?" But I'm not going to get the answer to that! So it's just coping with it.'

For others, dementia brought more challenging changes. Lucy (Australia) felt her relationship with God had changed amid caring for someone with dementia. She felt 'abandoned,' and struggled to engage in some practices:

I don't feel like reading the Bible and I don't feel judged by God for not reading the Bible [...] I listen to worship music. And sometimes I can sing the song and other times something I think "No, it's not well with my soul" - I can't sing that one.

She felt her faith had been

totally stripped back [...] right back to what's essential [...] I feel like my faith is simple [...] like I've got this hard faith inside me and nothing's gonna crack that. A kernel [...] I've got that. Nothing's gonna crack that. Getting there has been hard.

Though she did feel she received spiritual support 'from my friends, my friends and family. I've got a lot of Christian friends and family,' Lucy felt that discussions specifically about her faith and dementia 'can be quite hard to with friends. Because none of them have anybody with dementia.'

While Heather still felt 'God's with me all the time,' she felt that, since her diagnosis: 'sometimes I think he lets me go a little bit, to see if I can do it by myself [...] I just find that it gets hard.' Linda (UK), similarly, said:

God's with me all the time. That's what I feel. The problem for me is that when I get low I can't find him. So I think - I'm not able to say God makes dementia wonderful. I'm not able to say that.

These questions, uncertainties and accounts of faith changed and challenged are reminiscent of lament. Swinton describes lament as 'a very particular form of prayer [...] that takes the brokenness of the human experience into the heart of God,' calling it 'an act of faithfulness in situations where faith and hope are challenged' (Swinton 2007, 104, 109). Certainly these participants' accounts are redolent with complexity, uncertainty and pain – but they are also channelled through faithfulness in a God who cares and has a plan, however unclear that plan might be. In a separate paper (Riley and Swinton, forthcoming) we have used data from this project to propose that lament might provide a helpful theological framework for responding to dementia in a way which acknowledges grief and loss, but does not lose sight of personhood, spiritual vitality or hope.

As this short section has suggested, the relationship between people's personal faiths and dementia was complex and varied. Amid diverse journeys, some felt they lacked spiritual support. Others pointed to important but informal sources of spiritual support. Friends and family members – as we have seen above – supported some people's spiritual journeys, while others pointed to time spent in nature, and private rhythms of prayer and reflection. Some participants – particularly those interviewed in Australian care settings – highlighted the important work of specialist chaplains. As such, while this report emphasises local church settings, it is important to note that these are not the only locations in which spiritual support for those journeying with dementia is found: indeed, we suggest that

these informal sources, and their relationship with the kinds of complex personal faith journeys to which the above points, might prove rich avenues for further research and reflection. For now, though, we turn to the church, beginning with its buildings.

Physical and Material Accessibility

When asked what a 'dementia friendly church' looked like, many participants thought first of the church building. Participants highlighted several practical adaptations and considerations. These included guaranteeing level access, keeping the building warm, and ensuring there was clear signposting (or, people available to give directions or accompany people) whether to tea and coffee after the service, to accessible toilets, or explaining how things worked.

Some suggested having volunteers available to support people finding seats, and getting up and sitting down again as needed during a service. Information ought to be provided in large print, on clear displays, and there should be working hearing loops. Several participants noted the risk of sensory overload, requiring consideration of volume and (ideally static) lighting levels. Several recommended providing quiet spaces for those with sensory needs or struggling being around large numbers of people. All of this might mean – as Donna (UK TEI) pointed out – a 'need to rearrange the way we [...] set out churches.' On the other hand, it might mean 'not rearranging the church,' limiting physical adaptation with a view to consistency and familiarity.

Support getting to church was also important. While some people living with dementia had family or friends who provided this, others were grateful that church leaders and members had noticed and met this need. Lucy, for example, described how 'when she [Mum] wasn't able

to drive herself, they [church leaders] took up the rein of making sure she got to church and Bible study.' Similarly, Edie's mother was still able to go to church and benefit from fellowship because congregation members organised to 'pick her up and take her and include her.'

Some noted that online provision during and after the COVID-19 pandemic had improved access for those less able to travel, but that it was not without limitations. For example, Elizabeth, who lived with her husband some distance from their church, explained, 'I think the online is good for people like [my husband] and myself, where it's difficult to get out and attend something like that. Although I much I would much prefer to go for [...] socialising and being with other people.' She also pointed out that if her husband were living alone, he would struggle to access online materials without support.

Where it was difficult to bring somebody to church, an alternative lay in taking church to them. In the UK, many participants highlighted the importance of 'bringing church' to people living in care facilities or hospices, offering prayer, worship or communion services. For example, care worker Roseanna (UK) had worked to provide regular Sunday services at the residential care facility where she worked, delivered by 'a local vicar when available' or, when necessary, by her. The local catholic priest also came to offer 'communion for them on a regular basis,' and she praised his ability to adapt the ritual for 'different levels of dementia. Those who still have an understanding of what is happening participate fully. One resident who has advance dementia no longer understands communion, so the Deacon sits with them in prayer.'

Because the Australian sample of carers and people living with dementia was primarily recruited through residential care facilities, a

good deal of discussion concerned services hosted on-site in these locations by chaplains or by visiting ministers. Many spoke very highly: for example, Amy described them as 'familiar, safe places' whose convenors knew to keep 'things simple, so talks shorter, simple language, maybe just even prayer and praise with Bible readings and singing familiar hymns rather than sermons [...] a service that gets the need.' Heather was grateful that the words to familiar hymns were projected, and each line emphasised as it was being sung, helping her to follow songs.

Worship, Liturgy and Sacraments

Not least having witnessed such chapel services, many participants highlighted the importance of adapting services to enhance accessibility. Kate (UK TEI) suggested that many churches needed to do 'a lot more listening [and] consulting and thinking' in this vein. Several participants suggested shortening and simplifying sermons by preaching slowly around one main point, and shortening readings and providing clear print-outs of the words. Considering service design, Rebecca recalled her father's experience, whereby being expected to stand for long periods of time had caused fainting. She also wondered about reducing service times, and removing the expectation that everyone might regularly move between sitting and standing. Marian noted that being expected to navigate a prayer book could be 'confronting, confusing and stressful' for someone with dementia, even if they had used it previously. Amy made the same point, suggesting that reduced 'capacity to follow' complex services could be alleviated by having the liturgy 'just printed on a sheet straight, that would [improve] their capacity to participate and not stress about missing things so they could worship better.' Edie explained:

their [people living with dementia's] concentration span is very limited sometimes. And then they'll want to get up and go and do things and, you know [...] [And] from [my husband's] point of view because of the pains that he suffers he can't cope with long [services] and it's well and truly accepted that he can go.

The value of familiar music, liturgy and readings for people living with dementia was an important theme. Many cited examples of people with significant memory loss joining in with prayers, songs and liturgies – particularly the Lord's Prayer, Psalm 23, and songs such as 'Jesus loves me, this I know' and 'What a Friend we Have in Jesus.' They described these as 'simple' tools that enabled spiritual engagement and encouragement and facilitated inclusion, as well as bringing joy, calm and contentment. For example, Lucy explained that her husband 'really responds to music [...] even if he doesn't understand what is going on in the church service or the message he listens to the music.' Bernie described 'God in his great, great mercy [allowing] the seeds that were sown' in childhood to stimulate spiritual recognition later in life.

While several participants discussed developing services specifically for people living with dementia, others emphasised the value of including everyone in corporate worship. For example, Tabitha (UK) felt that it was 'much better for [Ted] to be with people of all ages. For social stimulation [...] If you have too much of "special things for dementia" it kind of overtakes your life completely.' Geoff felt this approach better signalled inclusion, explaining 'I can understand why, maybe, you would have a service that is specifically aimed at folks with dementia, but I would much prefer if it's possible for those people to be included in the service and worship that everyone else is included in.' Megan (Australia TEI) suggested some of corporate worship's value lay in being sustained by a congregation, citing theologian

Francis Lily, talking about:

when we're dry or in spiritual desolation, that if we're in church and we're surrounded by believers who are worshipping somehow that helps us to worship because we see them singing along [...] there's this sense of: we're coming together with other people who are worshipping God and it lifts us, even if we're feeling that we're in darkness.

For those living with dementia, Megan suggested, the 'presence of worshippers together' meant that even if they 'can't sing the words of the song, [they're] hearing it all around.'

Recognising that both dedicated services and inclusion in corporate worship had advantages, the solution perhaps lay in providing both and accommodating varying needs. Participants suggested there was a balance to be struck between designing varied worship services for the broader congregation, and ensuring familiarity for those living with memory loss. Marian suggested 'perhaps offering at least one older hymn every service' and educating the congregation 'as to why we're including that,' to build understanding and acceptance. Melissa similarly proposed having 'at least one, preferably two' familiar hymns which people living with dementia might recognise and be able to 'join in.' Bernie described deliberately choosing songs which 'aren't upbeat' because they were less overstimulating. Relatedly, Hannah (TEI, UK) wondered whether some worship styles might be more easily adapted for accessibility than others:

I go to quite a loud, happy-clappy church and I have trouble imagining how someone with dementia...like how you can do anything to make that accessible in a way [...] let's just say for some traditions it will be easier.

More broadly, several UK TEI participants suggested churches needed to counterbalance innovation and creative invention with the value of familiarity. Having noted that musical and liturgical familiarity were ‘key’ for her father, Rebecca suggested:

[I]t’s lovely that we [the church] do all these different new things and try and change things and do seasonal provisions and messy church and mix it up. But actually, I think for a dementia friendly church, I think it would need to be that kind of structure and familiar words [...] that it goes through in a way that [...] makes people recognise what they’re doing.

Similarly, Justin (UK TEI) noted that ‘we [the church] place a high premium on being innovative and creative and constantly changing and reimagining’ but sought to press upon his students the importance of ‘the frameworks that you get from familiar liturgy, familiar songs [...] familiar shapes to passages.’ He continued,

I try and remind them: for some people this might – these might be the only words that they remember, and that they are home for them, that they’re familiar for them, and even if they’re unable to participate in any other aspects of gathered worship [...] And they know they can recite these words because they’ve said them since they were children. And there’s a real gift that you can give [...] singing the old songs because those might be well-known and well-loved to people who really can’t participate in any other way for whatever reason [...] what they [trainee ministers] think of as dry routine might actually be very life-sustaining for other people who rely on it [...] holding those liturgical spaces [...] can actually be a real act of justice and service.

Participants also emphasised that how people responded to the unplanned was as important as such elements of service design, planning and delivery. Sharon (UK TEI) thus suggested that trainee ministers might helpfully consider how to balance ‘keeping a sense of order in church services alongside openness to where God might be leading the service’ which might include disruption or interruption. Equally, as Mary gestured, this implicated the whole congregation:

It’s creating the understanding that within a church service - because someone might react slightly differently or be tearful, or perhaps become incontinent, so you calmly and quietly and have materials to deal with it. There’s no need to make a fuss [...] it’s being aware, being sensitive, being informed. But then together the community can then work with it.

Many spoke highly of instances they had witnessed in which behaviour which might be considered ‘disruptive’ was not treated as a problem. For example, Ruben (Australia TEI) described one church whose regular attendees included people living with serious mental illnesses, who were considered

part and parcel of the congregation [...] even though there was sometimes difficult behaviour [...] there was no one there who said ‘Ohh, these people don’t belong here.’ They’re just part of where we are. And so we [...] deal with those things. We can’t solve it, but we can choose to be compassionate and loving.

He believed that the same attitude could – and should – be shown towards people with dementia. Geoff wondered whether this was easier where those living with dementia were ‘long-term, beloved members of the church’:

there are always going to be people in a congregation who are disturbed by people who 'disrupt' the service [...] the same sort of people we upset if a child's crying [...] in my experience, the people that I've had in the congregation who have been suffering from dementia are long-term, beloved members of the church. And most people are extremely tolerant in those cases, and understanding. More so than maybe when a baby cries.

Melissa had attended several churches since being diagnosed with dementia. On the one hand, she described:

the most inclusive church that I'd ever been to. They had disabled people in wheelchairs. They had people with learning disabilities, people with dementia. They had people who wandered around [...] But nobody who didn't have these things minded. It was all one big family and I thought 'Well, you've got it right.'

She hoped more churches might follow this pattern, being 'willing to accept interruptions.' On the other hand, she had had a more negative experience at another church, after having 'a meltdown because they did something unexpected. And I couldn't cope with the unexpected [...] they said - when they found out I have dementia, they said, "Well, we don't want you coming here then.'" Bernie similarly found it exclusionary when church leaders responded to disruptions by 'saying to the carer, "You really need to take her outside, please"':

Relatedly, some discussed the expectation that people will attend the same church regularly and consistently – something which some people living with dementia and their carers found very difficult. Charlotte for example, was pleased to have found a church where

There's never been any pressure to come more regularly or any expectation that we should come at certain services or whole services. We've just been welcomed each time we have [...] And everyone in that church environment [...] is just super accepting [...] [Mum] and I both feel really welcome and accepted.

Communion

Many participants drew particular attention to services of Holy Communion. We have already noted communion services conducted in residential care facilities. Megan's mother had benefitted from these, and the familiarity of having 'the same matzo bread, the same little cup with the same taste of grape juice.' Mary suggested, more broadly, that 'people with dementia will go back to the rituals of their childhood.' Some churches adapted how communion was distributed to make it more accessible. For example, Anthony (UK) noted that when his wife Ada became less mobile and more easily disorientated, ministers would bring the elements to her. Rebecca noted that embodied aspects of the ritual could change for someone living with memory loss. Her father 'had got to the point where someone gave it [communion bread] to him just to put it in his pocket because he didn't know that - he didn't even know that he was meant to eat it.'

The theological educators felt dementia provoked interesting theological questions about Holy Communion. The eucharist is theologically very complex, varying considerably in form and meaning across different denominations and eras – as well as between individuals. Noting that, in some traditions, children are not permitted to take communion until they have demonstrated a certain level or form of understanding, several participants raised the question of whether those with dementia who could no longer demonstrate

such assent ought to be similarly excluded. For example, Geoff recognised that ‘theologically, for some denominations [...] there might be some issues of whether or not the person with dementia has an understanding of what they’re doing when they receive communion.’ He pointed out, though, that including people living with dementia in communion was an important signal, to them and others, that they were part of a church community, and not excluded from it. He concluded, ‘I would hope that there are maybe not churches that would deny people communion on that basis, but that that could be a theological issue.’ Dementia’s capacity to unsettle assumptions about who can participate in ritual, and how, meant many TEI participants saw its rich potential as a topic for teaching and discussion.

Visiting and Community Ministry

Beyond church services, visiting people in their homes or places of residence were considered important dementia ministry, as valuable for the carer as for the person living with dementia. Catherine (UK TEI) described ‘sitting in somebody’s house with a carer and someone with dementia and talking to them about faith and singing a hymn’ as ‘a deeply theologically-informed task.’ Many participants described these visits’ importance for spiritual and social inclusion. Charlotte suggested such ‘spiritual support’ was particularly important for carers, supporting ‘deeper spiritual belief to get you through some of the more tedious, sad times.’ Bernie described the simple power of taking time to ‘sit down with this carer who you know has had a traumatic time [...] and just listen.’

While important, many recognised such ministry could be difficult. Christine (Australia TEI) called it a ‘challenge’ to ‘go and be present and contemplate what’s going on and understand.’ Morgan (Australia TEI) suggested that:

giving of ourselves to someone in relationship [...] [that] they’re not going to be able to reciprocate [...] that is gobsmackingly awful because we’re designed [...] to give and elicit responses in relationship with people. So when we give and we get nothing back, it is exhausting and hard and sad [...] if they’re [ministers] willing to do that, it’s going to be costly.

Participants suggested that some ministers’ reluctance related to perception that the person living with dementia was unable to benefit from such visits. Melissa remembered, disappointedly, one church’s pastoral team concluding that ‘there’s no point visiting because they’ve got dementia [because] they won’t know whether you visited them or not.’ Tabitha pointed out that it was also important for churches and their leaders to avoid the assumption that carers could cope and did not require help. Some recognised such ministry was not every minister’s strength. Amy, for example, described one minister who:

just didn’t handle Mum well [...] would get irritated by the repetitive questions [...] [M]inisters have different spiritual gifts and his just wasn’t [...] he just didn’t have the skill-set to deal with it [dementia] [...] some people can handle people with dementia and other people just can’t.

While interviews focussed primarily upon pastoral care for congregation members, participants also highlighted the importance of looking outwards: for churches to ‘reach out’ to local people (Christine, Isobel and Ian); to ‘open up and be outward looking’ (Mary); and to ‘be serving their communities [...] seeking to be a blessing, to help them flourish in whatever format [...] most particularly for those who are weak or marginalised or at risk’ (Robert – Australia TEI). Bobby (Australia TEI) suggested that churches should ‘always

be responding to issues facing our Australian people in Australia, whether they're Christian [or] not Christian.' Supporting people living with dementia was thus a matter of 'Christian compassion and missional concern.' Mike suggested one of the 'privileges and challenges' of ministry was 'equipping people to use their gifts well and wisely within the fellowship within the wider community [...] not simply caring for this distinct group within the church, but recognising that you are part of a wider community.'

Gifts and Service

Many participants attached importance to building church cultures where everyone could serve and share their gifts, including those living with dementia. Kate called this 'creating a church where they can both be served, but also give,' rather than one in which they were only seen as 'consumers' rather than 'active disciples who minister.' Isobel pressed home the importance she and Ian attached to their church 'roles,' explaining: '[My husband] does readings [and] I'm on the rota¹ for the door to welcome people into the church. So we've got [...] roles in the church. And you – you just feel part of the family.'

Megan echoed the importance of service for belonging, noting how important it was for her mother to continue volunteering hospitality following her dementia diagnosis, feeling 'that she's got a role even when she's got reasonably [...] advanced dementia, she's included.' Equally she was pleased that there was 'no obligation [...] [Mum and Dad are] allowed to just receive [...] their presence is valuable and good in and of itself.' Others echoed this, advocating a balance between valuing people for who they were – rather than their ability to contribute – without therefore assuming those living with dementia had nothing to offer. After her dementia diagnosis, Linda had been frustrated

by assumptions that she therefore could not help run the church community groups she had previously established – something she felt able, with support, to continue doing. She felt there needed to be a more positive church culture 'about trusting people with dementia to still have gifts and ways that they can serve.' Similarly, Kenneth (Australia TEI) wanted:

the church to recognise that there are people - children of Christ - who deserve [to] and can profit by the church's ministry [...] And if, even more importantly, if we can learn that we can profit from their involvement, that would be a miracle.

Sharon suggested this required a realisation that '[it's] not just about including just people to be nice to them. But including people in communities because we learn from them – we benefit.' She suggested that this shift in perspective might see churches inviting other neurodiverse people to take on volunteer roles.

Fellowship

Participants consistently ranked fellowship among the most significant aspects of church life, fostering support and belonging. Such fellowship ranged from groups and activities – including those specifically for people living with dementia and their carers – to the more informal and incidental.

Deborah (Australia TEI) described a weekly church group designed to provide carers with 'respite,' explaining:

They have a number of volunteers and they have a number of people with dementia, but you don't know who's the volunteer and who has got dementia. Because they take all of that out of it and treat them all as normal human beings and they do things together [...] they worship together. They have fun together.

¹Or, in Australia, a roster

Isobel and Ian attended a local church's weekly dementia 'hub.' Though initially reluctant, she described arriving for the first time:

Somebody came and took my hand and said "Oh hello. Would you like a wee cup of tea or coffee?" And that was that. That sentence, "Would you like a wee cup of tea or coffee?" has been totally life changing.

They had also since joined the church's Sunday congregation, where they felt they could 'lay off' problems:

We're not the biggest congregation, but we are the friendliest [...] our heart is as big as the world [...] there's no judgement. Anybody - everybody is accepted. You never have a problem to yourself. You've always got somebody you can lay that problem off [onto].

Elizabeth and her husband also attended a church group specifically aimed at people living with dementia which 'really helps us considerably.' She described it as a 'godsend' – a weekly opportunity for her husband to socialise and enjoy 'talking to people and mixing with people' while she could spend time with carers in similar positions, coming to 'realise, then, you're actually not doing this on your own.' Similarly, Amy suggested the value of such groups lay, partly, in providing a space where carers could have a 'break,' knowing 'that they're [their loved one living with dementia] is in a safe place.'

Others described 'small groups' and 'home groups' not specifically designed for people living with dementia. Megan described a group to which her father belonged:

They call themselves The Gents. Dad hosts it in his kitchen around his kitchen table and it's about five or six men who meet [weekly]

and chat and drink tea and eat biscuits. And these men have known each other for decades [through] the church [...] chewing the fat [...] peers at your age that are living through the same realities. So here's a bunch of men together, [coming] together as community and supporting each other.

Tabitha and Ted (UK) were grateful for their 'lovely home group' which Tabitha described as 'very, very supportive.' Having known them for many years, they found group members 'very understanding and helpful' with respect to Ted's dementia diagnosis. Tabitha explained: 'I know that I can ring any of them at any time to say [...] "We're having a really bad time. Can you pray for us?" So yes, very, very important. Probably more important than church really.' Tabitha continued:

The most important thing about going to church [...] is that it is a very friendly, sociable, warm place to be [...] the fellowship is really important. As well as the teaching, of course, but the fellowship with friends and new friends is very important.

This fellowship meant that they felt part of a 'big church family,' describing church as 'a comfortable place to be and therefore a safe place to be.' As a carer, Tabitha felt confident at church because she knew that 'when he [Ted] wanders off there are several people who will say "Oh don't worry! He's over there".'

Like Tabitha and Ted, others highlighted the importance of informal fellowship, particularly surrounding Sunday services. Charlotte described church as a weekly opportunity for her mother to connect 'with like-minded people' providing a 'burst of joy [...] of connection.' Similarly, for her mother, Edie explained, 'she just loves being at church and being included and having friends there.' Asked what she most valued about church, Shirley

(Australia) who lives with dementia said, 'I like the people that go there [...] [who] know you and they recognise you and they say your name [and ask] "Oh, how are you going?"' Kenneth thus identified the importance of including people living with dementia in all aspects of church life:

We've got some people [at church] who don't really know what the minister's talked about last week and hardly know what he's talking about today. But we welcome them and have a cup of tea and enjoy their time and involve them [...] it's accepting the interest that old people have in still being part of the church and accommodating that.

Not everyone, however, had such positive accounts of inclusion. Lucy contrasted her experiences at two different churches. She described her old church showing 'kindness and love' by including her partner, who lives with dementia. She had felt 'gathered in' and appreciated the 'intimacy' of fellowship, feeling 'comfortable' there, able to 'express how you're feeling safely and with support.' Having since moved to a new church, she found it difficult that 'there's times where people just don't acknowledge [partner]. Because - I don't know what they're thinking. Maybe they think [...] that he's a sort of a nonperson because he's got dementia.' Similarly, Sharon was disappointed that when she took her mother (who lives with dementia) and her friends to a church coffee morning, those running it:

come and ask me questions like "Would they like a cup of tea?" Well, you think, just ask them! [...] But I think that shows fear and you know, "Will they understand the question? What response am I going to get? Is it appropriate to ask them?" And so I feel like there's a distance about dementia and other people in church.

Bernie suggested that building congregational awareness of dementia would encourage the inclusion of people living with dementia in such informal fellowship:

Let's just say [...] 25 or 30 people go to these information sessions. You've got 25 or 30 people in your congregation now who understand more about dementia [...] [So] they may make an effort to, next time they see her [person living with dementia] in church, to approach her and encourage her [and] the person who cares for her.'

Ethos, Attitudes and Understanding

Echoing Bernie, it was striking that, when asked what churches needed to better support people living with dementia and their carers, understanding, kindness and a desire to include them were among the most common answers. Thus Marian spoke for many others when she replied: 'Respect. Acceptance. Kindness. Being willing to accommodate people.' Indeed, an ethos of inclusion was presented as a bedrock, underpinning a desire to design inclusive services and diverse fellowships, tolerance of interruptions, and the impetus to ensure that people are able to travel to church, and, where possible, both serve others and be served when they arrived. Thus John (UK TEI) wanted churches to be 'deeply welcoming,' able to 'handle – in a very caring, welcoming way – those who are struggling with dementia,' showing them that they 'are still loved and cared for and welcomed, regardless of that.'

In this respect, participants often saw dementia as an indicative issue. They wanted to see churches cultivating such attitudes—kindness, acceptance, accommodation, care, welcome, sensitivity – to bolster inclusion more broadly. For example, Megan aspired to:

[H]onouring those who are more frail. However that frailty shows itself. Whether you're intellectually disabled or you have advanced dementia, or you're a battered wife, or you have complex mental health. Whatever it is, that those who are most frail and fragile are the ones that should be welcomed the most and made to feel the most included.

Similarly, Mike suggested that a 'healthy church' was one which:

recognises the reality of diversity. A church that has both [...] a real sense of unity – even though [...] we're not all the same [...] that welcomes all, that affirms all, and that has an appropriate level of care, of encouragement, of teaching etc. [...] that not only affirms the individual who may have dementia or other capacity issues, but that recognises [...] that each of these individuals represents a family or circle of friends and that these conditions have very obvious knock-on effects.

Many participants suggested building understanding of dementia and its effects was a crucial step in bolstering such ethos and – as John phrased it – get to 'a place [...] where the broader congregation understand [...] what this [dementia] is like' such that they could 'both empathise with those who are suffering with dementia and those who are caring for those with dementia.' Acknowledging that '[D]ementia causes a lot of fear in our community, a lot of uncertainty, and leads to isolation,' not least because people were 'not always informed,' Eric (Australia TEI) suggested that education might give 'structure and opportunity' to churches full of 'kind, generous, interested' people to become 'great friends of people with dementia.'

Charlotte suggested giving congregations 'a quick snapshot' of how to support people living with dementia would alleviate 'the burden away from people who are trying to care for them.' Indeed, Bernie described a course she had taken where lay people 'learned a little bit about what it's like to have dementia and how to relate to people with dementia.' This had helped build understanding and initiative in a congregation where, previously, very few had 'experienced anything to do with dementia.' Linda argued that, fundamentally, becoming certified 'Dementia Friendly,' also lay in attitudinal change:

There is a great need for education within for both the clergy and the congregations, and for people [...] Dementia is messy and difficult. And the Church of England needs to come to grips with that. [...] They [specific churches] can seek to become 'dementia friendly' which is -- there is a sort of, you know, a sort of process. But it's being open [...] to the unexpectedness. And the spontaneity of messy, untidy, real life [...] we just all need to be aware.

Some acknowledged that changing attitudes and building such understanding might be a slow, imperfect process, but would nevertheless represent important progress. Donna said 'educating the church is like turning around on an aircraft carrier [...] it's a very slow process, but even one degree of turn changes the direction.' Morgan highlighted the importance of 'recognising that community is complicated [...] that there're gonna be some people in church who are going to say and do stupid things [...] some people are foolish, everybody's sinful.'

Section summary

This section has explored participants' experiences of faith and church in light of encounters with dementia. It has illustrated the wide-ranging implications of dementia for different domains of church life. Across these, participants' experiences varied. Some shared excellent examples of support; some had more cautionary tales. In this sense, this section echoes both Megan and Brian (both Australia TEI):

'My guess is that on the whole, they're [churches] not that well equipped [to care for people living with dementia and their carers].'
(Megan)

'When we as the church are living as the church, there is no community on Earth like this [...] [fuelled by] God's kindness [and] common grace.' (Brian)

Similarly, the accounts of people's personal faith and relationships with God were complex and nuanced, evidencing both struggle and strength as they journeyed with dementia. In sum, the evidence suggests that both difficulty and divine and human faithfulness characterise the life of faith amid dementia.



Case Studies

Using the case studies

Below are two composite case studies. Neither is based on the experience of real individuals: rather, they are both constructed from stories told in interviews. In this sense they are 'true to life.'

They also capture themes which ran through this section of the report and illustrate the extremes of participants' experiences in local churches.

They also begin pointing to the broader applicability of issues relating to access and inclusion which affect people living with dementia, but are also of broader concern regarding other categories of exclusion, vulnerability, disability and neurodiversity to which the church ought to give greater consideration.

We hope readers find these case studies useful for personal reflection, or discussion with others. These suggested questions might help as a starting point:

- What do you think it is like to be a member of these two churches? Which church would you 'fit in' better?
- What is each church doing well?
- What are each church's weaknesses?
- What more could these churches do to support people living with dementia?

The Recommendations towards the close of this report include some further suggestions for reflection aimed at churches.



Doris and Dave

Married couple Doris and Dave are both in their mid-70s. Having enjoyed stimulating careers, and after raising three children, they embraced retirement and downsized to a new area several years ago. This meant leaving the church where they had been for decades - but they had instead joined St Mary's church. St Mary's was vibrant and intergenerational, with thriving children's ministry. The main Sunday family services were often noisy affairs, so sometimes Dave and Doris went to the earlier prayer-book service for some peace and quiet.

Dave was diagnosed with Alzheimer's a few months ago. For Doris, that explained several things that had been troubling her for a while. She felt increasingly reluctant to leave Dave alone in case he became forgetful, disorientated and distressed. Always so polite, Dave had rather lost his filter, now much more likely to verbalise his thoughts about people's appearance. His knees had long troubled him, but Doris had started to notice how laboured Dave looked getting up and down – especially given the suddenly increased frequency of his toilet breaks.

Newly attuned to Dave's needs, Doris had realised how tricky church could be for someone with mobility issues. Getting to the toilet required a long walk to the church hall next door, and they had only recently had the ramp installed to replace the rickety steps. No-one explained how you were supposed to get up and queue for communion – it was just assumed everybody knew. Same with navigating the prayer book, actually. She was quite nervous about Dave's new tendency to talk out of turn in public too. Noisy though

family services were, Doris had heard rumours about a family whose son with a diagnosis of autism stopped coming to St Mary's because people told them his habit of shouting out at strange moments was disruptive.

While Doris and Dave's daughter, Sarah, came round whenever she could to chat and to check Doris was managing, she was busy with young children and a full-time job. And the other two children lived too far away, really, to 'pop in', and only visited once or twice a year. Doris also felt a strange grief when, on occasion, Dave didn't seem to know who Sarah was. She wondered who he might forget next.

While Doris and Dave had told a few friends at church about the diagnosis, they were reluctant to spread word around – not that it was easy to hide Dave's forgetfulness. But they had noticed recently that fewer people were checking in with them on Sundays, or inviting them for dinner. Both Dave and Doris had previously volunteered to help with tea and coffee on Sunday mornings, and for the occasional charity coffee mornings the church hosted. But in the last few months, they hadn't been asked to.

The minister at St Mary's had recently left and been replaced by a new minister, Rachel. Nice as Rachel was, Doris didn't really know her very well, and didn't want to admit how badly she was struggling to process what was happening to Dave. She didn't want the new vicar to think her faith was weak. It wasn't weak – she was just adjusting. It did make her pine, though, for the minister at their old church, who had known her and Dave so well. She fondly remembered a time when she was in hospital after an operation, and he made the time to come and visit her.

Jim

Jim is 82 and long retired from a successful career in sales that saw him travel the world. Nowadays, he lives in a retirement village. He moved there after his wife, Jane, passed away a few years ago. Their only son, Simon, visits regularly, and is pleased to see that, despite being diagnosed with vascular dementia a few years ago, Jim is still active and sociable, keeping up old hobbies of pool, bridge and reading.

When visiting places for Jim to live, they had looked for somewhere with friendly staff who knew how important it was to facilitate activities. They had also been pleased to find somewhere with a chapel and a chaplain, who hosted prayer sessions and made time to sit and chat with individual residents of all faiths, as well as leading two interdenominational services a week. Jim often goes along to the Wednesday services and can regularly be found in the lounge sharing a joke with Pete, the chaplain.

On Sundays, though, Jim heads to the local methodist church. The minister there – Richard – has known Jim for many years, since before he moved. Knowing Simon often works weekends, Richard asked some congregation members to set up an informal schedule for someone to collect Jim to take him to church each week.

A lifelong methodist, Jim is known for his beaming smiles and booming voice as he joins in with old favourite hymns with gusto (though not necessarily in tune). Provided he's given a

helping hand up to the lectern, Jim does the Bible readings every so often, using a large-print Bible that's kept on stand-by to make it easier for him. Others in the congregation – particularly some who are dyslexic - also find this Bible helpful, whether they are leading the readings or following along from the congregation. Every week after the service, the congregation enjoys tea and coffee served at the back of church, and Jim wouldn't miss it for the world – provided someone can point him in the right direction: he has been known to wander off outside rather than to the kitchen. He loves an opportunity to natter and - ever the salesman - needs no time at all to charm his way to an extra biscuit or two.

When Jim was recently hospitalised with pneumonia, both Pete and Richard came to visit him. While they enjoyed their usual talk about sport and played some card games, they both noticed Jim was more tired and confused than normal, and the nurses seemed concerned about how quickly his health was deteriorating. Though Pete wasn't sure Jim would remember it, he made sure to spend some time praying, and was pleased to hear him muttering the Lord's Prayer along with him. Both Pete and Richard spent time listening as Jim told stories about Jane, his travels, and snooker tournaments from the 1970s. Richard made a mental note to call Simon and check on him. He didn't know the man well, but knew from his own experience of caring for his mother that someone else taking the time to ask after you was very valuable.

Dementia in Theological Education

We move now to explore dementia in the context of ministerial training and formation. The first subheadings – *Leadership, Trends and Theological Breadth* – build the case for preparing future church leaders for dementia ministry, while the later headings – *What Ministers Need, and Mechanisms for Training and Education* – illustrate what this preparation can and should look like.

Leadership

Participants agreed that church leaders played a significant role in shaping churches' attitudes and approaches to dementia, speaking highly of those who embraced dementia ministry. For example, Elizabeth described her minister as 'fantastic [...] she has loads of empathy, she understands dementia [...] [and listens] to what carers need.' Confirming this negatively, some noted that without leaders' support, dementia ministries rarely thrived: Eric reasoned that 'where resources end up is heavily determined by leadership [...] [So] if church leadership is not for it, it's going to be a hard battle.'

Forming church leaders' attitudes and values was therefore considered central to their training. Edie, for example, suggested that the most important thing ministers needed to care well for people living with dementia was 'Compassion. Compassion for not just the people living with dementia, but family, and the concern to be wanting to support and help in any way that they can.' Church leaders should, in turn, model such attitudes to congregations. Megan explained:

Church leaders should be the ones that set the tone for their communities. They should be the role models [...] modelling how to be community [...] if it's a strong Christian leader [with] lots of fruit of the spirit and lots of emotional intelligence [...] it makes for a good,

healthy church [...] They really need to have the conviction that people with dementia are as valuable, in fact, possibly more valuable [...] and model it to the community.

Extending this sentiment beyond dementia, Thomas said ministers should:

lead by example, making it clear that the inclusion of people who may not be neurotypical is good, and helpful, and an appropriate thing for the life of the church. And that can be through the way they educate the congregation, the way they address the congregation.

Likewise focused on preaching, others suggested that 'what church leaders value and talk about from the front sets a culture [...] and conveys "What do we value here?"' (Eric). Similarly, John explained:

More than anything else, ministers set something around the culture and ethos of the church. To what extent [this] community is deeply welcoming and values all regardless, and that works hard to understand and empathise, would be something that would be set, predominantly by them [...] Because they're the person [...] saying a lot of things at the front of the church and therefore they're setting the tone.

Participants were conscious, however, of church leaders' stretched capacities. Indeed, asked what church leaders needed to care better for people living with dementia, Steve (Australia) – himself a dementia patient – simply replied 'Time', Marian said, 'most pastors are busy people,' for whom visiting those unlikely to remember their visit 'might appear to be, for want of a better word [...] not a valuable use of their time.' She felt ministers needed to 'see that there is value in ministering to people

who appear to be, for want of a better word, past it.' Similarly, Rebecca said:

I don't think most clergy are getting enough headspace to be able to think about dementia as well as children, young people and families, and schools [...] and I think if we're in a church that's always focused on numbers and growth and getting families in, then it's a church that is saying those that are older are less valuable [...] it's hard to buck that trend sometimes, as clergy.

Many therefore agreed that good leaders would delegate effectively and build strong teams, being both 'a modeller of good practice and then an equipper of other people' (Eleanor). As Amy put it, dementia ministry 'absolutely shouldn't just be the minister's job [...] [or] responsibility' but should use 'different people's skill sets,' drawn from across congregations. Tabitha clarified that she 'wouldn't expect the vicar [...] to have hands on care himself, but there might be somebody in the team [...] who looks after pastoral care and organises home visits.' Anthony suggested that, where leaders struggled in this domain of ministry, wisdom lay in recognising this, and being 'able to spot [...] the people that can do it, and to support them.'

Mary suggested that 'this has to be a community response [...] rather than a hierarchical triangle' precisely because 'there will be people in your congregation who are very well experienced, very well informed about this [more] than you ever will be.' Several theological educators noted, though, that this would require a shift in attitude to overcome 'a temptation that you expect the minister to be omni-competent' (Mike). Mike allied this to 'a biblical model where all of God's people are equipped for works of service' and 'God is in control, he's in charge, but he has gifted his people.' Resultingly, one of the 'privileges and challenges' of church ministry lay in 'equipping

people to use their gifts well and wisely within the fellowship within the wider community.' William (Australia TEI) observed that the most effective dementia ministry he had witnessed was carried out by

a pastoral care team to whom the minister would provide leadership [...] training and pastoral preparation [...] a quality minister or ministry leader who knows it's not all about her or him, and they have prepared members of their congregation to be part of an active pastoral care team.

The minister also used 'simple acts of prayer and preaching on a Sunday morning [to bring] awareness to the community.' Certainly some of the most powerful accounts of dementia ministry in this study were of convicted leaders working alongside church communities with that same conviction. Describing the dementia ministry at his church Ian explained, '[Minister] is really amazing. She's the wheel, and the helpers are the spokes [and that] keeps it all together.'

Clergy with dementia?

Briefly, two UK TEI participants wondered how churches might respond to scenarios in which clergy themselves had dementia. We have neither the data nor capacity to explore these questions further in this report, but acknowledge their importance, and both practical and theological significance, meriting further exploration.

We always seem to think [about] clergy as though they're somehow immune? But we will have clergy who have dementia, whether it's undiagnosed or diagnosed [...] [So] how do we care for our clergy who have dementia? What does preaching look like if you got dementia?
- Kate

I suppose the interesting thing that we haven't thought about is those in training who might have dementia themselves [...] I'm betting that we would probably think they shouldn't be trained. And that would be an interesting discrimination. – Rebecca

Trends

At the end of the previous section, *Dementia, Faith and the Church* we suggested that ethos, culture and attitudes were foundational to creating an inclusive church environments. The TEI participants suggested that, to create such cultures, churches would need to deliberately challenge existing norms, trends and assumptions which fostered exclusion. Justin described these as important questions of 'justice' which theological educators needed to grapple with in relation to numerous forms of exclusion, relating to dementia, but also to race, class, neurodiversity and disability. They discussed five intersecting trends.

Excluding the margins

When asked why they were keen to participate in this project, some TEI participants' motivation stemmed from concern that many churches were under-equipped for dementia ministry. Thus Matthew (TEI, UK) cited his 'conviction that the church has been pretty poor and caring for people in this part of life.' Similarly, Daniel (Australia TEI) referred to 'very often inadequate responses by churches.' There was a shared sense across the interviews that this was, however, part of a broader pattern whereby churches excluded those 'on the margins.' Thomas, for example, suggested that where churches were not currently well-equipped for dementia ministry inasmuch as:

churches are not very well equipped to deal with anything that falls without the parameters of what one might think of as, sort of, "normal

participation" in the life of the church. And that they tend to find anything that pulls them out of those parameters as difficult to assimilate or difficult to accommodate.

Correcting such exclusion would, Donna stated, require the church to 'be more welcoming of noise, difference, change [...] willingness to toss the agenda out the window [...] flexibility and openness, which takes courage and bravery.' Similarly, while Catherine considered including those outside 'normal parameters' was an important part of the churches mission to act 'counterculturally,' she acknowledged this would be a challenge: '[The church's] capacity to totally challenge how we understand the world [...] I think is very rich – but it is flipping hard [and] it's not very sexy.' Relatedly, Eric suggested it was important to 'switch disability around [...] from being something that' a rare tragedy to actually a very normal part of being human.'

Outsourcing

Commenting on a related trend, several participants suggested churches and their leaders needed to reclaim ownership of pastoral care. Thus Matthew hoped to show trainees that '[engaging] with dementia and mental illnesses [...] [and] special needs [...] is not something you can simply outsource. It belongs in the church.' He wanted to instil an 'unshakable conviction that a significant part of your time is going to be spent caring for - or overseeing the care of - people in their congregation, rather than prioritising other aspects of ministry,' such that this might become a 'ministry of the church that it was glad about,' seeing 'car[ing] for people with dementia [as] one of their privileges.' Echoing these sentiments for Australia, Christopher (Australia TEI) suggested that the church was 'in danger of washing our hands of our responsibilities' for pastoral care. Ruben

similarly noted that such care had substantially 'moved outside the church to other providers.' Alasdair (Australia TEI) instead wanted churches to 'recognise it [care for people suffering with dementia or other long-term illnesses] as an area of significant, important ministry.' More broadly, Terry (Australia TEI) suggested that churches should show 'care and responsibility for people [...] more generally [...] around mental health, informed around dementia, other neurological issues. So there's a whole range, I think, of pastoral issues that pastors should be on top of.'

Assumption of cognitive norms

As noted above in relation to Holy Communion, dementia shone a critical light upon the cognitive biases which underpinned many theologies of salvation, faith acquisition and discipleship. Thus Matthew suggested dementia should force people to question the 'assumption' that 'you get saved by your ability to understand and articulate the gospel.' Similarly, Morgan suggested that conditions such as dementia should force churches:

to rethink the overly cognitive perspective we have on faith, and the notion that somehow somebody has to be able to articulate a particular form of words or a particular credal statement [...] for their faith somehow to be legitimate, or to for us to have confidence [...] or because the person with dementia can't remember [...] that somehow their faith is in question.

Donna suggested that dementia also raised questions concerning discipleship where '[cognitive] functions are affected [...] can transformative learning still happen?' While it was widely agreed that dementia raised such questions, there was also a shared sense that there were, presently, few settled answers, and a need to think more deeply about 'the whole

subject of discipleship [for] people on the margins of church [...] [and] how do we progress the[ir] spirituality and increase discipleship' (Sharon).

Goal-orientation and production-orientation

Dementia also shone light on what John called the 'danger in church life that [...] you're particularly looking for people who can contribute.' Churches, he suggested, needed to be less 'goal-oriented' and more 'person-centred,' aspiring to 'demonstrate culturally that actually [...] older people with dementia are still utterly valued,' as part of a broader pattern of 'fundamentally [...] valu[ing] people for who they are [and] their God-given nature rather than value them because they are economic contributors to the system.' This would mean asking 'countercultural questions' about what it means 'to put at the centre of our church communities those who [...] aren't productive, aren't contributing in a capitalist, consumerist sense.' Similarly, Catherine suggested churches needed to challenge a broader social norm of being 'driven by what's productive and what's gratifying,' instead embracing 'the upside-downness of the Kingdom [of God].' Alasdair similarly framed the challenge as one of resisting unhelpful cultural values, suggesting churches:

need to have a view of people as inherently valuable, regardless of their capacity [...] [We] can tend to diminish the value of people who can't contribute [...] And we tend to have a very instrumental view of people in the West that bleeds over into the church [...] [W]e need to in some ways unlearn, and help people to see people as inherently valuable, and time spent being, not doing, as important.

Eric echoed this, suggesting some church leaders are 'tempted to go with what's impressive and efficient and seen to be successful. And the slow, inefficient, strange

work of being with somebody with dementia isn't - it's kind of not sexy.' Similar ideas underpinned Kenneth's critique of

the misguided opinion [...] that if we're not getting a result for our ministry then it's a waste of time [...] if we preach to dementing people and they don't immediately join the congregations and increase their giving each week, then there's no point wasting our time with them. Well, that's a terrible approach and very un-Christ-like [...] churches need to be able to be challenged [...] to see ministry with dementing people to be relevant and worthwhile.

Ageism

To see such ministry as 'relevant and worthwhile,' Justin suggested churches must overcome 'ageist prejudice' which 'wouldn't see ministry to the elderly as having the same value as ministry to the young.' Similarly, Deborah suggested that many churches had long acted as if 'we didn't have to worry about older people.' But, she continued, 'If we're going to be true about the mission of the church, we need to engage with all God's people.'

Theological Breadth

Dementia thus functioned as a critical lens, revealing assumptions and norms which served to exclude. Moreover, the TEI participants identified numerous theological sub-disciplines wherein dementia might similarly unsettle and disrupt norms, assumptions and ideas. Illustrating each of these with quotations, Table 7 also highlights dementia's wide breadth of theological interest.



Disability theology	‘Our understanding of God [...] must transcend any form of disability or any form of incapacity [...] God can meet people at their point of need in their particular situation - that nothing about an individual’s capacity or lack of capacity can any way, in my view, limit God.’ Mike
Ecclesiology	‘What does it mean to be a part of a church community, and what are the things that hold us as part of that church community? Especially [if] we have a strong belief in justification by faith alone?’ Bobby
Eschatology	‘In the eschaton we are all versions of ourselves and [...] who knows what lies ahead. It may be forms of dementia. [So] who will we be before God at the end of time, informing, then, how we understand our present lives now.’ Catherine
Gifts and Discipleship	‘What happens when somebody’s [...] agency as a disciple is compromised [...] how do we hold people in their faith when their capacity to hold themselves in it is diminished?’ Morgan
Pastoral care, pastoral ministry	‘Pastoring to me is about [...] what God has done is doing and will do in Jesus Christ - the compassionate impulse of Christ to pull those who are compromised in any way or vulnerable in any way into the bonds of a salvific relationship is core to the church’s work.’ Christine
Personhood, theological anthropology	‘Dementia raises all sorts of really fundamental questions about human personhood and our sense of personal identity across time [...] to do with what it means to be made in the image of God, what it means to be a person, what it means to remain a person at the end of your life, what we might think of as the existence of someone beyond the grave.’ Thomas
Practical theology	‘How do you lead in a context where you have to consider the different [...] priorities in terms of a local setting. And worship as well, and worship practice.’ Karen
Scripture, Biblical Studies	‘I lecture within [...] a Christian tradition that’s high on the value of the word. [So we] default time and time again to ministry that’s heavily verbal, that relies on people’s cognition [and] assume cognition and memory are key to discipleship, and [...] have trouble articulating ways of being a faithful disciple if you can’t join a verbal Bible study group where you can answer comprehension questions.’ Eric
Soteriology	‘It certainly brings in conversations about people’s understanding of salvation and thinking. Is this person still saved?’ Terry

Theodicy, the problem of evil	'We're a death- and pain-denying society [...] including in the church [...] we have an inadequate theology of sin, we don't deal with the brokenness of the world very well [...] what theology do leaders have about the challenges of being a mortal human being?' Alasdair
Theology, Christology, Pneumatology	'[Dementia raises questions about] pneumatology - theology of the spirit [...] What is the spirit doing? How does God relate to human beings?' Megan

Table 7

What ministers need

Participants therefore recognised the breadth of dementia's significance for theology and for the church, not least highlighting room for improvement and growth. Participants noted the church leader's particular role in this journey towards inclusion, for the sake not only of people living with dementia and their carers, but more broadly for those 'on the margins.'

As institutions which have formative influence on future leaders, there is a clear role for TEIs to play in building a church better-equipped to care for people living with dementia and their carers, and better-poised for inclusion. Rich theological work also takes place in TEIs, ranking them among the organisations who should be advancing understanding of dementia's theological complexity and significance. Building theological understanding, Christine suggested, would help to build pastoral capacity:

[T]he number of people who have dementia are [sic] going up, the fact that the church attendance is increasing in age [...] I think it's right at the beginning of being able to understand the phenomenon and work out how to bring that human phenomenon into their pastoral embrace of the church. There's a long way to go.

While there might be, as Christine put it, a 'long way to go,' TEIs are among the places where this journey needs to start. In the remainder of this section, we therefore explore what this start might look like.

Forming dispositions, building knowledge

Like church communities, participants suggested church leaders needed both dispositions towards inclusion and specific understanding of dementia. Lucy suggested that 'first of all' ministers needed 'a basic understanding of dementia and how life-changing it can be,' not least for carers. But they also needed to show 'kindness.' Similarly, Marian suggested 'I think it needs education and I think it needs a willingness to want to include people [...] [to] be accommodating and accepting and welcoming to people with dementia.'

Both forming dispositions and nurturing specific knowledge are central to most TEIs' aims. For example, Matthew explained that his institution's student outcomes constituted 'goals in three areas [...] character, skills and knowledge.' Many indicated that formation was central: indeed, several participants therefore agreed that the term dementia 'curriculum' was unhelpful, preferring terms such as pedagogy, formation and equipping. Megan used 'the

word formation very deliberately rather than curriculum' to emphasise that bestowing 'head knowledge' alone was not the institution's aim. Similarly, Bobby aspired to 'equipping students' and 'shaping their hearts [...] to have a deep love for other people.' Donna explained:

[We focus on] attitudinal change: the mindset, the principles [...] and then based on the context within which they find themselves, then they can use those tools to engage with a more open and more friendly, welcoming church.

Many echoed Donna's emphasis on 'tools' and 'principles' future leaders could translate into diverse and unknown future ministries. Thus Mike described 'equipping students with good principles and with good practice [so] when it comes to the interface with real people that they will have the personal skills as well as a theological education [...] the timeless principles to equip them.' Similarly, Kate explained

'[Students are] being given the transferable skills [...] tools so that no matter what you face [...] you know what healthy church culture looks like.'

Some presented foundational dispositions and transferable skills as pragmatic emphases given the impossibility of preparing ministers for an unknown future concerns. Catherine described equipping 'theological improvisers' with foundations of theological and scriptural knowledge. As Megan explained:

We [are] not only preparing clergy or pastors for the future that we can predict, but also for the future we can't yet predict [...] clergy or pastors who are formed to be able [...] to educate themselves theologically, being able to maintain the long distance in terms of prayer and relationship with God.

Participants identified a range of skills and dispositions that made up this versatile 'toolkit.' Table 8 illustrates these non-exhaustively.

Theological reflection; reflective practice	'How to think on the ground and do theology on the ground.' Hannah
Pastoral care; pastoral theology	'Some general pastoral skills and methods that are applicable across a whole lot of human contexts.' Eric
Listening skills	'Listening well and listening with our spirits as well as our ears [...] for any kind of situation.' Hannah
Counselling	'We do cover listening skills, counselling skills, they're quite important.' Sharon
Contextual ministry	'How do they interpret that information within their own congregations and communities and parishes.' Kate

Communication skills	'They're taught nuts and bolts of any pastoral conversation.' Hannah
Engaging with/ interpreting scripture	'All that stuff in the curriculum that needs to be there for being able to write sermons and lead Bible studies.' Megan
Worship design and conduct	'[We explore] preaching as pastoral care, communion as pastoral care, worship as pastoral care – so worship leading, so the structuring of the service. So how do we pastorally care for a group of people through how we structure our services, how we preach?' Donna
Research	'I want to help students to develop a research acumen to understand, "How do I look at this issue? How do I identify at something going on here? Where do I go from a Christian worldview to find that information?"' Terry
Prayer	'I believe helping students in their lives of prayer and intimacy with God is foundational for teaching them about how to love people.' Megan
Curiosity	'Give people a gift of being hungry and being curious [...] of wanting to keep on learning.' Kate
Person-centred	'They'll have an openness and a heart and an understanding [...] of people.' Bobby
Spiritual rhythms	'We are trying to prepare them for a long life of being pastors and that means good rhythms of self-care, so they last the distance and don't burn out.' Megan
Love	'They need to be taken on a journey that is about loving God and loving neighbour.' Megan
Emotional intelligence	'[We do] work in emotional intelligence [...] because we found many people in ministry didn't know how to manage their own or others' emotions.' Alasdair

Table 8

Most TEI participants agreed, however, that formation and versatility needed to be complemented with specific, focussed attention on certain likely scenarios. John explained: ‘What I don’t feel I’ve got to do is cover every possible pastoral care scenario [...] But I am going to quote some pastoral care scenarios because they’re important ones.’ Participants widely agreed that dementia was one such ‘important’ pastoral scenario, an ‘obvious area that the pastor [...] will encounter’ (Mike). Thus most echoed Kate’s suggestion that

[T]raining is about giving people tools to face whatever happens. And it’s about creating a spirit and creating [...] a character [...] But on the other hand, I think it is really important to look at specifics. So it’s a balancing act. [...] So I think giving specifics on things like dementia [...] because it’s such a massive thing that is happening in our society, and because other congregations tend to be elderly, how can we not mention it, at least?

Carers and people living with dementia concurred: as Edie phrased it, ‘before they [leaders] can really do anything, they need to understand what they’re dealing with, with dementia.’ Shirley said church leaders ought ‘to understand the basic principles of dementia [...] to not only encourage the person with dementia, but also the people that care for them.’ Some emphasised awareness of dementia’s varied effects and presentation: Linda suggested ministers needed to ‘understand’ that ‘when you’ve seen someone with dementia, you’ve just seen someone with dementia. So somebody could have been diagnosed at the same time as me, and [...] our experiences of dementia could be totally different.’

Others noted that education was necessary to help prevent harm. Kenneth highlighted the importance of correcting ‘unhelpful and

uneducated approaches’ which presented dementia as a ‘sort of a punishment’ or the result of ‘unresolved anger’ or demonic possession. Catherine explained that a ‘working knowledge’ would help stop new ministers ‘bowling in and causing all manner of harm and upset because they just have no understanding whatever.’ Others suggested building church leaders’ understanding would help overcome widespread ‘uncertainty’ (Charlotte) and ‘nervousness’ (Kate) regarding dementia. In this vein, Sharon argued that ‘knowledge can build confidence’ suggesting that ministerial candidates ‘need to be guided’ in how practical skills ‘apply to specific contexts.’ Specifically, she argued that they ‘need exposure too,’ not least since such experience would reduce people’s ‘fear factor in their engagement with people with dementia. Similar to engaging with people with autism.’

There was near unanimous agreement with Sharon’s suggestion that effective dementia training would involve ‘exposure.’ Christine suggested that spending time with both people living with dementia and their carers would, hopefully, mean that ‘the phenomenon of dementia, is not this sort of scary exotic presentation [...] they’re familiar with [it], they know how to read it.’ Several carers and people living with dementia similarly suggested that the best way to build such understanding was ‘to physically do it, to be with people and [...] in amongst people with dementia’ (Elizabeth). Alasdair described such learning as an opportunity to ‘see the challenges, the realities, and start to see the way people care for these people as valuable [...] and to get a vision of that for the church.’

Emphasising first-hand encounters was part and parcel of many TEIs’ approaches, in which ‘placements,’ ‘practicums,’ and ‘shadowing’ – and reflection on these – were fundamental. Indeed, Mike described a TEI’s goal as ‘to equip

and prepare,' noting that his institution aimed to do so through 'a dynamic interface between the theological learning community and the local church [...] recognising that learning takes place in several different venues [...] [as] there's no substitute for [...] on-the-job training.' Echoing this, William stated 'classroom learning is only a patch on "dropping in"'. Summarising many participants' sentiments, Megan explained:

I believe profoundly it [ministerial training] needs to be formational and it needs to include real life immersion, reflective practice and it needs to be experiential. And that is so that the students are moved. And when they're moved, they learn.

Top-down pressure

Broader denominational structures play varied but often significant roles in shaping TEI curricula, including: validating them; informing their design; and delineating learning and training outcomes and criteria. Several participants therefore suggested that some impetus to include dementia within TEI training needed to come from such bodies. Ilse (Australia) drew parallels with the way in which many denominations had created structures that now meant learning to work safely with children was 'compulsory across the board' for trainees. Justin suggested TEIs would be most likely to incorporate dementia 'if our feet are held to the fire by the criteria that the church give us,' arguing that 'the real test for whether any [dementia education tools] get adopted in colleges like ours would be whether we are required to demonstrate this.' By contrast, he suggested, the absence of such a mandate would likely see dementia deprioritised. Kenneth similarly called upon denominational authorities to 'encourage and support this [dementia education] – both through funding and through their own moral support, regarding it as important.'

Continuing Ministerial Education

Some participants suggested that in addition to – or instead of – incorporating dementia at TEIs, it should be integrated into post-qualification training and professional development opportunities – what Morgan called 'ongoing education that clergy are rightly expected to be involved in.' Participants pointed to the compulsory schemes many denominations ran for new ministers, including: Newly Accredited Ministers Studies (NAM Studies), Continuing Ministerial Development (CMD) and Initial Ministerial Education 2 (IME 2), Internship, Post-Ordination Training, and Probationer Programmes.

Advocating this, some highlighted the greater likelihood of ministers having encountered dementia in their ministry, and of therefore having a 'felt need' (Daniel) to engage with the subject because it would come 'out of their practice' (John). Christopher suggested that:

proximal is what you need to be [...] So [teach dementia] when people are in parish ministry, rather than before [...] [So] it's only those whose awareness has been raised. They see their specific shortcomings and therefore have the desire for input [...] At college it doesn't work because it's too early.

By comparison, Christopher described pastoral theology as 'typically [...] the area that they [students training for ministry] are least motivated.'

While acknowledging they would alleviate pressure on pre-ordination curricula, most participants also voiced considerable concern about post-ordination training's capacity to provide consistent, effective education – including with regards to dementia - describing schemes as 'loose,' 'vague,' 'unregulated' and 'ad hoc.' Certainly these schemes vary

considerably. Some are run by denominational church structures, while others are partially or wholly TEIs' responsibilities. They last between one and six years; some are certified and others not. Few are highly structured, often because those participating had undertaken varied pre-ordination training at diverse institutions.

Some resolved that the way forward lay in a 'both-and' approach: while the topic ought to be introduced by TEIs, some of the more in-depth, practice-based consideration would also need to take place after qualification.

Mechanisms for training and education

Below, we explore existing approaches and possible mechanisms for specific, 'focused' dementia education at TEIs: modular teaching; placements and reflection; allusion across the curriculum; and extra-curricular spaces.

While we note that dementia's place in post-ordination training merits further consideration – amid broader conversation regarding the design, consistency and effectiveness of such schemes - this project's concern is with pre-ordination training, and we believe at least some consideration of dementia belongs in the latter. Post-ordination training is therefore not included in the mechanisms below.

The below discussion also takes for granted that most TEIs already seek to develop the dispositions and transferable skills important to caring for people living with dementia and their carers as part of students' 'toolkits' for future versatility.

We are also assuming an individualised approach. As Catherine pointed out, this perpetuates the 'expectation' that 'each individual has to be expert in everything' at the expense of 'a more collaborative approach

to ministry where people can specialise,' developing and sharing particular gifts, vocations and callings with other ministers. While there are doubtless questions about whether a collaborative approach might be more appropriate, this report speaks both from and into the individualised model which currently dominates.

Modular teaching

By far the most common way in which TEIs currently included dementia was as part of the taught content – typically seminars and lectures – of another module or modules (see below re placement modules).

Of the 30 institutions represented, 21 included dementia under the auspices of pastoral care (or, variously, pastoral theology, pastoral ministry, counselling). More often than not, pastoral care modules were mandatory for most ministerial candidates. Two TEIs incorporated dementia in modules exploring discipleship and spirituality, two within disability theology modules. In one instance each, dementia was incorporated in modules exploring: mission; reflective practice; worship; human finitude; ethics; and theology and psychology. Most of these modules were optional 'electives.' Where incorporated, dementia was classified in various ways (Table 9). While arguments could be made for dementia belonging in each of these categories, participants acknowledge that different classifications framed dementia in different ways.

Life stage ministry or generational issues

Disability

Neurodiversity, learning disabilities and cognitive impairment

Mental Health
Ministry with the elderly
Death, dying and bereavement and palliative care
Illness and suffering
Crisis ministry

Table 9

When included in other modules, dementia was explicitly mentioned in two sessions at most, amounting to between 1 and 3 hours of contact time. In some cases, it was only raised as a case study, and might not be covered every year, depending on who taught particular sessions. In several modules, dementia was an optional focus for assessment or assignment, though never a requirement for all students.² While dementia was therefore, in some senses, incorporated widely, many participants nevertheless raised concerns about the extent and sufficiency of such coverage: Hannah described ‘one session’ as ‘really quite inadequate in many ways.’ However, participants also consistently and emphatically argued that giving dementia any more curriculum time would be very difficult. Karen (UK TEI) explained:

[I]n the confines of ordination tracks, everybody is vying for a position within the curriculum [...] And, you know, is that enough [time for dementia]? I don't think it is! But can I, within the competing demands of the overall curriculum, put in any more?

Relatedly, as Daniel framed it, giving dementia more time would mean giving something else less: ‘[We could] try to do a full dementia education programme [but] there just isn't the time there. And the Hebrew folks won't like it

if you say, “Well, we can chuck out Isaiah” or whatever.’ Others suggested new ministers would have forgotten teaching a single session towards the beginning of their training programmes, or pointed to low enrolment on optional modules within which dementia was considered. Robert explained:

There is a such a limited amount of space in in the curriculum, and everyone wants a piece of that space [...] [W]e provide our students with quite a lot of flexibility in terms of what they can study, and [so] we've often found that when we've offered niche or boutique units of study that we think, ‘Yes, people need this,’ students then do not enrol.

In two cases – one in each country – participants had successfully run modules focussed heavily on dementia. In Australia, one TEI ran a course exploring dementia and end of life care. In the UK, one participant had convened a module on dementia and old age ministry, which blended classroom and field learning. Matthew explained: ‘there was such a buzz about that [...] I got emails from students saying thank you so much for asking me to do that preparation. It was really good.’

Other participants suggested it might be ‘useful if the Educating project were to create a model, optional module on dementia which TEIs could adopt and adapt. Most participants, though, raised the same concerns about implementing a ‘dementia module’ as they did about expanding its presence in other modules. Terry doubted ‘there would be the demand’ and also queried whether a ‘particular unit’ on dementia ‘would integrate it into a person's life and education.’ Geoff similarly suspected such a module would be ‘sidelined’ and suggested it ‘would be better [for someone] who has that real background in this doing the teaching. Which may be more

² Two participants who took this approach provided students with a finite list of assessment topics, including dementia, ensuring that each year, at least one student explored dementia in depth. Students were either required or encouraged to present this research to fellow students. These strategies helped to stimulate reflection on dementia among the broader student cohort.

realistic on a sort of one-day basis.' Mary and Justin (both TEI UK) both raised concerns about 'siloin' dementia into one module, which not everyone might wish or be able to take, while Justin also asked, rhetorically, 'Where do you stop?' noting that one might hypothetically construct modules exploring any number of topics and issues.

Format

Participants highlighted that it was as important to consider the format and approach to delivering such modules as their content. Many noted the importance of flexibility, facilitating evening, weekend and part-time study options to broaden access to their courses. Several advocated online teaching, which many institutions had embraced following the COVID-19 pandemic. On the other hand, there was widespread agreement that ministerial candidates would need to undertake at least a significant proportion of their training in person, echoing Deborah's suggestion that to learn 'pastoral care you need to be able to be present and face to face and actually interact in learning, which you can't do to the same extent on Zoom.' Balancing the two, Megan suggested TEIs needed to be:

alert of how pedagogy is changing. So that's thinking about online and remote curricula and interactive and collaborative projects, real life scenarios, cultural differences [...] [and] online learning [...] how technology can enhance the course materials. But also I really believe we need flesh and blood [...] relationships need to be built and experienced in real-world contexts. [...] a curriculum that's delivered through multimedia and of course involves field exposure, action, reflection.

Several participants were particularly enthusiastic about training modes which blended online learning, digital resources,

placements and periodic 'intensive' residential learning, facilitating flexibility without removing in-person learning opportunities.

Dissertations and special topics

While clear about the 'possible corollaries of giving dementia more curriculum time, several participants did note that it was important to be able to support students keen to undertake independent research or dissertations on the subject as part of their course. Students might also be supported to present research to others in their cohort, such that others can benefit from such input. Where an institution lacked either the supervisory capacity or expertise to support such research – particularly for an advanced degree – participants suggested forming partnerships with other TEIs and universities.

Reading and resources

Several participants emphasised the importance of providing students with resources and readings about dementia they could pursue independently, whether in addition to curriculum time or in lieu of it. For example, Eleanor explained that while she and colleagues could only briefly allude to dementia in the content of their pastoral care module, 'we give them a good bibliography, a lot of stuff about dementia so they can go and dig down deeper than they get in [...] classes.' Resources included books and pamphlets written by experts, including those invited as external speakers on the subject. Participants were particularly enthusiastic about resources which allowed students to 'hear the voices of people living with dementia [...] testimonies written by wonderful people with dementia [...] about their journey' (Megan). Some raised concerns that literature exploring dementia and theology was sometimes too 'heavy-going' for learning and teaching pitched first-year undergraduate

level, and others pointed to cost implications. As such, there was some suggestion that there was a need for more resources pitched specifically at such cohorts. Others highlighted that lists needed to be 'living' documents, kept up to date as new resources emerged, and as understanding continued to develop.

External speakers and provision

Where dementia was included in the taught curriculum or extra-curricular activities (see below) some TEs invited external speakers with expertise and experience of dementia 'in the field,' or those with lived experience, to deliver this content. Though conscious of budgetary constraints and available time, external speakers' had experiential authority, contributing to what Mike called an 'ethos' of 'wherever possible [...] want[ing] practitioners to be the teachers.' They could also alleviate concerns about the topic being too 'personal' for some staff, or too far removed from their expertise. Indeed, Karen allied this to the metaphor of the church as Christ's body:

[Be] willing to invite people in [rather than] feeling that we have to have all the expertise ourselves [...] perhaps if we extend the Pauline metaphor, ours is a larger body and there are a number of parts which we can bring into the classroom.

As Matthew pointed out, though, it was nevertheless important to ensure external speakers could pitch at an appropriate level, explaining: 'my one concern about [some] experts [...] is that they're too expert and they don't really speak to pastors as [with] something that would be within range for them.' Participants felt similarly about partnering with secular dementia charities and organisations. Many were enthusiastic at the prospect, recognising that there was a lot to gain from such organisations' expertise and resources.

Some might, however, need to be 'reframed' (Matthew) to be brought into dialogue with Christian ministry, such that they could 'help ministers do their job well [...] [with] enough grasp of what ministers might actually be doing' (John). Participants identified that dementia organisations with Christian origins or ethos might be a particularly valuable starting point for such collaborative work.

Placements and reflection

We have already explored above the importance of first-hand experience and encounter within ministerial training, noting that, in addition to supporting ministers' broader formation, 'placements' and 'practicums' might also be specific opportunities to gain understanding of dementia, its effects and manifestations.

Most TEs consulted already incorporated placements and shadowing within their modular teaching and assessment structures. For the large part, ministry placements were not specifically designed as opportunities for trainees to gain experience working with people living with dementia and their carers. Nevertheless, participants recognised such encounter was likely as part of the breadth of experience many placements were designed to generate. Mike explained:

you would hope that in any congregation [or] local fellowship of the church that that variety of people would be well represented: the old and the young the healthy and the infirm. And then if you have an experienced leader [...] you learn by seeing and you learn by doing.

Matthew described supporting students to evaluate which experiences they particularly needed to gain from their church placements, identifying:

the holes they want to try and fill [...] [and] it quite often comes up that they haven't really spoken to older people, so then that might [...] provoke them to go and look [for that] in their placement churches and have a conversation with them and reflect on that.

Some TEIs facilitated long- and short-term placements in hospices, residential aged care facilities and nursing homes and hospitals, or working with community initiatives such as memory cafes. Participants presented these as particularly rich opportunities to get to know people living with dementia. At Ilse's institution, students could undertake an elective placement working with people living with dementia. She stressed, 'everyone that's done that has come back [saying], "This was something else. We feel that we are a lot more equipped to communicate, to pray, to support those people"'

Kenneth's institution ran a scheme wherein students spent half a day a week for several weeks at a residential care facility with a specialist dementia unit. Before visiting, students received training on dementia, and afterwards wrote an assessed reflection on their experiences. Kenneth described it as a 'transformative experience' for many, 'where they can see God at work in the lives of a dementing old person who's still there, still alive, but they can't talk - and that they need to have that experience.' He explained:

Every time we have a group of new students [visit] they are amazed and taken aback at the tranquillity of the people they meet in the dementia unit. And one bloke put it like this, he said, "I felt I was in the presence of an angel." The elderly old lady who couldn't talk, but she just smiled and looked at him and held his hand. And there was something peaceful about it.

He also stressed that this was a 'safe environment' in which students were able to 'ask a lot of questions,' and have them answered by 'living human documents [...] the experts, the people who are going through the experience.' Others agreed such experiences would, beneficially, enable people to encounter dementia with the support of more experienced practitioners. Matthew suggested there were:

some situations that you can get experience of without having to feel very equipped or forewarned for it, but [...] talking to someone with dementia is not one of them [...] there's a familiarisation exercise there so that the first one they're having to see is not the one where they're asked to go and be the pastor and know what to do.

Where TEIs did not already host placements which facilitated encounter with people living with dementia, there was widespread enthusiasm about developing them. William explained:

[E]nsuring [...] one of those placements puts them in a circumstance where they [could] engage with families and individuals living with dementia [...] would be another way of ensuring there's space within the program for ministry candidates to learn how to be good pastoral carers in that setting.

Participants agreed reflection was an important complement to experience. Reflection was often already built into TEI placements, learning outcomes and expectations, taking place alone, one-to-one with supervisors or tutors, or within a small group. Many participants suggested guaranteeing opportunities for reflection on dementia was a further way to increase students' exploration of the topic. Indeed, Hannah suggested that there might already

be theological reflection on dementia taking place in light of students' placements which – by virtue of being student-led and somewhat incidental – is not reflected in course outcomes or outlines, or recorded, but rather 'slips through the cracks.'

Participants were cognisant of possible logistical challenges in establishing such placements, raising considerations about access, safeguarding and ethical practice. Equally, though, some pointed out that TEIs already deftly managed such concerns for other placements. Justin explained that expanding placement or shadowing opportunities to local residential care homes:

could be challenging from various kinds of safeguarding perspectives [...] [A]nd it wouldn't necessarily always be helpful to the old person, [so] we need to make sure we attend to that [...] [But] we already administer placements and so [...] it's a question of [...] the range of placement opportunities that we've got [...] it wouldn't be that hard [...] there's scope - maybe not for every student, but scope for some students to have that experience.

As Justin suggested, questions about scope also remain. Several participants suspected or had noted that the popularity of such placements was 'a bit hit and miss.' For example, Rebecca found that, when students were given suggested topics for reflection, 'the elderly one does often just get hardly any kind of answer.' Matthew suggested that in some instances, experience working with people living with dementia might leave 'people saying that they never want to go back because they found it so alienating.'

Allusion across the curriculum

Some participants advocated an 'integrated' or 'diffused' approach to incorporating dementia, suggesting 'the best way [...] is to

show that through the curriculum rather than having it as an isolated unit' (Morgan). In this vision, teaching staff across fields would be encouraged to use dementia as an example, illustration or critical counterpoint. Justin contrasted this 'diffus[ing] [dementia] through the curriculum [...] carefully [and] intelligently' to a 'tick box' approach of 'just design[ing] one more course.' Similarly, Matthew felt dementia would ideally be 'woven like a thread through everything you're teaching.' Whereas a specific module or unit on dementia would 'never find its way into their diary,' a dementia 'thread' would 'come out everywhere' and become 'part of the bedrock.'

Such an approach would help prevent dementia from becoming a niche, optional topic, or siloed part of the curriculum, instead encouraging students to begin 'making the connections' (Mary) between dementia and a wide range of theological fields (see Table 7). Analogously, Alasdair advocated 'integration of lifespan thinking' across the curriculum, such that the ministry implications of different life stages became 'fold[ed] into your thinking, in your ministry subjects, in your theological subjects,' forming future ministers' dispositions to consider 'what does it mean that we work with people across a range of ages?' Hannah drew parallels with her institution's proposal for integrating environmental consciousness:

That's not about adding a module on environmental science [...] It's how do we flood the entire experience for three years with a green ethos [...] it's about, from the very beginning, as we worship, as we socialise together, through the hidden bits of the curriculum also having this – this thread woven through [...] I would say the same thing about dementia.

Indeed, there was shared sentiment this was not just about 'dementia, it's the bigger

issues of mental health, it's the bigger issues of disability, it's all those issues that we somehow need to look at' (Mary).

Several participants particularly advocated this approach as realistic amid a 'curriculum [...] absolutely jam-packed' into which 'we cannot squeeze anything more' (Eleanor). For example, Mike explained 'I'm very much aware that I am time limited' and that dedicating smaller amounts of time to dementia as part of 'a wider discussion and conversation' was much more feasible than dedicating whole teaching sessions to the topic.

Participants recognised that this approach would require all academic staff to have what Justin called 'a constant attentiveness not just to the content but also to the way in which you teach [...] that takes quite a pedagogical shift.' Relatedly, Eric explained:

[I]n a perfect world [...] the theological syllabus is heavily integrated and applied [...] but then I know for myself when I'm lecturing [...] I really should be interacting, you know, with all these different voices on this. But I don't - but I just can't in the time that I've got.

Additionally, some participants queried whether this approach would provide sufficient depth. Equally, others suggested that, given the limited attention typically otherwise awarded to dementia, it was important that at least 'somehow this should be named and articulated and included in [...] cursory is better than nothing [...] naming it is better than not naming it.' There is perhaps, therefore, a balance to be struck between dispersing dementia and other issues across curricula, and facilitating dedicated, focussed teaching on these topics. Alasdair suggested that 'you do need some focused stuff' and 'deliberate theological reflection' but that this should be complemented by embedding

dementia as 'part of a foundation [...] [within] our anthropology and our theology and our practical ministry.'

Extra-curricular spaces

Most TEIs operated extra-curricular programmes. While their precise format and nature varied, these extra-curricular spaces had several things in common: they operated outside the main validated curriculum; they were (therefore) not accredited or assessed; and their subject matter was flexible and varied. Some were mandatory for ministerial candidates, and were variously also open to staff, other students, or visitors. Very often, they involved external speakers or facilitation. Examples included:

- Movie nights, followed by discussion and reflection
- Reading groups
- Regular seminars, webinars or discussion groups, often on weekday evenings
- Stand-alone evening or weekend seminars, training workshops or small conferences
- Taster sessions or short talks in orientation weeks
- Short courses hosted over a finite number of weeks (perhaps accruing into a qualification)
- Annual conferences, summer schools and study weeks
- Study days

Sharon and Eleanor also suggested that shared worship - typically mandatory - might be a site for awareness-raising around dementia or other issues, for example, as part of a sermon series.

Many TEIs had previously dedicated time in these extra-curricular contexts to dementia, and others agreed this might be an effective approach. By virtue of being extra-curricular, such sessions did not pile additional pressure

onto an already crowded curriculum. Several suggested that removing the ‘pressure of assessments’ might encourage student engagement. Equally, however, some highlighted that assessment for learning was a valuable tool for scaffolding high-quality training. Recognising the range of issues which, like dementia, might validly be incorporated into the main curriculum, some were concerned that such extra-curricular spaces might simply become an additional, non-assessed parallel curriculum which, with time, became equally crowded.

While flexibility was among the virtues of these extra-curricular spaces, this might also mean that particular topics might realistically only receive ‘sporadic’ consideration, limiting the extent to which such training would have a meaningful impact across cohorts. Recognising this limitation, some colleges had developed rotational systems such that their extra-curricular programmes and topics varied annually, but everyone undertaking ministerial training would have the opportunity to take every available extra-curricular session during their programmes.

Furthermore, as with optional taught modules, participants depicted the mixed appeal of extra-curricular sessions on dementia. While some had seen large numbers of students enrol, others had met with limited interest or enthusiasm. Catherine explained that hosting ‘workshop weeks’ - in which dementia was one of several available - ‘became a lot of work for students not opting to take them. Because they have other pressures.’ As Rebecca framed it, the most important thing to consider when designing extra-curricular spaces was to ‘go with what students are wanting to learn,’ which may or may not include dementia. Catherine suggested that a related solution might be to financially and practically support students who identified external opportunities to explore dementia.

Barriers and Concerns

TEIs have found, and therefore might utilise, a range of mechanisms for incorporating dedicated consideration of dementia within their ministerial training programmes. While most TEIs consulted were using at least one of the approaches just described, all participants felt their institution had room to improve. Equally, though, practical, candid reflections on the challenges of expanding such provision were among the most striking features of the interviews. The above has highlighted many such concerns, several of which cut across the different mechanisms explored. Indeed, none of these mechanisms was without drawbacks or potential limitations.

The confines of time and curriculum capacity were perhaps the most widespread concern: those who would advocate for more emphasis upon dementia lamented the very real constraints within which this would need to be achieved. This was all the more complex for TEIs whose students were on multiple courses or pathways, at different academic levels, and – in some cases – training for ministry in multiple denominations.

In this vein, some presented the challenge in terms of a hypothetical trade-off. Time and capacity were finite and therefore, as John put it: ‘If I’m going to put in more on this, I’ve got to take something out.’ Several echoed this sentiment, arguing that something else ‘great and important’ (Catherine) would need to be ‘cut’ (Justin). Matthew said, ‘There’s so many things one wants to do [...] if you were going to put together a list, that list would be impossibly long [...] and what are you not going to do [in order to include dementia]?’

Indeed, some participants turned questions back on researchers, asking “Why dementia, and not something else?” Several identified

other topics which they felt needed more coverage at TEs, but which they felt similarly powerless to include in any meaningful way. Significant among them were: sexual exploitation and safeguarding; sexuality, gender and transgender; care of the dying; mental health; unconscious bias and racial justice; bridge building, community liaison and evangelism; and disability and neurodiversity. None of these are unimportant, and few get the coverage at TEs participants felt they deserved. While there was therefore a sense that dementia could be taken as an indicative issue, or test case, for how best to expand coverage of under-considered topics within

ministerial formation, the corollary of this was valid questions about the extent to which dementia ought to be privileged over and above other important topics.

To incorporate dementia in a sufficient, effective way, such that enough students might learn both experientially and in the classroom in a way which avoids siloing yet takes account of the confines of time and a crowded curriculum is an ambitious aim. The challenge is to present a realistic solution which takes seriously these concerns, even if it cannot wholly resolve them. We turn to this in the next section.



A Way Forward

It would be unhelpful – indeed, impossible – to propose a one-size-fits-all solution that would suit every TEI's needs: there is too much inter-institutional variety in programme structures, denominational requirements, and existing provision for dementia education. Rather we propose a suite of five 'options' designed to be used in combination such that they might have an impact greater than the sum of their individual parts. As such, crucially, none of these options are designed to be used in isolation. Each has some limitations, and implementation would require careful consideration of, for example, delivery mode and timing, and whether and how to mandate student engagement.

Whereas, in most cases³ the expectation that an institution will develop, deliver and mandate a full module or unit of teaching exploring dementia in depth is unrealistic, each of these smaller-scale options are proposed with feasibility in mind. By combining them, institutions might be more realistically placed to begin taking smaller, mutually-constitutive steps towards improving dementia education among future church leaders.

We invite each institution to consider what it already does well, and which two options it might utilise to enhance its activity in this area. To this end, we include an exercise to support these considerations at the end of this section.

We also advocate:

- ongoing evaluation of each option's effectiveness. As illustrated above, what works well at one institution does not necessarily always work as well in others;
- the importance of formation, and equipping students with transferable skills such that they become adept 'theological improvisers' alongside and, indeed, through each of these approaches;

- ensuring there is suitable pastoral support available for students who find the topic of dementia troubling, or for whom it has personal resonance;
- urging churches and their denominational authorities to support this work, not least financially, and through the broader endorsement and development of schemes and resources which explore what it means to be church, and to be a minister, in view of growing worldwide dementia incidences. Where applicable, denominations should work with TEIs to consider including explicit emphasis upon working with the elderly - including those with dementia and/or caring for those who have dementia - within formation criteria or expectations they set for ministers.

Dementia is a known, growing concern for which ministers currently are not consistently well-prepared. As such, we believe it merits specific, explicit consideration. We are conscious that it will not satisfy everybody to give it attention while leaving other important matters of justice and inclusion unconsidered. Equally, though, we sincerely hope that the composite approach and options proposed here could and might be adapted to other themes and topics which merit greater consideration.

Option 1 - Curriculum Time and Assessment

Despite pressures on their curricula, many TEIs already dedicate time within one or more modules – whether whole lectures or seminars, or examples and case studies - to exploring dementia; others designate it for explicit reflection or assessments. TEIs should consider their capacity to offer this, whether independently or in collaboration with external organisations or individuals. Dementia might most obviously fall within modules exploring: pastoral care; disability theology; discipleship;

³ As noted, some TEIs have developed and utilised dementia modules – often to good effect. While we anticipate that, for most institutions, this would not be a helpful approach, we would be very pleased to hear from and support anyone keen to develop such a module.

or life-cycle ministry. While we advocate including dementia in a compulsory part of the curriculum or assessment, individual TEIs are best placed to assess whether it might be more feasible in an optional unit. They will also know best whether online or hybrid delivery would support such coverage. Additionally, dementia should be encouraged as a topic for theological reflection, both individual and corporate, in conversation with students' experiences (see further Option 3 below).

Such inclusion should be supported by a suitable reading and/or resource list – ideally maintained electronically and centrally such that it can be updated and referred to for several years post-ordination. This too could be developed collaboratively.

Option 2 – An Integrated Approach

All module convenors should review their course content for opportunities to integrate consideration of dementia and ways it might serve as an 'acid test' to disrupt norms and assumptions. This is particularly important for compulsory modules.

As an initial aim, convenors might identify three instances within a module's taught content, accompanying materials or assessment where dementia could be considered. These questions might provide a starting point for reflection:

- Does this topic make assumptions about people having working short-term or long-term memory? What might the absence of such a faculty mean for how we think about it?
- How might we do this differently to accommodate somebody who can be disruptive at unexpected times?

While this approach relies on widespread staff 'buy-in', it has the advantage of embedding dementia as a topic for consideration, significantly increasing the likelihood that all students will have explored dementia and its complexity from a range of perspectives before finishing their training.

Option 3 - Placements and theological reflection

Short- and long-term placements are already an important aspect of ministerial training. TEIs should consider how to bolster them to increase the number of students who have opportunities to encounter people living with dementia and their carers in structured, supported environments, and to reflect upon these encounters.

TEIs should review the placement opportunities they already offer, assessing how many are likely to facilitate encounter with people living with dementia or dementia carers. This will enable institutions to estimate what proportion of their student body will likely undertake such a placement. Where this proportion is low, TEIs should consider expanding their placement opportunities to include contexts and communities home to people living with dementia. In parallel, they should consider what resources and/or training might support students undertaking these placements, and how best to deliver this. This might valuably include a course in basic dementia awareness.

Such first-hand experience should be complemented by designated opportunities for theological reflection on dementia, whether individually, in small groups or one-to-one with mentors (or equivalents), building students' theological reflection skills.

Where such theological reflection takes place in groups, those with more first-hand experience of dementia could lead others in exploring the issues raised. This would ensure that even in situations where a relative minority of students can undertake placements which expose them to dementia, their learning can nevertheless be shared.

Option 4 – Extra-curricular spaces

Incorporating consideration of dementia in non-assessed, non-curriculum spaces (which almost all TEIs already have) can alleviate pressure on the taught curriculum.

Each TEI will need to consider what their existing extra-curricular spaces look like to best assess where and how dementia might be incorporated within these. For example, those institutions where it is not realistic to run a dementia workshop annually might instead run one biennially, such that most students can attend once during the course of their training. Whether or not attendance should be compulsory ought to be considered in conversation – indeed, consultation - with practical and pragmatic consideration of what students will find most engaging and helpful.

Individual TEIs should consider how best to develop or host such extra-curricular opportunities in light of available time, expertise and resources. Running these activities in conjunction with other organisations, or opening them up to people other than students training for ministry, might alleviate some financial and practical burdens.

Like curriculum time and assessment, any extra-curricular sessions would also ideally be supported by a considered list of resources and further reading, and perhaps suggestions for reflection.

Option 5 – Befriender Scheme

The fifth and final option we propose is a befriending scheme, based on a model whose effectiveness in medical education has been demonstrated in recent years. It is a close parallel to the scheme run by Kenneth, albeit without an assessed component (pages 40-41).

In 2014, Brighton and Sussex Medical School and the University of Surrey, both in the south-east of England, collaborated with Alzheimer's UK to establish a mandatory programme for undergraduate medicine and healthcare students called Time for Dementia (Daley et al 2017; Banerjee et al 2017). Groups of two or three students are paired, based on location, with couples or individuals living in the community with a diagnosis of dementia. Across two years, the students visit once a term, for a total of six visits of approximately one hour. While conversation is the main emphasis, students are encouraged to offer practical support if they felt it was appropriate – for example, helping prepare lunch. Importantly, they do not offer medical care – indeed, doing so would almost certainly be beyond their professional capabilities, and therefore inappropriate. Students receive some preparatory training, but the scheme is not assessed except insofar as attendance is recorded.

Evaluations have suggested that Time for Dementia successfully improved students' felt preparedness for working with people living with dementia and their carers in the future. Community members also reported benefits of participating in the scheme, enjoying the students' company, and consistently opted to continue participating in the scheme with future cohorts (Daley et al. 2017; Banerjee et al. 2017; Cashin et al. 2019).

A befriending scheme for ministerial candidates might represent an effective way of ensuring all trainees gain first-hand experience working alongside people living with dementia and their carers. It could be paired with opportunities for theological reflection. It could also feed into formative or summative assessments, though consideration should be given to the relative merits of removing such pressures.

Developing and running such a scheme does have cost and administrative implications, likely proportional to the number of students in a cohort. Pooling resources across several institutions, or partnering with secular charities as in the case of Time for Dementia, might represent helpful ameliorating steps. Appropriate consideration would need to be given to training and to safeguarding.



An Exercise

This short exercise is designed to help TEI staff begin thinking about dementia education in the specific context of their institution, exploring what they already do well, how effective this is, and how they might – realistically – bolster their offerings.

- 1) Find five objects - you might find that different-coloured LEGO bricks, Smarties, M&Ms or Jelly Babies works particularly well. Each object or colour represents a different one of the five options proposed above. Lay all five objects out in front of you, and place a small container to your right.
- 2) Is your institution already facilitating any of these 'options,' fully or in part? If your answer is yes, put the object(s) corresponding to that option in the container to the right.
- 3) Are there any of these options completely unrealistic to implement in your institutional context? If your answer is yes, move the corresponding object(s) to the far left of the space in front of you.
- 4) Consider the remaining objects. What are the advantages and possible limitations of each of these? Make a note of any challenges you would foresee if you were to propose introducing each of these at your institution.
- 5) Based on these considerations, rank the objects still in front of you in order of how straightforward or feasible they would be to implement.
- 6) Return any objects you placed in the container at the end of stage (2) to the table in front of you, placing them at the top of the ranked objects from stage (5).
- 7) Focus on the top two ranked objects, asking: do these approaches primarily lend themselves to growing knowledge and understanding; values and dispositions; experience; or transferable skills? Do these two 'ways forward' emphasise different, complementary kinds of learning? What are they? Might another option help to counterbalance some or all of these options' weaknesses? If so, you may wish to change your selection of two options.
- 8) Reflecting on these two options, consider:
 - Any changes you would need to make to existing dementia provision at your institution
 - What support you would require to implement a new way forward at your institution.

Concluding Statement

In the dynamic landscape of caregiving within religious communities, the *Educating for Inclusive, Caring Communities* project illuminates the pressing need for compelling and compassionate training for Christian clergy and leaders.

This report not only underscores the escalating prevalence of dementia but also the pivotal role church leaders play in fostering communities that are both inclusive and nurturing for those affected by this condition and their support networks.

The research conducted - generously enabled by HammondCare, The Sir Halley Stewart Trust, and the Kirby Laing Foundation - has yielded significant insights and laid down a path for constructive change.

We have explored the multifaceted experiences of individuals with dementia and their carers in the spiritual realm, investigated the current state of theological education concerning dementia care, and proposed a suite of options to enhance training protocols within Theological Education Institutes (TEIs).

The recommendations outlined in this report are intended as a catalyst for a cultural shift within TEIs, advocating for a curriculum that's responsive, adaptive, and reflective of the

diverse needs of congregations. This shift is not one of convenience but of necessity, calling for a strategic embrace of dementia education that goes beyond mere academic engagement to a transformative pastoral approach. To this end, the report concludes with an invitation to TEIs to engage in a reflective exercise, evaluating their present engagement with dementia education and selecting two 'options' from the proposed five to prioritize and implement. This action-oriented step is a recognition of the unique contexts each institution operates within while maintaining a collective vision for inclusive ministry.

Finally, our concluding recommendations and resources are curated to serve as a springboard for TEIs, researchers, and church communities. They are an open call to collaborate, innovate, and perpetuate a legacy of care that resonates with the core tenets of Christian faith – compassion, service, and community.

As we look forward, the *Educating for Inclusive, Caring Communities* report is not merely a conclusion but a commencement – a stepping stone toward a future where clergy and religious leaders are empowered and equipped to embody the ethos of caring communities, particularly for those touched by dementia and their dedicated carers.

HammondCare 


Laing Family Trusts

Sir Halley
Stewart Trust

Recommendations

For Theological Education Institutions

There is both a need and a demand to prepare those training for ministry to encounter and care well for people living with dementia and their carers, and to lead churches which contribute to such care. While such preparation is not solely the responsibility of theological education institutions (TEIs) these do play important, formational roles in trainees' ministries.

As such, we believe it is important that TEIs not only prepare adept 'theological improvisers,' equipped with transferable skills and core dispositions, but also provide trainees opportunities to focus specifically upon dementia – through classroom-based teaching, experience, and reflection.

There is already activity taking place in this vein at many TEIs in the UK and Australia. There is also broad consensus that more could – and should – be done. Yet theological educators also have numerous, practical concerns about how this might be achieved.

Rather than attempting to propose a one-size-fits-all solution – particularly in the form of a 'dementia module' – we instead encourage TEIs to reflect on their existing provision, and to bolster this. We propose five 'options' and invite TEIs to consider their ability to implement two of these (by refining existing provision, and/or adopting new or additional options):

- 1) Curriculum time and assessment
- 2) An integrated approach
- 3) Placements and theological reflection
- 4) Extra-curricular spaces
- 5) Befriender scheme

Additionally, TEIs should consider:

- Evaluating the effectiveness of any options they choose to implement (or, integrating it into existing evaluative systems)
- Exploring or embracing partnerships with external individuals and organisations to assist in the delivery of this dementia-focused content.
- The needs of their particular cohorts and candidates with respect to accessible and flexible modes of study.
- Reinforcing existing structures of pastoral support, for those staff and students for whom dementia is a difficult or sensitive subject.

We also firmly believe that TEIs should not be left alone to conduct this important work, but given support and encouragement by their denominations and other validating bodies.

Finally, we would warmly endorse the establishment of a community of practice – whether on a national or international scale – wherein TEI representatives might collaborate, not least regarding their takings from this report and implementation of its findings (fruitful and unsuccessful). This community might also create space for sharing literature, information and resources concerning dementia and the church, and support the maintenance of a 'living document' such as we posit above.

For further research and exploration

Research into and explorations of dementia, theology and the lived experience of faith is thriving. The below is therefore by no means an exhaustive list of suggestions of research which would extend the agenda and observations of this report.

- Consideration of how well-equipped existing clergy feel for ministry among those living with dementia, identifying and addressing their support and training needs in this area, and aiming to share examples of good practice.
- Exploration of the experiences of ministers – and, indeed, trainee church leaders – who live with dementia, considering the theological and practical implications of this, and how best to provide sensitive and appropriate pastoral support.
- Continued exploration of the relationship between dementia, personal faith and experiences of churchgoing, emphasising the nuance and complexity of these experiences and their relationships, and elevating the voices of people living with dementia and their carers.
- Relatedly, consideration of the different and overlapping sources of spiritual care for those living with dementia and their carers/supporters.
- Trialling applying the options explored in this report for dementia education to other typically under-considered areas which deserve space on TEI curricula and programmes. Significant among these might be environmental consciousness; decolonisation and racial justice; and disability and neurodivergence.



For churches

We strongly encourage church leaders to make contact with people who already host dementia friendly church services, including in, for example, aged care facilities. We believe effective learning will come from witnessing good practice, for trainees and seasoned leaders alike.

In the same vein as the recommendations we make for TEIs, the additional below suggestions for churches are framed by our recognition that it is very difficult to generalise about what dementia care currently looks like in churches, and thus what changes might be needed. As such, instead of generic suggestions, we pose a series of prompts for reflection and consideration, intended – in the first instance – at church leaderships.

To inspire further reflection, church leaders – lay and ordained – might benefit from reading the section entitled Dementia and the Church and engaging with the case study exercise included at the close of that section. We also endorse the resource list (see pages 52-53) as a starting point for further information, support, examples and wisdom.

- Are there people living with dementia – or carers – in your congregation? If so, has anybody asked them what works well for them at church, and where they see areas for improvement? How can you respond appropriately to such insights in your context?
 - o It might be particularly important to consult them concerning worship services. Five headings might be useful: Music; Liturgy; Movement; Communion; Sermons
- Reflect carefully on where you think God is in dementia. This might involve considering the impact of your own personal encounters with dementia. In such cases (and, indeed, more broadly) it might be helpful to do so with the support of others whom you trust. If you know a Christian who is living with dementia currently, perhaps ask them about their journeys with God and in faith in light of this diagnosis.
- Are there people living with dementia in your church who have historically enjoyed contributing to ministries and service (or who might wish to) but are not currently encouraged to? Have you talked to them about this? Are they in a season where they need to receive, rather than give, or could you support them to serve others at church?
 - o Where people living with dementia already serve others at church, have you asked what they gain from doing so?
- Can you conduct an assessment of your church's accessibility, both for people living with dementia and for others who might benefit from adjustments? [This resource](#) developed by the Church of England and Dementia Friendly Church, includes a self-review tool for churches.
- Equally, could you evaluate how you 'do church' for people living with dementia outside the church's walls? What does your church offer in terms of visiting ministries, or hosting services for local care facilities? If there is limited provision for these, what would help your church to build them up, and ensure those conducting them have appropriate training?

- What fellowship opportunities does your church have which are open to people living with dementia and their carers? What benefit might come from establishing something new in this vein? Could you do so in partnership with another church, or with a local secular or non-Christian organisation?
- Do you have a sense of the congregation's attitudes or understanding regarding inclusion – broadly, as well as specifically with respect to dementia? How might you garner this? Would a short sermon series on this topic be helpful or feasible?



Resources

Table 10 collates the resources, organisations and initiatives which participants described in their interviews as having helped them to manage dementia, think about its place in the church, or to think more broadly about issues of inclusion and accessibility.

This list is non-exhaustive as we took the decision to exclude those which might risk de-anonymising our participants.

Link	Description
https://www.ageuk.org.uk/	Leading UK charity providing support to help people live well in later life.
https://www.alzheimers.org.uk/	Leading UK charity working towards a world where dementia no longer devastates lives.
https://www.annachaplaincy.org.uk/	Equipping UK churches for more effective ministry with rapidly ageing populations.
https://baptistcare.org.au/	Christian-based care organisation for older Australians and people living with disadvantage.
https://christiansonageing.org.uk/	UK organisation providing a voice for older people through conferences, publications, commentaries and resource.
https://christinebryden.com/	Advocate and author of books and resources about her own journey with Alzheimer's and dementia.
https://www.dementia.org.au/	The source of 'trusted information, education and services' about dementia in Australia.
https://www.methodist.org.uk/safeguarding/dementia-friendly-churches/	Resources and webinars to help UK churches become welcoming and inclusive.
https://scmpress.hymnsam.co.uk/books/9780334055532/dementia-	Dementia: Living in the Memories of God by John Swinton
https://faithinlaterlife.org/fill-resource/developing-dementia-friendly-churches-livability/	Free download developed by Livability and Alzheimer's Society (UK).

Link	Description
https://shop.hammond.com.au/products/faith-for-life-book-series	Series of ten books, developed with the support of people living with dementia, families, carers, and pastoral care workers.
https://faithinlaterlife.org/	UK organisation aiming to inspire and equip Christians to reach, serve and empower older people in every community, through the local Church.
https://gloriousopportunity.org/?fbclid=IwAR3yuafugedDyDMMDqIgt_fiG6dNI5sLIAfs4UYUT838RBGFanPYEiqNEls	Run from the UK by former GP Jennifer Bute, helping doctors, carers and those living with dementia to understand more about dementia.
https://www.waterstones.com/author/malcolm-goldsmith/90116	Author of books exploring Ageing, Spirituality and Wellbeing (Scotland, UK).
https://grovebooks.co.uk/products/mev-120-memory-cafe-how-to-engage-with-memory-loss-and-build-community	Grove Pamphlet by Steven Morris (UK) exploring how to engage with memory loss and build community.
https://missioncare.org.uk/	Provide residential, social nursing and dementia care in the community from Bromley, England.
https://ourplacecc.org.au/	Support churches In Australia to become more disability inclusive, offering resources, training and consultancy.
https://www.playlistforlife.org.uk/	UK initiative supporting people living with dementia to build a playlist of personally meaningful music.
https://respiteforall.org/	Organisation based in the USA aiming to help build successful local respite communities for families living with dementia.
https://www.mdpi.com/2077-1444/13/5/462	Meta-Synthesis of qualitative evidence demonstrating the value of spiritual care as an aspect of holistic palliative and dementia care.
https://uk.jkp.com/products/spiritual-growth-and-care-in-the-fourth-age-of-life	Spiritual Growth and Care in the Fourth Age of Life by Elizabeth MacKinlay

Link	Description
https://shop.teepasnow.com/product/spirituality-in-dementia-care-dvd/	Video-based course hosted by Teepa Snow and Linn Possell about basic spiritual needs throughout life, what may or may not change when someone is living with dementia, and how to best meet those needs.
https://www.hammond.com.au/our-expertise/dementia-centre	HammondCare Australia's hub for world-leading research, knowledge and solutions proven in practice to enhance quality of life and support people living with dementia, their care networks and the healthcare sector.
https://sanctuarymentalhealth.org/sanctuary-course/	Course developed in the UK aiming to equip churches to become places where people living with mental health challenges feel safe, supported and a sense of belonging.
https://vox.divinity.edu.au/news/interview-with-rev-cathie-lambert-about-her-work-for-the-spirited-project/	Project based in Australia exploring how family and friends of people living with dementia can best provide spiritual care for their loved ones.
https://www.brf.org.uk/the-spiritual-care-series/	Eight session training course, licensed by the Bible Reading Fellowship and Anna Chaplaincy from the UK and Health Television Network in Australia.
https://www.bsms.ac.uk/research/neuroscience/cds/time-for-dementia/time-for-dementia.aspx	A programme at Brighton and Sussex Medical School (UK) designed to develop, deliver and evaluate an innovative educational initiative, a longitudinal programme in dementia.
https://umbrelladementiacafes.com.au/cafes/	Social peer support groups in Australia, established with the purpose of improving the wellbeing of people living with dementia and their carers, families and communities.
https://unitingcare.org.au/	National body for the Uniting Church's community services network - one of the largest networks of social services providers in Australia.
https://www.wave-for-change.org.uk/	UK-based organisation seeking to connect, encourage and support those who want to see vibrant mixed-ability social and worship groups in their communities.

References

- Banerjee, Sube, Nicolas Farina, Stephanie Daley, Wendy Grosvenor, Leila Hughes, Molly Hebditch, Sophie Mackrell, et al. 2017. 'How Do We Enhance Undergraduate Healthcare Education in Dementia? A Review of the Role of Innovative Approaches and Development of the Time for Dementia Programme'. *International Journal of Geriatric Psychiatry* 32 (1): 68–75. <https://doi.org/10.1002/gps.4602>.
- Braun, Virginia, and Victoria Clarke. 2006. 'Using Thematic Analysis in Psychology'. *Qualitative Research in Psychology* 3 (2): 77–101. <https://doi.org/10.1191/1478088706qp0630a>.
- Carter, Erik W. 2021. 'Equipped for Inclusion: Western Theological Seminary's Graduate Certificate in Disability and Ministry'. *Journal of Disability & Religion* 25 (3): 261–78. <https://doi.org/10.1080/23312521.2021.1895022>.
- Cashin, Zoe, Stephanie Daley, Molly Hebditch, Leila Hughes, and Sube Banerjee. 2019. 'Involving People with Dementia and Their Carers in Dementia Education for Undergraduate Healthcare Professionals: A Qualitative Study of Motivation to Participate and Experience'. *International Psychogeriatrics* 31 (6): 869–76. <https://doi.org/10.1017/S1041610218001357>.
- Collins, Kathryn S., Rich Furman, Ruthanne Hackman, Kim Bender, and Elizabeth A. Bruce. 2007. 'Tending the Soul: A Teaching Module for Increasing Student Sensitivity to the Spiritual Needs of Older Adults'. *Educational Gerontology* 33 (9): 707–22. <https://doi.org/10.1080/03601270701364420>.
- Daley, Stephanie, Zoe Cashin, Miriam Miller, Leila Hughes, Molly Hebditch, Juliet Wright, Wendy Grosvenor, and Sube Banerjee. 2017. '[P4–539]: Participating in Undergraduate Healthcare Professional Dementia Education: The Experience of People with Dementia and Their Carers'. *Alzheimer's & Dementia* 13 (75_Part_32): P1557–P1557. <https://doi.org/10.1016/j.jalz.2017.07.701>.
- 'Dementia UK Report | Alzheimer's Society'. n.d. Accessed 24 May 2023. <https://www.alzheimers.org.uk/about-us/policy-and-influencing/dementia-uk-report>.
- Epps, Fayron, Virginia Heidbreder, Karah Alexander, Audrey Tomlinson, Valencia Freeman, and Nancy Williams. 2021. 'A Dementia-Friendly Church: How Can the African American Church Support Families Affected by Dementia?' *Dementia* 20 (2): 556–69. <https://doi.org/10.1177/1471301219900416>.
- Fahey-McCarthy, Elizabeth, Mary McCarron, Kevin Connaire, and Philip McCallion. 2009. 'Developing an Education Intervention for Staff Supporting Persons With an Intellectual Disability and Advanced Dementia'. *Journal of Policy and Practice in Intellectual Disabilities* 6 (4): 267–75. <https://doi.org/10.1111/j.1741-1130.2009.00231.x>.
- Farrow, Maree, Kathleen Doherty, Fran McInerney, Shannon Z. Klekociuk, Aidan Bindoff, and James C. Vickers. 2018. 'O1-07-03: Improving Knowledge and Practice Through Massive Open Online Dementia Education: The Understanding Dementia and Preventing Dementia Moocs'. *Alzheimer's & Dementia* 14 (75_Part_4): P233–P233. <https://doi.org/10.1016/j.jalz.2018.06.2368>.
- Foster, Kimberly, and Fayron Epps. 2020. 'Content Analysis of Church Leaders' Perceptions and Attitudes Toward Dementia'. *Innovation in Aging* 4 (Supplement_1): 160. <https://doi.org/10.1093/geroni/igaa057.521>.
- Friedrich, Robert, Bob Woods, and Sion Williams. 2021. "'Just Because the Mind Is Confused It Doesn't Mean the Spirit Is Confused": Exploring the Role of Anglican Clergy in Ministry to Persons with Dementia'. *Dementia* 20 (2): 698–716. <https://doi.org/10.1177/1471301220910572>.

- Goh, Anita MY, Colleen Doyle, Ellen Gaffy, Frances Batchelor, Meg Polacsek, Steven Savvas, Sue Malta, et al. 2022. 'Co-Designing a Dementia-Specific Education and Training Program for Home Care Workers: The "Promoting Independence Through Quality Dementia Care at Home" Project'. *Dementia* 21 (3): 899–917. <https://doi.org/10.1177/14713012211065377>.
- Gore, Janelle, Jamilla Toliver, Miranda A. Moore, Dawn Aycock, and Fayron Epps. 2022. 'A Mixed-Methods Formative Evaluation of a Dementia-Friendly Congregation Program for Black Churches'. *International Journal of Environmental Research and Public Health* 19 (8): 4498. <https://doi.org/10.3390/ijerph19084498>.
- Hudson, Rosalie Evelyn. 2016. 'God's Faithfulness and Dementia: Christian Theology in Context'. *Journal of Religion, Spirituality & Aging* 28 (1–2): 50–67. <https://doi.org/10.1080/15528030.2015.1041669>.
- Kevern, Peter. 2010. 'Alzheimer's and the Dementia of God'. *International Journal of Public Theology* 4 (2): 237–53. <https://doi.org/10.1163/156973210X491895>.
- Kevern, Peter, and David Primrose. 2020. 'Changes in Measures of Dementia Awareness in UK Church Congregations Following a "Dementia-Friendly" Intervention: A Pre-Post Cohort Study'. *Religions* 11 (7): 337. <https://doi.org/10.3390/rel11070337>.
- Kevern, Peter, and M. Walker. 2013. 'Religious Communities: What Can They Offer?' *Journal of Dementia Care* 21 (July): 26–28.
- Mason, Jordan. 2020. 'Attending to the Suffering of Dementia: A Practical Theology Approach'. *Journal of Pastoral Theology* 30 (2): 107–20. <https://doi.org/10.1080/10649867.2019.1702794>.
- Plunkett, Robyn, and Peter Chen. 2016. 'Supporting Healthy Dementia Culture: An Exploratory Study of the Church'. *Journal of Religion and Health* 55 (6): 1917–28. <https://doi.org/10.1007/s10943-015-0165-8>.
- Powers, Sara, Silvia Orsulic-Jeras, Jessica Empeno, Regina Lagasca, Amy Abrams, Sarina Barker, Rebecca McDaniel, and Marcie Hanna. 2020. 'Improving Dementia Capability Among Law Enforcement: Evaluation of Dementia Education Training in San Diego County'. *Innovation in Aging* 4 (Supplement_1): 495. <https://doi.org/10.1093/geroni/igaa057.1600>.
- Riley, Jennifer, and John Swinton. Forthcoming. "'God hasn't given up on them": Christian dementia carers' narratives of experiencing and challenging 'anticipatory grief' and 'social death'. In Jo Horne and Kerry Jones (eds.) *Understanding the Grief and Loss Experiences of Carers: Research, Practitioner and Personal Perspective*.
- Swinton, John. 2007. *Raging with Compassion: Pastoral Responses to the Problem of Evil*. Grand Rapids, Mich. ; Cambridge: Eerdmans.
- 'Vision and Strategy'. n.d. The Church of England. Accessed 8 December 2023. <https://www.churchofengland.org/about/vision-and-strategy>.
- 'World Failing to Address Dementia Challenge'. n.d. Accessed 8 December 2023. <https://www.who.int/news/item/02-09-2021-world-failing-to-address-dementia-challenge>.
- World Health Organisation [WHO]. 2023. 'Dementia'. 2023. <https://www.who.int/health-topics/dementia>.

Glossary

Alzheimer's, Alzheimer's Disease	Progressive mental deterioration that can occur in middle or old age, due to generalized degeneration of the brain. It is the commonest cause of premature senility and dementia symptoms.
Autism	A diverse neurodevelopmental condition with lifelong effects that can be recognized from early childhood, chiefly characterized by difficulties with social interaction and communication and by restricted or repetitive patterns of thought and behaviour.
Automatic Transcription	Using computer software to convert speech or recordings of speech into text
Bible study	Used as a noun, a by-word for a small group of Christians (often from the same church congregation) who meet regularly to read and discuss parts of the Bible. See also Home Group; Small Group
Biblical Studies, Biblical Theology	The academic application of a set of diverse disciplines to the study of the Bible
Body of Christ	A term in Christian theology with two main meanings: First St Paul's description (see Ephesians, 1 Corinthians) of the church, that is, all who are 'in Christ' as part of his 'body,' playing different roles but contributing to this whole; Second, what Jesus says the bread used in Holy Communion represents.
Bridge Building	The promotion of friendly relations between groups.
Chapel	A place of Christian worship; often specifically refers to a place of worship, sometimes non-denominational that is part of a building, complex, or vessel with some other main purpose, such as a school, college, hospital
Chaplain	A chaplain is, traditionally, a cleric, or a lay representative of a religious tradition, attached to an institution other than a church (such as a prison, a hospital, a regiment)

Christology	Christian reflection, teaching, and doctrine concerning Jesus of Nazareth, the second person of the trinity, and divine incarnation.
Communion, Eucharist, Holy Communion	A Christian ritual and sacrament which Jesus instituted at the Last Supper with his disciples, centred on the the two 'elements' of blood and wine. Also known as, e.g. Blessed sacrament, Lord's Supper, Mass
Congregation	A group of people gathered for religious worship; more colloquially, the people who come to or belong to a particular church
Contact Time	In Higher Education, contact time or 'contact hours' refers to the amount of time spent learning in contact with teaching or associated staff when studying for a particular course.
Continuing Ministerial Education	The broad term for the ongoing learning and training undertaken by church leaders after they are ordained/licensed.
Core Module	In Higher Education, a core/compulsory module is a module that must be taken to meet requirements of your programme.
Course(s)	In Higher Education, a course may be used to refer to a whole programme of study (consisting of multiple modules, or units) OR to a specific unit or module within a broader programme.
Curriculum	The subjects comprising a course of study in a school or college.
Dementia	A general term for the impaired ability to remember, think, or make decisions that interferes with doing everyday activities. Alzheimer's disease is the most common type of dementia. Though dementia mostly affects older adults, it is not a part of normal aging.
Dementia Friendly Church	A loose scheme supporting churches across denominations to consider how accessible and suitable their spaces and activities are for people living with dementia (that is, how 'dementia-friendly' they are)
Denomination	A recognised, autonomous branch of the Christian Church, typically (though not always) differentiated from other denominations by distinctive doctrine. Sometimes glossed as different 'traditions' of the church.

Diocese	A district, typically geographic, under the pastoral care of a specific bishop in episcopal denominations within the Christian Church
Disability theology	The attempt by disabled and non-disabled Christians to understand and interpret the gospel of Jesus Christ, God, and humanity against the backdrop of the historical and contemporary experiences of people with disabilities
Discipleship; disciple	A disciple is someone who believes in Jesus Christ as their Lord and Saviour. Discipleship is a widely-used word to describe a journey of spiritual growth.
Dissertation	A dissertation is a research project completed as part of an undergraduate or postgraduate degree or other programme of study.
Ecclesiology	The branch of theology which explores the Church, the origins of Christianity, its relationship to Jesus, its role in salvation, its polity, its discipline, its eschatology, and its leadership
Ecumenical	Representing a number of different Christian Churches or denominations; related to unity among different churches or denominations.
Elective Module, Optional Module	In Higher Education, a module that a student selects according to preference from a specified list of module options, subject to approval.
Eschatology	The part of theology concerned with death, judgement, the end times, and the final destiny of the soul and of humankind.
Fellowship	Friendly association, especially with people who share one's interests, or with others in a group (such as a church)
Formation	With respect to Christian ministry, the deepening of relationships with God, maturing of faith, and development of dispositions, characteristics and qualities deemed important for church leaders.

Formation Criteria	Qualities which a TEI or denomination aspire to nurture and develop in those who are training for ministry in the church.
Formative Assessment	Assessment tasks for which the outcomes (results) do not contribute to the overall final grade of the student, but primarily provides feedback and information during the instructional process.
Happy-clappy	Typically used as a by-word for charismatic churches, a Christian group whose worship is marked by enthusiastic participation
Home Group, Small Group	A small group of church members meeting regularly to share life and grow in faith together.
Hospice Care, Hospice	Hospice care is a type of health care that focuses on the palliation of a terminally ill patient's pain and symptoms and attending to their emotional and spiritual needs at the end of life. Hospice care prioritizes comfort and quality of life by reducing pain and suffering.
Lament	A form of prayer that takes the brokenness of the human experience into the heart of God; an act of faithfulness in situations where faith and hope are challenged
Liturgy	The customary public ritual or patterns of worship performed by a religious group. Liturgy can also be used to refer specifically to public worship by Christians. Often relates specifically to the words used.
Lord's Prayer	A Christian prayer which Jesus taught as an exemplar for prayer and is used by many Christian denominations, often with great regularity. Also known as the 'Our Father'
Matzo	An unleavened flatbread used in Jewish cuisine and as part of the Passover festival, and by some Christian denominations as bread for Holy Communion. Sometimes Matzah or Mazzah.

Memory Café, Dementia Café	A group for individuals with Alzheimer's Disease or any other form of dementia, or other brain disorders, typically informal and offering hot drinks and refreshments
Ministerial Candidate(s)	Someone who is training for ministry in the Christian church; a collective term for the majority of students studying at teis.
Module(s)	Most higher education courses have a 'modular' structure. This means that you can build a personalised course by choosing modules or units of study from different subject areas.
Neurodiversity	A framework for understanding human brain function and mental illness. It argues that diversity in human cognition is normal and that some conditions classified as mental disorders are differences and disabilities that are not necessarily pathological.
NVivo12	A software program used for qualitative and mixed-methods research. Specifically, it is used for the analysis of unstructured text, audio, video, and image data, including (but not limited to) interviews, focus groups, surveys, social media, and journal articles.
Orientation Week(s)	A period before the start of an academic year at a university or tertiary institutions, designed to introduce students to their courses, programmes and institutions
Parachurch	Parachurch organisations are Christian faith-based organizations that work outside and across denominations, often to engage in social welfare and evangelism.
Pedagogy	The method and practice of teaching
Placements (Practicums)	A practical learning experience that complements and enhances your academic study.
Pneumatology	The branch of Christian theology concerned with the Holy Spirit
Practical theology	Academic discipline that examines and reflects on religious practices in order to understand the theology enacted in those practices and in order to consider who theological theory and practices can be more fully aligned, changed or improved.

Prayer Book	A book containing the liturgy and scriptural readings designated for specific services, daily offices, sacraments and other rituals and holy days. A prayer book service is one in which these designated provisions are used and followed.
Programme	In Higher Education, typically a whole course of study, the individual components of which are typically known as ‘modules,’ ‘units’ or ‘courses.’
Psalm 23	The 23rd chapter of the book of Psalms in the Bible, which begins ‘The Lord is my Shepherd.’ A well-known Psalm.
Racial Justice	Relating to the combating of racial discrimination, going beyond preventing individual cases to understand and combat structural oppression.
Reflective Practice	In theology and in other vocations, the practice of and ability to reflect on one’s actions to engage in a process of continuous learning.
Residential Care	Long-term health and social care provided in a care home, for people who need substantial help with their personal care.
Retirement Village	Also referred to as retirement community; a residential community or housing complex designed for older adults who are generally able to care for themselves. Assistance is provided in some communities, to varying degrees, and activities and socialization opportunities are often provided.
Safeguarding	Denotes measures to protect the health, well-being and human rights of individuals, which allow people—especially children, young people and vulnerable adults—to live free from abuse, harm and neglect.
Seminar; webinar	A class in which a topic is discussed by a teacher and a small group of students. (webinar when hosted or mediated online)
Sermon	A religious discourse or oration by a preacher, usually a member of clergy. Sometimes ‘homily’ or ‘address’.
Soteriology	Branch of theology which concerns salvation.

Spiritual Gifts	A spiritual gift or charism is a power, grace or disposition given by the Holy Spirit such that individual Christians can help fulfil the mission of the church.
Student Outcomes	Skills, knowledge, proficiencies or dispositions which students are expected to gain by completing a course or programme of study.
Summative Assessment	Assessment tasks for which the outcomes (results) contribute to the overall final grade of the student, designed to evaluate student learning as a result of a unit.
Theodicy	The branch of theology which deals with the problem of evil; the vindication of divine providence in view of evil's existence.
Theological Anthropology, Theological Personhood	Theological attempts to think through the nature of humanity, what it means to be human, and the meaning of the human story as it is lived out before, with, and by God.
Theological Education Institute (TEI)	A learning organisation or community whose primary goal is to train candidates for ministry in the church, including ordained ministry; also called seminaries, theological colleges.
Theology	Broadly: the academic study of religious beliefs and theory, especially when systematically developed; or, Narrowly: the study of the nature of God
Unconscious Bias	Unconscious biases are social stereotypes about certain groups of people that individuals form outside their own conscious awareness
Unit(s)	In Higher Education, specific 'units' (or 'modules') are combined to create a student's programme or course of study.
Validation	In Higher Education, the process by which courses and modules are scrutinized and approved by internal and external parties.
Vocation	In church contexts, a sense of calling or career in ministry and church leadership.
Worship services, corporate worship, gathered worship	A church service is a formalized period of Christian communal worship, often held in a church building. It often but not exclusively occurs on Sunday

Appendices

Appendix 1 – Participant Pseudonyms

TEI interviewees - Australia	TEI Interviewees - UK
Alasdair Bobby Brian Christine Christopher Daniel Deborah Eric Ilse Kenneth Megan Morgan Robert Ruben Terry William	Catherine Donna Eleanor Geoff Hannah John Justin Karen Kate Mary Matthew Mike Rebecca Sharon Thomas
Carers – Australia	Carers - UK
Amy Arthur Bernie Charlotte Edie Lucy Marian	Anthony (married to Ada) Elizabeth Ian (married to Isobel) Roseanna Tabitha (married to Ted)
People living with dementia - Australia	People living with dementia - UK
Heather Henry James Michelle Shirley Steve Wendy	Ada (married to Anthony) Isobel (married to Ian) Linda Melissa Ted (married to Tabitha)

Appendix 2 – UK advert used to reach prospective carer/PLWD participants

Interviewees wanted!

Are you...?

- Living with a diagnosis of early stage dementia, or caring for someone who is?
- Interested in sharing your views and experiences of how Christian churches and charities support people living with dementia and those who care for them?
- Happy to participate in a 1-hour online interview? (Telephone or in-person interview can also be arranged)

If so...

Please consider taking part in a research project being conducted through the University of Aberdeen. Get in touch with researcher Jennie Riley (jennifer.riley@abdn.ac.uk or 07908159524) to find out more.



Notes



Notes



Notes





Educating for Inclusive, Caring Communities