



ADMINISTERING PASTORAL CARE

A new Method for People Suffering from Dementia

ABSTRACT

'What's the use of administering pastoral care to people with dementia? They will not remember it anyway'. 'How can I keep the attention of the person with dementia? I find it extremely difficult to communicate with them'. These are some of the things one might hear people say about people with dementia. The way one thinks about a person with dementia will impact how one cares for them. That is why this paper discusses the reasons why pastoral care is beneficial for people with dementia. It looks at what it means to be human from a theological aspect and continues to research different methods of administering pastoral care to people with dementia. The study in this paper used the grounded theory to discuss the best methods of administering pastoral care to people with dementia. The results form the base of a new method for administering pastoral care to people with dementia.

Hilbert Lubbinge

160638 | 2020

G-B-AFP-14|19-

09|Afstudeerproject

Table of contents

Introduction	1
Context	1
Outline of this paper.....	1
Chapter 1: Terminology & Definitions	2
1.1 People suffering from dementia	2
1.2 Dementia & Alzheimer's	2
1.3 Explicit and Implicit Memory	4
1.4 Pastoral care	5
Chapter 2: The significance of administering pastoral care to people suffering from dementia	6
2.1 What is the use?	6
2.2 Reasons to administer pastoral care to PSfd	7
Chapter 3: Theological discussions on administering pastoral care to People suffering from dementia	8
3.1 What being human means according to Christian doctrines.....	8
3.1.1 Creationism	8
3.1.2 Covenant theology.....	8
3.1.3 Christology	9
3.1.4 Eschatology	9
3.1.5 The Christian doctrine of justification.....	10
3.1.6 The Christian doctrine of the Trinity.....	10
3.2 The implication of Imago Dei	11
3.3 A person is a life story and a body	12
3.4 Love and the Spirit of God in the person	14
Chapter 4: Developing a method for administering pastoral care to PSfd.....	16
4.1 Study aims.....	16
4.2 Research question.....	16
4.3 Method	16
4.4 Reliability and validity.....	17
4.5 Methodology.....	18
4.5.1 Gathering data and type of data.....	18
4.5.2 Coding, analyses, comparison and results	18
4.5.2.1 Selection of data to be coded.....	18

4.5.2.2	Open coding.....	19
4.5.2.3	Axial coding.....	22
4.5.2.4	Selective coding and focused coding.....	23
4.6	Discussion of the results	26
4.6.0	Communication through emotions.....	26
4.6.1	Environment.....	27
4.6.1.1	Reality orientation	28
4.6.2	Relationships.....	29
4.6.3	Dementia differs from person to person	29
4.6.3.1	Knowledge about dementia and the experience of the PSfd	29
4.6.3.2	Knowledge about the person behind the disease	30
4.6.4	Presence / Here and now.....	30
4.6.5	Familiarity	31
4.6.5.1	Memory and memories	31
4.6.5.2	Making use of what is familiar.....	32
4.6.6	Focus on what is still working	34
4.6.7	Multidisciplinary endeavour	34
4.6.8	Worship / Church	35
4.6.8.1	Traditional cognitive methods.....	35
4.6.8.2	Non-cognitive methods focussing on experiences, multisensory interaction and emotions.....	36
4.6.9	Gestures, rituals and symbols	36
4.6.10	Touch	37
4.7	Conclusion.....	39
Chapter 5.	Summary	40
References	a
Appendix A: The Pastoral caregiver		i
Appendix B: What is a person?		iii
Appendix C: Theological-based reasons and benefits of administering pastoral care to the PSfd		v
They are still human		v
Their spirituality does not get extinguished		v
Benefits of receiving pastoral care as a PSfd		vi
Appendix D: Preliminary method list based on data from 25 scholarly articles.....		ix
Appendix E: Final list of codes for the new method		xi

Appendix F: New method	xii
1. Environment	xii
1.1 Reality orientation	xii
2. Relationships	xiii
3. Dementia differs from person to person	xiii
3.1 Knowledge about dementia and the experience of the PSfd	xiii
3.2 Knowledge about the person behind the disease	xiv
4. Presence / Here and now	xiv
5. Familiarity	xiv
5.1 Memory and memories	xiv
5.2 Make use of what is familiar	xv
6. Focus on what is still working	xv
7. Multidisciplinary endeavour	xvi
8. Worship / Church	xvi
8.1 Traditional cognitive methods	xvi
8.2 Non-cognitive methods focussing on experiences, multisensory interaction and emotions	xvi
9. Gestures, rituals and symbols	xvii
10. Touch	xvii



Introduction

Context

Het Maanderzand asked the author of this paper to create a new pastoral care method based on theoretical knowledge and proven methods for people suffering from dementia. Het Maanderzand is a residential care centre for older people, including older people who have dementia. Het Maanderzand regards life satisfaction, and living arrangements of residents are as essential as the care they receive.¹ Therefore, they want to be able to answer questions like whether it has any meaning to administer pastoral care to this group and what the best methods to use are. Maartje Zielman, the pastoral caregiver and **instructing party**, asked the author of this paper to research or create a method for administering pastoral care to people who have dementia.

During an interview with the instructing party, it became clear that she sometimes feels that she cannot get through to her clients and that it is difficult to make contact and keep their attention. During the interview, she said that some patients fall asleep during visits and others have trouble following the conversation. Other times they fall into repetition by repeating the same line of questioning. The current method of administering pastoral care to the target group seems to have little effect or at least does not give the instructing party the idea that it is of any use. On the one hand, she feels that some things she does are good and works well. On the other, she does not think it is based on theoretical knowledge. She said that it is something she adopted and adapted through time and experience. She wants her work and method to be based on grounded theory and research.

Therefore, this paper explored why it is worth administering pastoral care to people suffering from dementia and researched different methods or techniques applicable to the target group. The author also hopes to reassure the instructing party by comparing her method of administering pastoral care to the research done on the subject matter. In this way, the caregiver can see how much of her process has a good foundation and can be backed up by theory and empirical evidence. The outcome of this study is a grounded method (method based on theory and empirical evidence) that can be implemented by people working with and administering pastoral care to people suffering from dementia.

Outline of this paper

The study in this paper researched and developed a new method for administering pastoral care to people suffering from dementia. The article starts with the definitions of terms relevant to pastoral care for people suffering from dementia. Next, it discusses the significance or importance of administering pastoral care to people suffering from dementia, first from a scientific approach and then theological motivations to administer pastoral care to people suffering from dementia. Next, the paper shows how the research was done using the grounded theory method, a methodology used in qualitative and quantitative data research to discover, generate or construct theory from said data.² The data was then analysed and compared to the method of the instructing party and an already existing approach. There after the research outcomes and results on which the new method was built are discussed. The new method of administering pastoral care to people suffering from dementia is located in Appendix F.

¹ For more information visit their website <https://maanderzand.nl/woonzorgcentrum/>

² For a more detailed description of the grounded theory method please refer to [method under chapter 4](#).

Chapter 1: Terminology & Definitions

1.1 People suffering from dementia

The research papers consulted for this study made use of the terms ‘confused (elderly) people’, ‘people with dementia’, ‘patients’ and ‘clients’. In this paper, these terms are considered synonyms. For this paper, ‘people suffering from dementia’ is used, and all of the above definitions can be read into it.

The author considers the term ‘people suffering from dementia’ to be a more appropriate term. The person behind the disease tends to be forgotten. One must remember that behind the forgetfulness and general deterioration caused by dementia, there is a person — a human created by God, in the image of God – worthy of our love and attention. The term ‘people suffering from dementia’ suggests that it is first and foremost about the person. The disease is not the focus but the person suffering from it. Lastly, dementia does not change the person into a vegetable, nor is it over fast. It lasts many years and causes suffering in the lives of the person suffering from dementia, their friends and loved ones.

Other terms considered were ‘dementia sufferers’ or ‘people with dementia’. NAPA³ uses the acronym (PWD), which stands for ‘People Living with Alzheimer's Disease and Related Dementias’ or ‘People (or Person) with Dementia’. These terms almost portray the message that it is about the people and their suffering, but not quite. Therefore the term ‘people suffering from dementia’ is used. A new acronym for the term was created to prevent the paper from becoming too wordy. The acronym **PSfd** can be read to mean: ‘people (or person(s)) suffering from dementia’.

1.2 Dementia & Alzheimer's

Dementia is an incurable chronic disorder of mental processes. It is caused by brain disease or injuries and involves the deterioration of the brain. Dementia is not a disease in and of itself; instead, it is a family of diseases characterized by cognitive and behavioural deficits - of which Alzheimer's is the most common, 70% according to Cavanaugh & Blanchard-Fields (2015). Even though Dementia is an umbrella term that includes Alzheimer's disease, they are considered synonyms in this paper. Dementia affects a person's memory and cognitive functioning, whereby they gradually lose their autonomy (Aglia, Bailly, Ferrand, & Martinent, 2018). According to Cavanaugh & Blanchard-Fields (2015), PSfd display various symptoms, the largest of which are memory loss and loss of cognitive function. It starts with a loss of the most recent memories and the processing of information. Then, it worsens until one loses the ability to recall memories. Gradually, people have more and more trouble learning, paying attention and making decisions. Time and space become increasingly difficult to grasp, and people become quickly disoriented. They start finding it increasingly difficult to find ‘the right words’, and verbal communication slowly becomes impossible. It is also not uncommon for someone to show unwanted social behaviour or a personality change. Although it is different for everyone, dementia is generally considered to have three phases; early, middle, and late. Table 0⁴ below represents the general cognitive decline and process of dementia.

³ NAPA is the National Alzheimer's Project Act (of the United States) see: <https://aspe.hhs.gov/napa-acronyms>

⁴ Table 0 was adapted from <https://www.dementiacarecentral.com/aboutdementia/facts/stages/>

Table 0. Stages of dementia

Early-stage: Moderate Cognitive Decline Average duration - 2 years.	<ul style="list-style-type: none">• Difficulty concentrating• Forgets recent events• Cannot manage finances• Cannot travel alone to new places• Difficulty completing tasks• In denial about symptoms• Socialization problems: Withdraw from friends or family• Physicians can detect cognitive problems
Mid-Stage: Moderately Severe Cognitive Decline Average duration – 1.5 years.	<ul style="list-style-type: none">• Major memory deficiencies• Need assistance with ADLs (dressing, bathing, etc.)• Forgets details like address or phone number• Does not know the time or date• Does not know where they are
Mid-Stage: Severe Cognitive Decline (Middle Dementia) Average duration – 2.5 years.	<ul style="list-style-type: none">• Cannot carry out ADLs without help• Forgets names of family members• Forgets recent events• Forgets significant events in past• Difficulty counting down from 10• Incontinence (loss of bladder control)• Difficulty speaking• Personality and emotional changes• Delusions• Compulsions• Anxiety
Late-Stage: Very Severe Cognitive Decline (Late Dementia) Average duration – 1.5 - 2.5 years.	<ul style="list-style-type: none">• Cannot speak or communicate• Require help with most activities• Loss of motor skills• Cannot walk

It is interesting to note that personality and motor skills are affected last and stay intact for almost the whole duration of the disease. This may prove to be important when administering pastoral care to the PSfd. If their body stays unaffected for so long, communication through touch, song, emotions and other senses could be an avenue worth exploring when administering pastoral care to the PSfd. Likewise, if their personality stays intact for so long, it could prove helpful in one's attempts to connect with them. Likewise, if they still have a personality, they could also have memories that degrade slower than others. The different types of memory need to be considered to understand why some memories might stay intact longer than others.



1.3 Explicit and Implicit Memory

The types of memory of importance for this paper consists of two categories, **implicit** and **explicit** memory.

Explicit memory is the deliberately and consciously remembering of information – having to work or think about something to remember it. Explicit memory is used in the active learning of new things. To make new memories, one has to explicitly think about them and work at it to remember them. To remember new things, one has to be able to **encode** the information. In simple terms, it means assigning labels or attaching meaning to the things one wants to remember. To do this, one needs to think about it consciously. Learning new things when one has Dementia is compromised due to the deterioration of the **explicit** memory's functioning. Kandel (2018) describes explicit memory as a system responsible for allowing people to remember facts, places, events and people consciously. For these reasons, one should not be discouraged or think that no progress is being made or 'that it is not worth it' when the PSfd does not remember who one is, for example. PSfd are physically hindered or even unable to create new memories, not to mention remembering someone they have not known for their whole life. Explicit memory heavily relies on the functions of the hippocampus. The hippocampus helps us make new memories. The hippocampus is one of the areas in the brain that is affected first by the disease. The older the PSfd are and the longer they have struggled with Dementia, the harder it will be for them to create new memories, remember or follow difficult and complex tasks or conversations. However, some memories stay intact for longer and are accessible by the PSfd.

There is a growing consensus that **implicit** memory stays relatively preserved in the PSfd (Harrison, Son, Kim, & Whall, 2007). **Implicit** memory allows for the retrieval of memories without conscious thought. It is the ability to perform specific tasks without consciously thinking about them (Cavanaugh & Blanchard-Fields, 2015). Kandel (2018) explains it as the automatic remembrance of learned motor- and procedural skills like riding a bike or playing the piano. Things one can do without actively thinking about it. For example, **implicit** memory is remembering how to dress, walk, eat, and do other everyday activities. It also includes knowing who one is, one's past lived experiences and one's personality. **Implicit** memory stays intact for most of the duration of the disease and only deteriorates in mid and later stages, as can be seen in Table 0. Son, Therrien and Whall (2004) confirm this in the conclusion of their research: Neuro- and cognitive psychology has shown that elderly PSfd or Alzheimer's disease patients have weakened explicit memory, but implicit memory is retained. The implicit memory relies on other brain systems than that of explicit memory. It uses the brain areas that respond to stimuli like the amygdala, cerebellum and basal ganglia. These are the memories that we accumulate throughout our lifetime and that have to do with conditioning. In short, it is one's experiences, lived and learned memories. **Implicit** memory influences one's life and the choices one has made.

If implicit memory is retained, then religion should theoretically also be retained. Much of what we believe has been learned before we were capable of conscious thought. Therefore, religion or spirituality might even help enhance communication with the person suffering from dementia. Spiritual- or pastoral care, in other words, could be used as a communication method with PSfd. In the next section, the terms pastoral- and spiritual care are defined.



1.4 Pastoral care

In this paper, 'spirituality' and 'religion' as well as 'pastoral care' and 'spiritual care' are regarded as synonyms, respectively. This paper defines spirituality or religion based on Dalby, Sperlinger, & Boddington (2011, p. 76).

Spirituality and religion:

- means thinking, talking about and feeling or experiencing that what has meaning and value in life
- goes above, transcends or expands the boundaries of self and the situation one finds oneself in
- helps or improves the connection with oneself, God/higher power, others and the environment.

The author of this paper sees spirituality or religion as connecting with people and accepting others for who they are, not what they do or what they can or cannot do. It is about helping each other deal with life, searching for what makes life worth living and building relationships with other people. Rather than focusing on what is correct or incorrect, it tries to look at what is suitable and helpful for oneself and the people in one's life. It does not focus on the nitty-gritty or try to prove the 'real' truth/reality. It is about seeing, listening and understanding what is valid for the other. Genuinely seeing and listening to who the other person is and what he or she finds important. This has an impact on the way pastoral/spiritual care is defined.

Pastoral and spiritual care is not totally different from one another. Neither are they fully intertwined with one another. They do, however, overlap. It is best to know a bit about both and borrow from the one and give to the other to improve, develop and enhance both fields. A pastor/spiritual caregiver then help people find and give meaning to their lives. One might help others overcome problems, not by 'being an expert', but by listening and exploring the stories told. Help the other help themselves, by strengthening them in their autonomy and help them see that they have a say in how they experience the world. It focuses on the relationship, the client-pastoral caregiver relationship, but also the relationship between people and God. Please refer to [Appendix A: The Pastoral caregiver](#) for an in-depth explanation of how the author of this article views being a pastoral caregiver.

Pastoral care, then, is the spiritual, emotional and religious care for all people regardless of who they are, what they believe or their mental capabilities. Pastoral care also respects "all religious faiths and expressions of spirituality" (Pastoral care, 2021). It is the acknowledgement of the beliefs, essential relationships, and all that the other find meaningful. The pastoral caregiver aims to help the person (re)connect to what gives them meaning. The pastoral caregiver accepts the other as they are and have general unconditional positive regard towards the other. Accepting the other as they are, means making or taking the time to listen to them and what they have to say or communicate. This should not be any different when it comes to administering pastoral care to the PSfd.

The following section explores more reasons why it is vital to administer pastoral care to PSfd.




Chapter 2: The significance of administering pastoral care to people suffering from dementia

2.1 What is the use?

Some might argue that it is not worth it to administer pastoral care to people suffering from dementia. Reasons like: they do not or cannot understand what one is saying; they will forget again (Post & Whitehouse, 2001); they will not even know you are there; they are basically dead already, or it is just a waste of time and money, are some examples that come to mind. Researchers found reasons why people are hesitant to engage in pastoral care with people suffering from dementia. Bryden & MacKinlay (2001) cites Morris Friedell. They mention and warn against a toxic lie about dementia. Some believe that in PSfd, the “mind is absent and the body is an empty shell” (Bryden & MacKinlay, 2001, p. 5). This has a detrimental effect on dementia sufferers, their voices become silenced, and they are denied spiritual growth. They are sometimes considered to be mere shells of what they used to be – in effect, not even human anymore. VandeCreek mentions, for example, that Western culture is cognitively orientated and that it is effortless for us to forget about the forgetful persons. Therefore, some believe PSfd do not need pastoral care (VandeCreek, 2001). In some countries, legal systems are not sympathetic towards non-cognitive persons either. A **non-cognitive** person is a person that has little to no cognitive abilities. When a legal definition of incompetence has been made, the individual is no longer regarded as a complete person. “As the disease progresses and in the absence of being able to have a meaningful conversation including the issue of impaired judgment, courts cease to recognize these persons as relevant and so they appoint a legal guardian... their ability to make choices” (Corfield, 2012, p. 56) are taken away. Some might even argue that the person in question can be regarded as socially dead.

Corfield explains that death can be defined on a variety of different levels. Most people would define death as a physical event. The moment when all bodily functions stop. Some people in the medical field widen the term to include “clinical” or “biological” death. The term “**social death**” “evolved and relates to those who die in a social sense consequent to degeneration of the brain or disease, which limits interaction with those around them” (Corfield, 2012, p. 58). Related to social death is the idea that the PSfd slowly lose their personhood as the disease progresses. In a cognitively oriented culture, one might say that cognitive impairment is equal to the loss of personhood. One could then also argue that a PSfd does not need spirituality or is extinguished by dementia. If one cannot reflect on spirituality, what then is the use thereof in the lives of the PSfd?

Luckily, there is a “growing awareness in the health care field that dementia does not extinguish the spiritual lives of individuals” (Powers & Watson, 2011, p. 59). Spiritual care has been acknowledged as a vital part of the care of PSfd. Unfortunately, its use and development have not grown all that much. Maybe it is because of the false cultural assumption that “if one lacks the ability to reflect thoughtfully on spirituality, it does not exist” (Kirkland, Fortuna, Kelson, & Phinney, 2014, p. 15). The way we think about the ‘human being’ influences how we care for them. Our values and beliefs can either empower or silence the PSfd and their concerns (Bryden & MacKinlay, 2001, p. 6). Suppose we believe that cognitive functioning is needed for spirituality. In that case, it is only logical to assume that pastoral care has no use in the lives of those who have dementia. However, is that true? Are memory and cognitive functions necessary for receiving pastoral care? VandeCreek does not think so but does acknowledge that it will be challenging (VandeCreek, 2001). The author of this paper agrees with VandeCreek and thinks that one should think carefully about how one defines personhood. According to




Kitwood, as cited by Powers & Watson, personhood is “the standing or status that is bestowed upon one human being, by others, in the context of relationship and social being” (Powers & Watson, 2011, p. 60). He argues that cognitive impairment does not diminish personhood. He thinks that more harm is done to the PSfd’s personhood when they are withheld from meaningful connections with others. If we change the way we think about the human being, what it is to be a person and how we see religion or pastoral care, we can change how we care for PSfd. For the author of this paper’s personal view on what a person is, please refer to [Appendix B](#). Besides changing one’s view of humankind, it has been empirically proven that pastoral care and religion benefit the PSfd.

2.2 Reasons to administer pastoral care to PSfd

In a study about the Lord’s Supper and PSfd Lubbinge, Heij, & Geluk (2019) researched religious activities’ effects on life satisfaction. Religion and spirituality are receiving more attention in psychiatric research (Koenig, 2009). There is an increasing interest in spirituality and religion’s role in mental health (AbdAleati, Zaharim, & Mydin, 2016). Religion can **help people cope with stress**. It **gives them peace of mind and purpose in life**. It **helps** ageing people cope **with the ageing process** and **improves their quality of life** (Mukherjee, 2016). It **helps** them **integrate into** the stage of **later life** and “**gives them a sense of importance, security, belonging, identity and continuity**” (Mukherjee, 2016, pp. 348-349). Aglia, Bailly, and Ferrand (2014) found that religious engagement **helps** people **cope with stress, anxiety, and depression** by **giving** them a **sense of coherence, meaning, and hope**. There is no difference in spirituality between ordinary ageing people and PSfd (Aglia, Bailly, Ferrand, & Martinet, 2018). Religion continues to play a role in how people experience life and cope with problems, despite the loss of cognitive functions. Just like ordinary ageing people, PSfd have the need for connection with others through various rituals such as bedtime prayers, listening to music, and religious activities (Barclay, 2012). Religious involvement gives a sense of coherence, meaning and hope. According to Hill (2006), participation in religious activities may even stimulate cognitive ability. Kaufman et al. (2007) and Coin et al. (2010), as cited in Aglia, Bailly, and Ferrand (2014), prove that a higher level of **religion correlates with a slower cognitive and behavioural decline** in people with Alzheimer’s disease. Religion **correlates with better health, longer life as well as better cognitive functioning later in life**. Hill (2006) points out that **religious attendance or involvement reduces cognitive dysfunction by 36%**.

Religion is essential – also for those who have dementia. Religion is often part of implicit memory because it is rooted in childhood memories. Songs and prayers are memorized to the point that one does not have to think to recall them. It becomes part of implicit memory, which stays intact for almost the whole dementia process. Accessing these ingrained memories can play an essential role in understanding and communicating with PSfd. Kevern (2015) says that **spirituality help people understand or give meaning to their lives**. It is a fundamental component of being human, and everyone is born with it. Van der Kaaden-Huttinga (2006) states that people with disabilities – including cognitive disabilities - attach great value to religious celebrations. Behavioural experts reported that the **participants often calm down, enjoy themselves and participate in the celebrations**. This helps them get away from the things they are dealing with for a while. A PSfd needs more than just to be cared for in their basic needs, such as food, clothing and bathing. They need to be supported in what they can still do as well as receive the proper pastoral care (Wentroble, 2001). The next chapter discusses theological reasons for administering pastoral care to people suffering from dementia.



Chapter 3: Theological discussions on administering pastoral care to People suffering from dementia

3.1 What being human means according to Christian doctrines

Chapter two stated that one's view, perspective, or definition of what a 'human being' is would impact how one would care for the PSfd. Theological motivations to administer pastoral care to PSfd are based on what it means to be human. This chapter considers what it means to be human and discusses reasons to administer pastoral care to PSfd. Then, the implications of what it means to be human are considered. What role the body and life story plays is considered, and finally, God's love and spirit in the person are considered. The summaries and discussions of section 3.1 are based on Van den Brink & Van der Kooi (Christelijke dogmatiek, 2012, pp. 237-241).

3.1.1 Creationism

Unlike animals, human beings are not bound to live in the circumstances they find themselves in. Human beings can look beyond these circumstances and transcend them. A human being can transcend these circumstances and even him or herself in effect becoming a new person and creating new possibilities. According to Karl Rahner, a human being is characterised by an openness toward or fixedness on God. **Human beings are:**

- open too & fixed on God
- capable of self-transcendence.

Discussion:

A human being is inherently open towards and fixed on God. If we deny them spiritual care, we deny or impede their access to something that characterises what they are – a being searching for God. Administering pastoral care to PSfd might help them transcend their circumstances and give them inner peace, the knowledge or feeling that everything is in God's hand.

3.1.2 Covenant theology

We are not only open to and fixed on God, but the reverse is also true. God is seeking to initiate a sustainable and even permanent relationship with us. The whole Bible makes this clear by showing how God made a covenant with His people. This then must mean that we are relational beings first and foremost. We were not made, nor meant to be alone, but rather to function and work together. This relationship God seeks and initiate is founded in His love for us. From the very beginning till the very end, we were built on the love of God. The Word He used to create us and speak to us is filled with the holy love that is God Himself. He sent His son (the Word of God became flesh) so that everyone that believed in Him would live forever (John 3:16). We can understand and respond to the love that is God. According to Hendricks Berkof, this also means that we are free because (true) love is not possible without freedom. We as **human beings are:**

- relational beings
- grounded in the love of God,
 - o capable of giving & receiving it; understand, enjoy and respond to it
- essentially free.

Discussion:

God created us as **relational** beings. His love is in us from start to end. Denying PSfd pastoral care is the same as denying them relationships or the possibility of relationships. We are built on the love of God, not on His cognition. This means that love is at the core of who we are as human beings and not cognition. PSfd might not have a fully functioning brain, but they can still feel, give and receive love. Past and present relationships help people experience love. Goodall (2009) describes patients finding comfort, being at peace and being full of love because of remembered relationships.⁵ Corfield (2012) believes that the relationship with God can continue when we share the love of God with the PSfd. Showing the PSfd unconditional love and providing them with pastoral care can help them feel the love of God and grow closer in relationship with Him and others.

3.1.3 Christology

For Karl Barth being human is not focused on being able to self transcend. Instead, what it means to be human should be based on God's gesture and action of self-communication – God's manifestation through Jesus Christ. In this way, God revealed to us what it truly means to be human. Through Him, we now know that an actual human being is a person that stands in relationships with others. Jesus did not live for Himself, nor did He come to be served, but to serve. Out of His love for us, He came so that we might be preserved. Therefore, the true nature of human beings is, is being human together. A human:

- stands in relationships with other human beings
- sees, treats and respects others as fellow human beings.


Discussion:

Whether or not a person is him/her self, can or cannot think or is or is not able to understand – we should respect, help/serve and love them. God, manifest in Jesus, told us to love one another. He did even more than that. Jesus showed us how to love one another through the way He lived His life. He came to this world not to be served but to serve. He served us even though He was much more important than us. Like Jesus, we must show love to other people, even when we think we are more significant than them. Let us forget what the PSfd is for one second and focus on what we should be and do. We must be disciples of God-Jesus and follow in His footsteps. This means that we should seek to be in a relationship with others and treat all people with respect – as fellow human beings. If being human equals being in a relationship with other people, then having a relationship with other people must also be equal to being human. In other words, by treating other people with respect and showing them that they are worthy of one's time and relationship, one confirms their 'humanness'. Administering pastoral care to the PSfd can help them build relationships with themselves, others and God. Denying a PSfd, on the other hand, takes away opportunities for relationships to be formed and, in effect, denies them their humanity.

3.1.4 Eschatology

Wolfgang Pannenberg also places God at the centre of the definition of what it means to be human. He interprets the ability to self transcend as an openness focused on the all-encompassing reality of God. To him, however, this reality has not yet been realised. What we are as human beings will only be revealed at the very end – the eschaton. Every person knows this, whether it is implicitly or explicitly. That is why we can be seen

⁵ For example "Other staff with new grandchildren brought in photographs leading to conversations of babies in residents' lives and their relationships. They were able to making connections with events in their own lives and showed a sense of self. They showed love, joy and peace" (Goodall, 2009, pp. 176-177).



as future-oriented beings. Our true nature is revealed in the eschatological human – Jesus, who shone a light on what it means to be human. Therefore we could define a human:

- as a being focussed on the future
- as a being on the journey of becoming a true human being.

Discussion:

A human is a being focused on the future. One might call this future, heaven and just like Jesus' task on earth was only fulfilled in His death, so we will only reach our destination or future after we have left our earthly bodies. 2 Corinthians 5: 6-8 says that when we leave our earthy bodies, we will be at "home with the Lord". In life and after death, we – human beings – are focused on our Lord God. Dying or having dementia does not take this away from us. Therefore, we cannot conclude that a PSfd does not have spiritual or religious needs. It is literally ingrained into our being, and we should not take it away from the PSfd.

3.1.5 The Christian doctrine of justification

Eberhard Jüngel uses this form of eschatological openness. According to him, a person is defined through the justification received from God. A person is not defined by his/her will, endeavours, knowledge or (economic) worth. It is not linked to what we can and cannot do, nor our past or biological capabilities. It is externalised. It lies within Christ. We are receivers and receptacles of Gods love - His beneficiaries. We may live from His approaching and appealing Word. A person is:

- defined by God through Christ
- a beneficiary of God's love
- living on the approaching and appealing Word of God.

Discussion:

According to the justification doctrine, our humanness does not lie within us, but it is externalised. God defines who we are. If God defines what we are, then it does not matter what state we are in. His view of us does not change just because we might lose some of our capabilities. We are alive solely because of His love for us. His love for us lasts a lifetime. God created us, loves us and cares about us forever. We as created beings cannot demote the PSfd to something less than what God created them to be. We should love and take care of them just like God does.


3.1.6 The Christian doctrine of the Trinity

God is essentially personal. God consists of three separate entities identifiable by their everlasting and unbreakable relationship with each other. God is relationship. As human beings, we are the image-bearers of God and therefore not self-satisfied individuals. We are unique persons that find their identities in being relational-in-community with other persons – characterised by love and freedom. As human beings, we are:

- through and through relational
- image-bearers of God
- distinguished by our being in relational-in-community with others identity
- characterised by love and freedom.

Discussion:

We are the image-bearers of God – through and through relational. We need one another to find or understand who we are and our meaning on earth. Being in loving relationships with other human beings and God is what makes us free. Taking anything of this away from the PSfd is like denying them their human rights or



humanness. Other than that, it robs them of their identity, purpose and worth in this world. Administering pastoral care to PSfd helps keep their identity intact for longer, makes them feel loved and frees them from some of the pain associated with the disease.


This concludes the summaries of Van den Brink & Van der Kooi (2012). The intention is not to pit the different theories against each other. Instead, it is about learning and seeing that our identities or personhood are defined for us by God. This cannot be taken away by anyone or any disease. We are His image-bearers. We are created in His image – in relationship with Him, the earth and other human beings. Being created in the Imago Dei is considered by most as the definition of being human. It also means that, fundamentally, our identity does not lie within ourselves or with the other, nor the way we perceive ourselves or how we are perceived. **Our identity lies with God entirely** – He is the one who created us. He is the one who knows us better than we can ever know ourselves. He knew us even before we were born. He sees into our souls. He does not look at the outside but at the inside of whom we are. A human being or identity is thus defined by how God looks at us. This means that we cannot see the PSfd as anything less than a human being because their identity does not lie within themselves and, therefore, does not go away when they decline cognitively. What the implications of the Imago Dei are is considered next.

3.2 The implication of Imago Dei

Bons-Storm, Describes God as a God who is connected to, concerned with and related to human beings. Therefore, being created in the image of God implies the “possibility of empathy between God” (Bons-Storm, 2016, p. 7) and every person. God feels for, understands and wants to be there for literally every person in the world. Whether healthy, disabled, burned out, ill or cast out. This means that people with dementia and the people caring for them can meet God in one another. Kevern goes into more detail about this connectedness, or solidarity, between people and God. He quotes Stanley Hauerwas, who maintains that “God’s face is the face of the retarded; God’s body is the body of the retarded; God’s being is that of the retarded” (Kevern, 2010c, pp. 180-181). – revealed by the resurrected Jesus. He concludes that being created in the image of God cannot be taken lightly – “to see the person is to see God and to know God is to know the person” (Kevern, 2010c, pp. 180-181). When the world robs the PSfd of his/her identity, it can be found again by just being themselves – a child, a person created in the image of God (Bryden & MacKinlay, 2001).

Human beings are created in the image of God, and it can never be taken away from them. As cited by Hudson, Hart says: “no matter how far we stray, or how poor our understanding, or how faithless our response, God’s image in us is indestructible” (Hudson, 2015, p. 5). This functions simultaneously as hope and reassurance for those with dementia, fearing that they will lose their identity and a wake-up call for people labelling PSfd as anything other than human. According to Corfield (2012), if the general perception of a PSfd is not changed, the PSfd’s difficulties in life will not get any better. It needs to be realised that any and every person’s value and dignity lie with God – who created and sustains them.

According to Sapp, bearing the image of God gives humans unique dignity and worth. It does not stop only at having His likeness. Like we inherited characteristics from our parents, we have also inherited some of God’s characteristics and goodness. Every single human is created in the image of God. It is, therefore, safe to assume that the spirit of God dwells in all of us – no matter our physical, mental or spiritual circumstances (Sapp, 2001). Roxburgh describes these characteristics as intellect, imagination and creativity. We are more than just our intellect and memories. Only when we accept this can we love and care for the PSfd in a way they need and deserve (Roxburgh, 2000).



Bons-Storm believes that if we see the PSfd as imago Dei that it will be possible for us to treat them as they are, instead of comparing them to whom, or rather **how**, they were before the disease. They are still human beings created in the image of God, just like Jesus at Golgotha: His “body was mangled on the cross, but still, he was ‘God’s image’” (Bons-Storm, 2016, p. 7).


Discussion:

The PSfd should be seen as a person created by God, in the indestructible Image of God. When we look at them, we must see God Himself. When we see the PSfd this way, we will have love and respect for them. When we have love and respect for the PSfd, we will make time to care for them out of love and respect, showing them that they are worth making time for, rather than because it is our job. When the PSfd feels loved, respected, and worth other people's time, they will see who they are and find their identity again as a child of God. Because the PSfd is made in the image of God, it should be impossible for us to ignore a person with dementia or think of them as less of a human being. Doing so means that one does not know God, or even worse, think less of Him. To give a twist to Kevern's words: *to reject the person is to reject God, and to think less of the person is to think less of God*. James 3:8-10 talks about how it is terrible that we curse human beings, made in the likeness of God. He says that this is not the way it should be, nay he says that it should be impossible. Just like salt and fresh water cannot flow from the same spring or a fig tree to bear olives or a grapevine figs (James 3:11-12). Powers & Watson uses Imago Dei, or being *specialty created*, as the foundation of their principle to show every person, no matter their cognitive ability, the same respect for dignity. We should help them feel loved; be there for them in times of loss, loneliness and fear; it is up to us to help them live life to the fullest (Powers & Watson, 2011). Furthermore, we should look after those in need and not follow the way of the world (James 1:27). God asks us to respect, encourage and take care of old(er) people regardless of their mental health status throughout the whole Bible.⁶

3.3 A person is a life story and a body

Our identities or personhood is not defined by social standards, norms, values, status or worth. Neither is it linked to how we, others or science would define a human being. Being human means being created in and bearing the image of God. The image of the triune God. We are not defined by what we can and cannot do. Our identity does not lie in our capability or capacity to think. We are not our brains, and our brains do not define us. We are more – we are body, mind and soul. We have a soul, something eternal or everlasting, of which God is the Governor. We have a mind, which can be restricted or become extremely difficult to access because of the deterioration of the brain. We have a body that contains our whole life story – who we are. That story does not go away. No matter what the body looks like, it is still the image of God. We know this because Jesus's beaten, humiliated and crucified body was the only perfect sacrifice. It is, therefore, unthinkable, illogical, and even the opposite of what Christianity teaches us to think of a PSfd as less worthy, - acceptable or -human. Put simply, “a sound body or mind, is not required for acceptance by God” (Sapp, as cited by Morris, 1997, p. 127), neither is it needed for a person to accept God in his or her life or to practice their faith. The body and its life story contain the identity of the person. This life story is something that can be tapped into to connect the person with themselves, others and God.

⁶ 1 Timothy 5:1-8; 1 Peter 5:5; Leviticus 19:32; Ephesians 6:1; Exodus 20:12; Proverbs 20:29; Job 12:12; 1 Peter 2:17; Proverbs 23:22; Deuteronomy 5:16; Matthew 15:4; Colossians 3:20; Philippians 2:3; Hebrews 13:16; Romans 12:10; Leviticus 19:32; 1 Peter 5:5; Job 32:4-6; Job 12:12; Matthew 25:40; Matthew 7:12; Deuteronomy 27:16; Hebrews 13:16



The body is the bridge between the person and God. Through the Spirit, which lives in our body's we can come into contact with God. God's spirit not only gives life to the "whole body" (Hudson, 2015, p. 13), He also lives within us, as our bodies are a temple of God (Corfield, 2012). Thus, He has a physical connection with us. We should, therefore, honour, respect and care for "the body that has been the channel and vehicle for the now-lost intellectual operations and memories" (Sapp, 2001, p. 28).

It is the same body that grew up learning about God and throughout its lifetime learned and changed – growing closer to God. Our religion influences our lives, and our bodies take shape as we "practice the Kingdom" (Swinton, 2014, p. 163). In short, the body remembers God. It is not just an idea, not something that one merely think about. It is something that is lived with **body**, mind and soul.

"The body remembers God" might seem strange to some, but it should not be. The concept is nothing new. The apostle Paul talked about the result of their ministry being written on people's **hearts** in 2 Corinthians 3. The Greek word καρδιά / kardia translates to heart⁷; mind, character, inner self, will, intention, centre. It is the centre of our being and the capacity of our moral preference. It is that which determines how we live with and treat others – it influences our moral compass. One could argue that it should not be interpreted literally, i.e. the physical heart, but should be understood poetically – as the soul, mind, thoughts or feelings. The author of this paper proposes that one could and should read this literally - since the same word is used in Hebrews 10:16. It talks about God putting His law on the hearts of the people, referencing Jeremiah 31:33: "I will put My law in their minds, and write it on their hearts". Both words (mind and hearts) refers to the inward or inner-being.


Interestingly, though, the word *mind* refers to the inward part of the human body in the *physical* sense and *heart* to the soul, comprehending mind, will, thought and reflection. Nevertheless, God is talking about ingrainings His laws in the *most inward part* of man, the *inward part* of the human body, in both the physical and non-physical sense. According to Swinton, Hebraic anthropology saw the person as a "unitary whole" (Swinton, 2014, p. 163). This means that no distinction was made between the physical and non-physical. Soul, body and mind was seen as one. He further writes that Scripture never refers to the brain as the centre of consciousness, thought or will, but that the heart is at the base, the hub of it all. He describes Christianity as more than an idea. It is a bodily faith, a faith that must be lived through the human body. It is literally an embodied faith – a faith that manifests itself in and through our bodies. A faith that also lives on in the body of the PSfd.

Discussion:

By administering pastoral care to a PSfd, we can (re)connect them with the source of their identity and help them remember who they are. One might say that pastoral care is the bridge to identity, the way to help the person remember who they are. Connecting with the PSfd physically is to truly, fully connect with the PSfd and one of the essential methods of making contact with them. Making a connection with their body means connecting with their past life's, identity, faith and God.

We are more than our brains – one could say *more than the sum of our parts*. The same is to say for our religion and faith. What we know about our faith is ingrained into us even before we can think about it. In a sense, what we learn as a child, especially about our faith, happens mostly non-cognitively. "It involves the whole person, including our bodies... and orients us to the world—all before we ever start thinking about it" (Smith,

⁷ See <https://biblehub.com/greek/2588.htm>



2009 as cited by Swinton, 2014, p. 166). So it stands to reason that if what we have learned about faith was there before cognition, it would still be there even after losing our cognitive abilities. Therefore one could argue that a PSfd could also remember God and their connection with Him, as it is ingrained in their bodies.

The body needs to be taken care of even, or maybe even more so when it is sick or becoming progressively worse. A person is a body with a life story and faith, which continues to live in the body even though the mind may forget. This is why the PSfd needs to receive pastoral care. Pastoral care may enable the PSfd to reconnect with the ingrained memories in his or her body. By doing rituals with the PSfd like praying or receiving the Lord's supper, their body may start to remember – making them feel whole again. Faith is more than an idea; therefore, one should care for the PSfd's bodies functionally or physically and spiritually. The body not only contains identity and faith but also love and the spirit of God.


3.4 Love and the Spirit of God in the person

We may not believe, see or feel that God is near. He is, however, much closer than we think – He lives in us through His Spirit. Jesus Himself asked His Father to send His Spirit to come and live with us forever (John 14:16). What Jesus asked of His Father was the physical manifestation of a promise God made to us multiple times in human history. “I will never leave you nor forsake you” (Deut. 31:6, 8; Josh. 1:5, Heb. 13:5). God lives within us, making us His home or temple. God and his Spirit dwell within that temple (1 Cor. 3:16) forever.

If God lives in us through His Spirit, His love also lives in us. It flows in us and works through us. “God’s purpose in creating human beings was to share his love with them” (Corfield, 2012, p. 7). He not only wanted to share His love with us but also asked us to love one another. Again, this is nothing new. God created us in His Image – bearing His Image, to rule, or instead, take care of His creation. To take care of it as He would – with love and dignity. This was made clear by the Words, Life and Sacrifice of Jesus as well as in Jesus’s last commandments when He said to His disciples: “Love one another. As I have loved you, so you must love one another” (John 13:34-35). We are only capable of this love by the Sacrifice He gave and the Spirit that dwells in us. We are vessels for God’s love, and even though we might grow old and forget – God does not forget us. Put into other words, this means that the individual, his/her value and soul stays intact. An individual, a soul searching and longing for love and connection. A person over whom, a life over which we have “no authority to neglect, harm, or destroy” (Corfield, 2012, p. 76). The spirit of God in us remembers us and help us remember God.

Discussion:

Our bodies are temples of God, which means that God lives in us through His Spirit and that His love flows through us. We are asked to love one another as we love ourselves (Matthew 22:39) and do unto another like we would like to be done to us (Matthew 7:12). The same goes for the body of a PSfd. As pastoral caregivers, we must care for people, especially the sick. We should follow in the footsteps of Jesus, who took care of the sick and cast out - “love our neighbour as ourselves” and to “love one another as Christ loves us” (John 13: 34). It is our duty. Jesus came for the sick and cared for those in need. As pastoral caregivers, we might not always come into contact with the ill – but we are almost always talking to someone who wants or needs spiritual connection. This is our job, the task given to us by God-Jesus. As the PSfd is still a person and not devoid of spiritual need, we should follow the example Jesus set for us and care for them. Jesus instructed us to care for the less fortunate - “if you cared for the sick, you have cared for Me” (Mathew 25:44; Deut. 31:6, 8; Josh. 1:5 & Heb. 13:5). Caring for the sick and less fortunate is the same as respecting and caring for God in that person” (Corfield, 2012). We do not have the right to harm or neglect them but need to love them and care for them.



By taking care of and making contact with the PSfd, we can make contact with God through the spirit living in the PSfd, and they can be reminded of and be remembered by God (Hudson, 2015). This is much more profound than simply being reminded or remembered. Hudson purposefully wrote it as *re-membered* and *re-minded*. It means *becoming again, receiving* or being *placed within* – becoming a member and gaining one’s mind again. This is not something the PSfd does him/herself. It is done with the help of someone else. As the chaplain/pastoral worker/spiritual caregiver, we are that someone – we may represent “a God who never forgets us” (Corfield, 2012, p. 17). By re-membering the PSfd, one can let them know, or instead help them feel, that they have value. When we help them re-mind, they can feel and know that God is there for them, loves them and that nothing can ever separate them from His Love (Rom 8:38-39). For more reasons and benefits of pastoral care based on theology, please refer to [Appendix C](#).

They are still capable of making connections with others; one just needs to take the time to try and understand what they are trying to communicate and help them do so. Therefore, this study researched different methods of administering pastoral care to PSfd and developed a new method to help pastoral caregivers in their tasks.

Chapter 4: Developing a method for administering pastoral care to PSfd

4.1 Study aims

The instructing party believes that it is essential to administer pastoral care to people suffering from dementia and wants her work to be based on theoretical knowledge and best practice methods.

This study aims to gather information on methods or strategies of pastoral/spiritual care that could be used to administer pastoral care to PSfd. In addition, this study aims to select, compare and combine different theoretical and best practice methods to create a new method, grounded in theory, for administering pastoral care to people suffering from dementia.

4.2 Research question

As is the nature of the grounded theory method, this study does not try to prove something, nor does it have a hypothesis that needs to be tested. Instead, it starts with a simple question that it wants to explore or an idea it wants to develop.⁸

The question for this paper is: what methods or strategies are best for administering pastoral care to the PSfd?

4.3 Method

This study made a qualitative thematic analysis of the research data using the method of grounded theory. Grounded theory is the systematic gathering and analysis of data in order to develop a new theory or revise an existing theory. In the case of this study, it was used to develop a new method based on theory and empirical data. Studies using grounded theory usually start with a simple question or a collection of qualitative data. Data that includes but is not limited to conversations, interviews, videos, pictures, books, articles and research papers. This study focused on scholarly articles, books and research papers but also included interviews, conversations, previous experience and videos. One thing to note about the grounded theory method is that rather than choosing an existing theoretical framework and gathering data to prove a hypothesis, it explores a wide range of different frameworks to extrapolate and compare against one another to create a new hypothesis or theory. This study includes but is not limited to data from gerontology, psychology and theology.

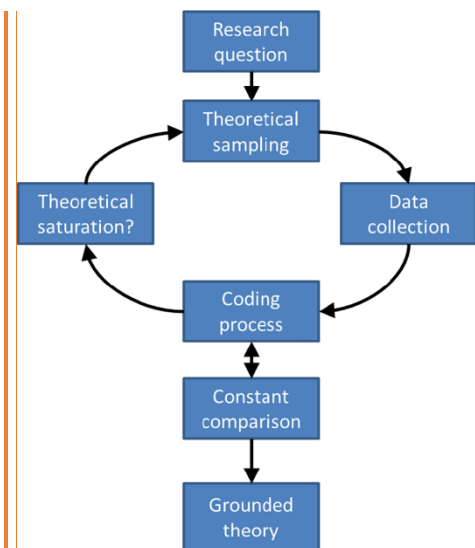



Fig. 1

The gathered data is then analysed using open-, axial- and selective coding (Wagner, Kawulich, & Garner, 2012). During the collection and coding of the data repeating ideas and concepts, or as was the case for this study,

⁸ "In grounded theory studies, the researcher's analytic focus emerges during the research process, rather than being determined before empirical inquiry begins" (Charmaz & Thornberg, 2021, p. 305)



strategies or methods start to manifest. As more data are collected, the process repeats and codes and concepts are grouped into categories and more prominent themes. Finally, the process ends when the theory is saturated – when ideas start repeating, no new concepts are discovered, and no new codes are created. Fig. 1⁹ shows a graphical representation of the process. It is an inductive reasoning cycle of observation, detecting patterns, formulating a hypothesis, analysing, discovering and comparing theories. The new method for administering pastoral care to PSfd is, thus, *grounded* or based on theory and empirical evidence.

4.4 Reliability and validity

In grounded theory, the researcher must not be biased or have answers to questions before beginning the study. Therefore, the researcher must not research the topic at hand before starting the research. If this is not possible, they should, at the very least, be aware of their biases and make them known. Knowledge about biases will help increase validity and reliability by preventing one from unknowingly searching for said bias and confirming it without critical assessment. As it stands, the author of this paper's previous research and experiences touched on the subject matter. Therefore, his biases are listed accordingly.

- Based on previous research and experience, the author is biased toward accepting that it is still possible to communicate with the PSfd. Previous experience showed that it is possible and helpful to administer pastoral care to non-cognitive people. Therefore, if it is helpful to non-cognitive people, the author believes that it will also be helpful for PSfd and that they should still receive pastoral care.
- The author is biased towards **touch** as a valid and helpful method. In previous experience with non-cognitive, blind- or people with poor sight, the author saw the powerful effect a light touch or the holding of the PSfd's hand had on the connection between PSfd and caregiver. Connections were easier established and more profound. The author believes that touch will also be a helpful tool when administering pastoral care to PSfd.

Other than the biases mentioned above, the author entered the study without prior knowledge about the subject matter. The biases of the author, like other findings, were rigorously tested against different sources of data and a previously established method on administering pastoral care to PSfd. Furthermore, the author thinks chapters two and three adequately show that pastoral care to the PSfd is helpful.

To improve the validity and reliability of the study, the author would have liked to observe the instructing party during pastoral care sessions. The author wanted to observe the method first-hand and make an independent analysis of her method. Unfortunately, due to personal and world circumstances¹⁰, this was not possible. The author instead interviewed the instructing party about her method.

The author believes the study to be valid as it used 25 previously published scientific articles on the subject matter as the sources for the study. In addition, all findings were cross-checked to the other sources, and findings with less than 5% confirmation or overlapping with other sources were discarded. How the data was gathered, coded and analysed is explained in the next section.

⁹ (Spinks, 2014)

¹⁰ In December 2019 the author had a burnout. In January 2020 the COVID-19 outbreak was declared official, complicating all matters of life.



4.5 Methodology

4.5.1 Gathering data and type of data

To better understand what was asked of him, the author, firstly, interviewed the instructing party to explore the question further and determine what she wanted from the study.

Secondly, desk research was done to gather information based on the aforementioned interview. This study focussed on literary research. It consists of books and articles on gerontology, psychology, dementia, biology, medical practices, theology, pastoral work and spiritual care. This was sourced in the form of scientific publications via Google Scholar (scholar.google.nl); Academia (academia.edu); SpringerLink (link.springer.com); ERIC (eric.ed.gov); EBSCOhost (ebSCOhost.com); Research Gate (researchgate.net) and SAGE Journals (journals.sagepub.com). The scientific publications were obtained using the following key phrases: pastoral care method dementia; pastoral care dementia; spiritual care dementia; spiritual care method dementia; best practice dementia care; religion dementia pastoral care, religion dementia spiritual care, religion dementia care; dementia care; symbol ritual dementia. Irrelevant sources, that is, sources that contained nothing on a method or advice on how to administer pastoral care to PSfd, were excluded. Fifteen publications were deemed relevant, analysed and coded in MAXQDA 2020.

Thirdly, the instructing party was interviewed again to determine which methods she used and which were known to her. Finally, another literary research was done using key phrases based on combined data from the first coding round and the second interview. These phrases include pastoral care and non-cognitive people; the effect of spirituality on people with dementia; spiritual care and non-cognitive people; the effect of religion on people with dementia; God and dementia; religion spirituality and people suffering from dementia; Alzheimer's disease and pastoral care; Alzheimer's disease and spiritual care; best practice pastoral and spiritual care of older people; bodies and memories; spiritual care and the senses; spirituality and person-centred care for people living with dementia; non-cognitive people spirituality and non-cognitive pastoral care. The term non-cognitive was included because of the nature of the disease of dementia. As the disease progresses, the once cognitive person – or person with cognitive abilities, slowly loses their cognitive abilities, therefore becoming less-cognitive or non-cognitive as time progresses. Another ten relevant publications were found and again analysed and coded in MAXQDA. The following section provides a detailed explanation and examples of the coding process.

4.5.2 Coding, analyses, comparison and results

4.5.2.1 *Selection of data to be coded*

The different data sources were read to determine which parts of the data were relevant to the study. Next, relevant data were isolated into separate documents per source. This step identifies the broad scope of data. Data was considered relevant if it contained information on the following:

- Whether or not pastoral care was useful for PSfd.
- Methods used to administer pastoral care.
- Mentioning the benefits of using specific methods.
- About what should and should not be done.
- About what has been empirically proven to work or not work.
- Theories of why a particular method should or should not be used.
- What the PSfd thought about pastoral care and what they find helpful.

4.5.2.2 Open coding

Open coding is the initial coding wherein data is “compared with data, data with codes and codes with codes” (Kathy Charmaz & Robert Thornberg, p317). In the open coding process, **units of data are identified** - the labelling or coding process is started by experimenting with codes and coding for meanings, feelings and actions. Next, it involves the coding or labelling of data with keywords. The more keywords are labelled, the more one develops an idea of what pieces of the information are essential and which are less critical. Then, codes are broken into subcategories and integrated to create more inclusive codes (Wagner, Kawulich, & Garner, 2012).

This study used MAXQDA for labelling and analysis. It is a software analysis tool for qualitative and mixed methods research, which helps with data coding, organising, and visualisation. Initial coding was done by experimenting with codes and writing memos to explain what they mean. By reading the selected data, different ideas and methods became prevalent and were coded according to their meaning, feelings or actions. Memoing was done to describe the meaning and purpose of the code. What follows is an example of the coding and memoing process¹¹ (Table 1. Initial coding) based on the initial fifteen sources. The same set of codes is used throughout this paper to show how they evolved.

Table 1. Initial coding		
Code	Memo	Selected data
New Method	Each person demented differently. It is about new and imaginative ways to care for PSfd. It is also about data mentioning that faith or pastoral care is still relevant for PSfd	“Willingness to examine curricula for content on ministering to older adults with dementia, conduct research, and engage meaningfully with others, beyond the boundaries of discipline-centred dialogues, will better serve to feed these, among their flocks, who hunger for their care.”
New Method		<p>"Six felt that there were many ways in which a patient's spiritual needs might be met; for example:</p> <ul style="list-style-type: none"> ■ Attending chapel/church services ■ Going outside for walks, including seeing the sunshine ■ End of life care ■ Providing quiet time/space ■ Listening to, and facilitating, the patient's wishes ■ Providing multisensory activities, including listening to music."
Familiarity	Mentions that one should use familiar items, clothes, songs or actions etc. to connect and communicate with PSfd	“The liturgy, familiar hymns and choruses, the Lord's Prayer - these are ways in which you can help me join with you in our walk with God.”
Familiarity		“Richards and Seicol suggest that pastoral caregivers can assist the person with dementia to maintain a spiritual connection to God through memories, life stories and sharing in music, prayers, sacraments, symbols and rituals that are familiar.”
Make time	They can communicate, realise that it takes time, slow down, relax and take your time with them. Don't be in a rushed	“Use reassuring facial expressions, touch, gestures, and body postures. Take time for a conversation, with long pauses as necessary.”
Make time		<p>"Giving the person time Wait for a response, hesitation may be due to a lack of understanding or, an inability to frame a reply."</p>

¹¹ This paper contains only examples of the process, but the process of the whole study is available on request. The process documents are available in an excel document and a readable MAXQDA file.

After the first coding round, some themes were prevalent and gave the researcher a better idea of what data to look for. The instructing party was interviewed a second time to gather more information about the pastoral methods she uses. With the new knowledge at hand, another theoretical search was done. The second research round provided ten additional sources of data, bringing the total sources consulted to 25.

The selection and coding process was repeated for the new data. Once no new codes were generated and codes started repeating in the different papers, theoretical saturation was achieved for the initial coding process, and the search for relevant data stopped. The result was a list of 73 codes (Fig. 2).

Fig. 2 displays the frequency, which is the number of different sources containing the specific code. The frequency gives an estimate of the relevance of the code or theme. In general, the more papers coded with the same code, the more relevant the coded theme. Because of the vast amounts of codes generated, it was essential to determine what was relevant and what was not. This was done by analysing the frequency with which a code was labelled. The percentage of frequencies was used to determine the statistical significance of a code. The frequency percentage is the number of sources mentioning a specific code divided by the total number of sources (25) multiplied by 100 (frequency / 25 X 100 = percentage mentioned by sources). A frequency percentage of more than 5% is generally accepted as statistically significant. This means that a concept, code or label must be in more than one document to be considered significant or of value for this research. Thus, to be statistically significant, at least two papers should mention the concept or contain the labelled code ($2/25 \times 100 = 8\%$). The statistical significance was set to 5% or $P=0.05$, and statistically insignificant codes were filtered out. This resulted in the deletion of codes that were found in less than two sources. Given the purpose of this paper, codes found in only one source was deemed less important for this paper and not less accurate or true in and of itself.

The codes and their data was examined and integrated to be more inclusive and then broken into subcategories. This was done by placing codes with similar data together, making them more inclusive and better representing the most repeated themes. Finally, other codes were moved or changed. See Table 2 for an example of this process.

	Frequency	Percentage
Focus on what is still working	19	76.00
Multidisciplinary endeavour (+)	17	68.00
Dementia is an individual (client based) process	16	64.00
Relationships	15	60.00
Prayer / well known prayers / lord's prayer	15	60.00
Presence (+) / Here and now (+)	15	60.00
Worship / Church	14	56.00
Life story (+)	14	56.00
Scripture	13	52.00
Their care needs	12	48.00
Touch	12	48.00
Familiarity (+)	12	48.00
Reflect	12	48.00
Help them remember (remember for them)	11	44.00
Music	11	44.00
Environment (+)	11	44.00
Rituals	10	40.00
Train other caregivers	10	40.00
Symbols / Symbolism	9	36.00
Holy Communion / Eucharist	9	36.00
(Old) Hymns	9	36.00
Awareness	8	32.00
Acceptance / unconditional positive regard	8	32.00
Advanced (Pastoral) Care Plan	8	32.00
Cognitive vs non-Cognitive	8	32.00
Sacraments	8	32.00
Tips / Stuff that help them remember	8	32.00
About client (+)	8	32.00
Young people and children / lay participation / family	7	28.00
Neglected	7	28.00
Observe	7	28.00
Tailor made	7	28.00
Participation / inclusion	7	28.00
Enter into their time realm	7	28.00
Reduction in stressors (+)	6	24.00
Themes	6	24.00
Eye Contact	6	24.00
The use of objects (+)	6	24.00
Candle	6	24.00
Involve them	6	24.00
Make time	5	20.00
Traditional as in familiar does work	5	20.00
Tips/Advice (+) (+)	5	20.00
The impact of AD on the care setting	5	20.00
Laughter	5	20.00
Blessing (+)	5	20.00
Lord's prayer	5	20.00
Gestures	5	20.00
Listen	5	20.00
Bible	4	16.00
Reasoning	4	16.00
Memory aids	4	16.00
Humour	4	16.00
Consistency and repetition (+)	4	16.00
Traditional cognitive methods do not work	4	16.00
Obtain information	4	16.00
Empathy	4	16.00
Sermon / Homily	4	16.00
Cross	4	16.00
Reality orientation	3	12.00
Silence	3	12.00
Get down to their level	3	12.00
About dementia (+)	3	12.00
Rosary	3	12.00
Social interaction	2	8.00
Remembering Boxes	2	8.00
Clothing	2	8.00
Don't correct rambling	2	8.00
Introduce yourself	2	8.00
Being aware of your good practice	2	8.00
Extempore Prayer	1	4.00
Visual aids and drama	1	4.00
Experience(s)	1	4.00

Fig. 2

Table 2**Make/take time don't rush**

The code was changed to **Listen**. Listening, genuinely listening means to the time to fully engage with the client instead of being rushed. It means doing your utmost best to try and understand them and their care needs. The clients and their needs are more important than keeping a tight schedule.

Talk about the past – reminisce

The code was to **Memory/Memories**. Talking about the past is making use of the memory parts of the brain that is still intact. It is about bringing up (fond) childhood or past memories that are worth talking about. By talking about these memories, the pastor can learn more about the client as well as make a worthwhile human connection with them.

Listen / understand

The code was combined with **Listen**. Listening, truly listening means making time to engage with the client instead of being rushed. It means doing your utmost best to try and understand them and their care needs. The clients and their needs are more important than keeping a tight schedule.

Memory

The code was combined with **Memory/Memories**. Talking about the past is making use of the memory parts of the brain that is still intact. It is about bringing up (fond) childhood or past memories that are worth talking about. By talking about these memories, the pastor can learn more about the client as well as make a worthwhile human connection with them.

Constant comparison was made between new and existing codes until no new codes were generated and only old codes were encoded, thus reaching code saturation for the more prominent codes. The review, comparison and integration of the codes together with the deletion of statistically insignificant codes resulted in a list of 23 prominent codes or themes (see Fig. 3).

After the codes were analysed and combined into more inclusive codes, line by line coding was done. The data was torn apart and looked at from another perspective to gain more information from it. Subcategories **or codes were created** by creating codes that belong to the same theme but highlighting more nuances.

Table 3 gives an example of this process. In the table, the last and bold code in the series is the actual code, all codes preceding it are the parent codes. The codes in the table is an example of how the code **familiarity**, found in the

previous table, can be split into different ideas, new codes and subcodes. The result of the line by line coding was a list containing a vast amount of codes and subcodes. This list also formed the starting point on which the new method was built. For the complete list of codes and subcodes, see [appendix D](#).

	Frequency	Percentage
Dementia is an individual (client based) process	21	84.00
Presence / Here and now	21	84.00
Familiarity	19	76.00
Focus on what is still working	19	76.00
Multidisciplinary endeavour	18	72.00
Worship / church	17	68.00
Memory	16	64.00
Relationships	15	60.00
Environment	13	52.00
Touch	12	48.00
Rituals	12	48.00
New Method	11	44.00
Symbols/Symbolism	9	36.00
Holy Communion / Eucharist	9	36.00
Cognitive vs non-Cognitive	8	32.00
Eye Contact	7	28.00
Humour	7	28.00
Gestures	5	20.00
Blessing	5	20.00
Empathy	4	16.00
Reality orientation	3	12.00
Social interaction	2	8.00
Being aware of your good practice	2	8.00

Fig. 3

Table 3. Line by line coding		
Focused coding	Memo	Selected data
New Method\Familiarity (+)\Music\ (Old) Hymns	Mentions that one should use familiar items, clothes, songs, actions, etc. to connect and communicate with PSfd. Specifies familiar or old hymns/songs from their past	"The liturgy, familiar hymns and choruses,
New Method\Familiarity (+)\Prayer\well known prayers\lord's prayer\ Lord's prayer	Patients show that prayer is important to them. Prayer is used during pastoral sessions. Specifies the Lord's Prayer	the Lord's Prayer - these are ways in which you can help me join with you in our walk with God."
New Method\Memory\Memories (+) proof en tip\Tips\ Stuff that help them remember	Memories and other triggers that prove that they can still remember and helps them to do so	"Richards and Seicol suggest that pastoral caregivers can assist the person with dementia to maintain a spiritual connection to God through memories,
New Method\Dementia is an individual (clientbased) process\ Life_Story (+)	Mentioning life story as important	life stories and
New Method\Familiarity (+)\ Music		sharing in music,
New Method\Familiarity (+)\Prayer\well known prayers		prayers,
New Method\Symbols\Symbolism\Rituals\ Sacraments	Mentioning sacraments as important	sacraments,
New Method\ Symbols/Symbolism	Mentioning symbols/symbolism as important	symbols and
New Method\Symbols\Symbolism\Rituals	Mentioning rituals as important	rituals that are familiar."

4.5.2.3 Axial coding

Axial coding involves exploring the codes, examining their relationships, (re)specifying the conditions associated with codes, reviewing their data to confirm associated codes, and comparing the codes with pre-existing theory and one another (Wagner, Kawulich, & Garner, 2012).

Before analysing the codes again, all of the codes were populated using the lexical search function in MAXQDA. The lexical search function allows the researcher to search all documents for specific keywords or phrases simultaneously. The search results can then be coded accordingly. This search function was used for each of the newly developed codes. Based on the knowledge obtained through the research process, appropriate keywords and phrases were developed for the different codes. The codes were then populated with the respective data found. In this way, the codes were populated with data from every single source containing data relevant to the search term. After completing the lexical searches and coding, the codes were independently reviewed and non-sensical data coded because of the lexical searches removed. Non-sensical or irrelevant data is data that does not fit in the code.

An example of this is a search for 'cross' to populate the code *make use of objects*. The purpose was to populate the code with data stating that a cross was an applicable object for use during pastoral visits. Irrelevant data, for example, are 'they were cross at me' or 'they crossed the road', were subsequently discarded.

After all the codes were populated and, irrelevant data deleted, the codes were compared to previous data and codes. Each code again was assigned parameters of what type of data it should include. Next, the codes' relationships were examined, and codes were integrated or moved to the correct subgroup or theme. Finally, the data in the codes were compared and reviewed to the existing codes to determine if they belong there, should be moved or combined. Table 4 is an example of how codes were combined or moved to more relevant parent codes. After the codes were saturated and compared, the list of prevalent themes was reduced to 16 codes (see Fig. 4).

	Frequency
Dementia is an individual (client based) process	21
Presence / Here and now	21
Familiarity	19
Focus on what is still working	19
Multidisciplinary endeavour	18
Worship / church	17
Memory	16
Relationships	15
Symbols/Symbolism	14
Environment	13
Touch	12
Cognitive vs non-Cognitive	8
Eye Contact	7
Humour	7
Reality orientation	3
Being aware of your good practice	2

Fig. 4

Table 4

Life_Story

Life Story and *talk about the past* were combined because they both had to do with talking about who the person was, their religion, and past times help one connect with the person. Their story, experiences and pasts

Familiarity

Familiarity was combined with *over learned material*. Because it is about familiar things, easy to recognise and remember, it is about things that are so ingrained into the person's memory that they do not have to use energy about thinking about it. The memories just come naturally. They are usually, although not always, things that have been learned as a child. It is about implicit memories, memories that are preserved in the PSfd.

4.5.2.4 Selective coding and focused coding

Other than comparing the codes to the existing codes generated, the codes were compared to the theory of an existing method¹² and the instructing party's method. This was done to increase the reliability and validity of the new method. It also aided in the further selective coding on what codes could be used in the final method, which would be excluded or combined even further. In other words, it helped with the identification of the main themes of the analysis. Comparing the three theories or methods to one another also helped determine how much the instructing party does is already based on theory or empirically proven methods. Being aware of one's own good practice can help one gain confidence in the work field and prevent one from second-guessing oneself constantly. Morris indicates that "whether through instinct, or based on knowledge gained through experience, pastors are doing many of the 'right things'" (Morris, 1997, p. 349) when administering pastoral care and communication with the PSfd. This study does not aim to reinvent the wheel nor demotivate the pastoral caregiver. Therefore, It is vital to know and build on what is already deemed worthy and working well. In this way, the new method builds and expands on what the instructing party already knows and practices well.

The existing method was isolated and only coded after all other data were coded to avoid bias to specific ideas or methods. It was coded based on the codes created for this study's new method. The method of the

¹² The method in question is one developed By Morris (1997, pp. 354-361).

instructing party was deduced from a focused interview with the instructing party¹³ and coded in the same manner. The results can be seen in *Table 5: Comparison*. In the table, a '1' indicates that the code is relevant to the source, and a '0' that it is not. **New method** is the method being developed in this paper, **Old method** is the existing method of Morris (1997), and **Current method** is the method currently used by the instructing party. The codes are arranged alphabetically based on the number of sources containing the code.

The old method was isolated and independently coded only after all sources were analysed and coded to reduce confirmation bias and enhance reliability.

Table 5: Comparison			
Codes	New Method	Old Method	Current Method
Familiarity	1	1	1
Multidisciplinary endeavour	1	1	1
Presence / Here and now	1	1	1
Reality orientation	1	1	1
Rituals / Symbols	1	1	1
Touch	1	1	1
Worship / Church	1	1	1
Dementia is an individual (client-based) process	1	1	0
Environment	1	1	0
Eye contact	1	1	0
Memory	1	1	0
Being aware of your good practice	1	1	0
Cognitive vs. non-cognitive	1	0	1
Relationships	1	0	1
Focus on what is still working	1	0	0
Humour	1	0	0
Grand Total	16	12	9

Based on the graph above, seven out of twelve codes of the current method correspond to the old method's codes. That means that 58.33% of what the instructing party does can be linked to the existing or old method. Nine out of sixteen codes match the independently coded data for the new method - that is 56.25%. During her years of working at Het Maanderzand, the instructing party tried and tested different methods, ideas and strategies. However, she had her doubts about how she should administer pastoral care to PSfd. The comparison of the different methods suggests that almost 60% of what she does is similar to theory and other best-practice methods. Without her knowing it, more than half of what she taught herself is relevant and helpful in the field. Therefore, her method forms a good foundation upon which a new theory can be built.

¹³ The interview was translated into English, transcribed and coded in MAXQDA. The files are available on request.

After the selective coding and comparing data and codes to general theories/methods, the codes were again compared to the data and other codes – as constant comparison is the nature of grounded theory. Again, some codes were integrated, and others removed from the final method list. Table 6 is an example of the process.

Table 6	
Eye contact	Eye contact was integrated with don't write , which was already a part of Presence / Here and now . To be able to stay in the moment and focus entirely on the PSfd, it is important to keep eye contact with them. By writing, one breaks eye contact, and it is therefore important to keep writing to a minimum.
Humour	Was integrated into Focus on what is still working as their sense of humour is something that the PSfd
Memory	While reviewing the code familiarity, it became apparent that the concept of memories and what the PSfd can remember fits better under familiarity instead of being a theme on its own. It gives further insight into why and how to focus on working with what is familiar to them. The final code, Memory/memories , has been moved and is now a subcode under familiarity.
Being aware of your own good practice	This code was removed because it does not contain directly relevant data on what methods to use when administering pastoral care to the PSfd. It, however, contains data on being aware of one's own good practice, which can help one gain confidence in the work field. It is something one should remember and use as motivation and to reduce or remove self-doubt.
Cognitive vs. non-cognitive	This code was split into two codes and placed as separate subcodes under Worship / Church .

This completed the selective coding and resulted in a final list of ten main codes on which the new method is built (see Table 7). The codes are sorted from highest frequency to lowest and then based on the total amount of times a single code was coded. This order is the order in which the data will be discussed except for environment and relationships, which will be discussed first. This order was chosen because the environment is the first thing that one should regulate as it can make or break the connection possibilities with the PSfd. The contact with the PSfd should be based on some kind of rapport, connection or relationship. The stronger a relationship one can create, the better a connection can be established with the PSfd. For the complete list of codes and subcodes, please refer to [Appendix E](#).

Table 7: Main themes		
Codes	Frequency	Times coded
Dementia is an individual (client-based) process	21	219
Presence / Here and now	21	179
Familiarity	19	310
Focus on what is still working	19	118
Multidisciplinary endeavour	18	173
Worship / Church	17	128
Relationships	15	91
Rituals / Symbols	14	168
Environment	13	59
Touch	12	108

4.6 Discussion of the results

4.6.0 Communication through emotions

Although **Communication of emotions** is not included in the study results, it is essential to have some knowledge on the topic. Communication of emotions was excluded from this study, not because it was irrelevant, but because of the vast amount of information produced. A whole separate study could be done on the subject matter. Although it is not irrelevant, it is not strictly necessary for the 'new method'. This researcher, the instructing party, and the previous theory find the many alternative ways of communicating with the PSfd important. What follows are short summaries of why it is essential to realize that the PSfd can still communicate and some tips on enhancing the communication with the PSfd.

According to Moyle et al. (2008, p. 124)., dementia makes it difficult for the PSfd to communicate, understand and convey information. Memory loss due to dementia, the hospital setting and acute illness further magnifies their communication problems. To get their message across, PSfd can often turn to disruptive behaviour as a form of communication. Unmet needs are communicated through agitation, restlessness, aggression and repetitive vocalizations that may change tone and urgency. Their behaviours and emotions, thus, start forming the base, and sometimes their only form of communication. In other words, PSfd still try to communicate - through behaviour and emotions - all be it through extends not ordinary in communication between adults.

Kevern argues that we should see "the breakdown in communication as a social problem suggesting that there may be an attempt to communicate, which we are unable to recognize" (Kevern, 2010a, p. 248). It is proposed that we should use a complementary approach. One should look for signs that the PSfd is trying to communicate and interpret their behaviour or emotions as communication attempts. For example, silence or a refusal to cooperate can be interpreted as responses to a situation rather than 'difficult episodes' or behavioural disturbances (Kevern, 2010a).

Through the healing process of recovery from burnout, the author realised that he could pick up on, or in better words, "feel and experience", a lot more non-verbal queues and emotions. He reflected on his experiences and the way one communicates with PSfd. They still have emotions, which is clear from their stubbornness and temper tantrums sometimes thrown. In discussions with a haptotherapist¹⁴, it was concluded that the body itself is a sensing organ. The body senses feelings, emotions and deals with them – the brain merely interprets what is happening. What is happening in the body happens regardless of whether one can understand it or not. The body can pick up very subtle changes in the atmosphere and emotions of others, regardless of one being able to explain or understand it. If they can still feel and have emotions, they might use getting angry, screaming or throwing things to try to communicate with us. Therefore, it seems that emotion and behaviour should be the main focus of our communication with them.

This means that one should be aware of one's own feelings or emotions when administering pastoral care to people with dementia. One should be congruent with oneself – in what one says and feel. One should not say one thing and feel something else because the PSfd will probably pick up on it and get confused.

¹⁴ A haptotherapist administers Haptotherapy. According to <https://www.blom-haptotherapie.nl/what-is-haptotherapie> haptotherapy is "a form of treatment which helps you experience being more 'present' in body and mind, and guides you in gaining more trust towards your own feelings".

While researching this topic, the author came across the following from Ryan et al. (2005, p. 49), it is essential when working with PSfd.


Nonverbal Approach within the person's visual field	Verbal Approach
<ul style="list-style-type: none"> - Use a calm tone of voice. - Maintain eye contact. - Use reassuring facial expressions, touch, gestures, and body postures. - Take time for a conversation, with long pauses as necessary. - Listen for the person's perspective and the feelings being expressed. 	<ul style="list-style-type: none"> - Use simpler, but adult grammar. - Avoid technical and jargon terms. - Communicate one idea at a time. - Ask questions with two alternatives from which to choose. - Beware of fatigue, reducing communication performance.
<p style="text-align: center;">Interpersonal</p> <ul style="list-style-type: none"> - Recognize the individual as a person. - Validate the person's emotions and reassure them. - Negotiate by taking into account preferences, needs, and anxieties. - Collaborate by working together and by responding to an expressed desire or need. - Facilitate accomplishments by providing the missing steps between intention and completion. 	

4.6.1 Environment

When entering the room, one must make sure that it is quiet and free of distractions. If the room is not free of distractions, it is better to move to another room. Ensure a quiet place to sit, whether inside or outside, but choose a place where the caregiver and client can be alone (with God). Make sure the tv is turned off (Ryan, Martin, & Beaman, 2005). Sunlight may bother the PSfd, therefore, do not sit in **front of a window or close the curtains** if there is no other option (Morris, 1997). One should choose a well-lit room so that the PSfd can see one's face as one speaks, helping them understand what is being said. Remove as many stressors from the meetings as possible – **stress reduction**. That means turning off cell phones, alarm clocks, TV, radio and anything that can interfere and cause stress while trying to communicate. Stress reduction includes but is not limited to the physical world. According to McCloskey (2004) as cited by Moyle et al. (2008, p. 125), "Unmet needs including physical, social and emotional needs can act as a stressor and lead to anxious and dysfunctional or confused states."

The Progressively Lowered Stress Threshold or PLST model is a helpful tool for pastoral care professionals. It is based on the assumption that everyone deserves unconditional positive regard and needs some control over themselves and the environment. All behaviour has meaning and cause. People have the right to be comfortable. Someone confused or agitated might not be comfortable. As discussed by Stolley et al. (2001, pp. 11-13), the following tips may aid in providing adequate pastoral care for PSfd.

- Ensure safe functioning by supporting them in areas of loss, like providing cues to compensate for memory loss.
- Give the PSfd unconditional positive regard. That means accepting the PSfd as they are.
- Use behaviour linked to anxiety and avoidance to determine when the PSfd is comfortable or has had enough.
- Teach others to listen to the PSfd. Help them learn how to evaluate verbal and nonverbal responses.
- Modify the environment to support losses and enhance safety.
- Provide ongoing support, care and problem solving for caregivers.



The room used and the atmosphere one creates should become a safe place where the PSfd can be free to talk/communicate, feel, and be him/herself. The room and atmosphere can help orient them to what they are doing. One should not constantly 'be forced' to bring them back to reality or orient them to 'reality' personally. That is the purpose of the room and the atmosphere one creates. It should help them remember what they are doing. For these reasons, it is also applicable to discuss reality orientation next.

4.6.1.1 Reality orientation

Reality orientation can be constructive but, at the same time, very destructive. Beneficial actions include:

- Wearing recognisable clothing or clothing pieces.
- Introducing oneself **clearly** (Morris, 1997).
 - o Touching the person while saying **their name** to get their attention.
 - o Clearly stating one's name and who one works for.
 - o Letting them see or touch significant religious symbols like a Bible.

Other things can be harmful and should be avoided. Therefore, do not:


- correct rambling
- correct them if they remember one's name incorrectly
- constantly bring them back to (one's own) reality
- remind them of what they have lost – loved ones, capabilities or otherwise.

Correcting a PSfd can be frustrating for them. It might even deter them from seeking social interaction even more and push them "further into isolation" (Morris, 1997, p. 53) and despair. Correcting them when they forget (one's name) is not helpful and might even cause damage as they are then confronted with their memory loss. Instead, validate their experiences and "go with the flow" (Stolley, Koenig, & Buckwalter, 2001, pp. 26-27). According to Stolley et al., a "religious or spiritual interaction is more positive if there are few reminders of losses" (Stolley, Koenig, & Buckwalter, 2001, p. 26). It might even be beneficial and valuable if they believe that they are talking to their beloved pastor or clergy (preacher/ minister).

Constantly bringing them back to what one perceives as 'reality' might confront the PSfd with all they have lost, causing unnecessary stress, pain and heartache. The caregivers need to ask themselves if the truth – reality as it is – will "harm or heal in a given situation" (Miller-Sinclair, 2001, p. 5). Rather than *bringing them back to "reality"*, – Stolley et al. suggest supporting "their reality" and validating "their experiences, focusing on the emotional overtones" (Stolley, Koenig, & Buckwalter, 2001, p. 26). Only use "information needed for safe functioning" (Moyle, Olorenshaw, Wallis, & Borbasi, 2008, p. 127).

The fact of the matter is that PSfd perceive time differently from the norm. They do not perceive time as being linear anymore, resulting in a different perception of reality. If one cannot distinguish how much time has passed between events, it would be possible to experience events as if they are currently happening. Due to cognitive decline, PSfd experience feelings more vividly. Memories seem more real to them, and they actually **physically enter into the memory** or, in other words, a different reality than what others perceive. A study on altered temporal awareness mentions that PSfd has a "tendency to relive past events" (Mai-Carmen, et al., 2020, p. 1).¹⁵

¹⁵ It happens because of the "relative preservation of a distributed left-sided temporoparietal grey matter network including hippocampus" (Mai-Carmen, et al., 2020, p.1)



One should also take the environment and safety of the other residents into consideration. If concerns that entering a room full of people might disturb the other residents or cause a commotion/confusion exists, one could ask the staff at hand if they would be so kind as to escort the PSfd to the hall where one can take over. Taking the person's hand and walking with them to the predestined room might be a good idea. The physical touch helps the person orient him/herself and helps them understand what is going on. Touch might be the single most crucial factor to consider when communicating with a PSfd (see [4.6.10 Touch](#)). However, for a person to be comfortable with one touching them, one first needs to establish a rapport or relationship.

4.6.2 Relationships

To enrich the experience and pastoral care, one should try to understand the PSfd's life story. It is essential for all caregivers working with PSfd to gather as much information about their past lives as possible. It can provide one with a glimpse of who the person is (VandeCreek, 2001). According to Roxburgh, the information gathered can help affirm the person's "sense of identity" (Roxburgh, 2000, p. 341).

The best way to get through to PSfd is by understanding them, getting to know them and respecting them as fellow human beings. In other words, not seeing them as just (another) client or as someone who needs help - but to make an effort to build a relationship with them (Ryan, Martin, & Beaman, 2005). One should see the person for more than his or her disease. They should become a part of one's life, respected and loved. Someone one would like to spend time with or simply be with - someone to whom one gives a piece of oneself.

Building a relationship will enable one to show more than sympathy. One will learn to feel empathy for the PSfd. What moves them should move one as well. One can be human together through feelings or emotions, and more profound connections can be established than would be possible through words alone. We were created to be in relationships – with others and with God (Corfield, 2012). Therefore, building and maintaining a relationship with the person is essential. It is one of the main building blocks of creating a new (custom/tailor-made) method, as it is part of every aspect of the new method in some way or another. Every person is unique and should be treated as such, people with an identity, their own problems, wants, and needs.

4.6.3 Dementia differs from person to person


Every person has his or her personality, way of dealing with things, lifestyle and quirks. Every person is unique. The same is true for PSfd. "When you've seen one person with dementia(Alzheimer's)... You've seen one person with dementia" (Sapp, 2001, p. 27). It is therefore vital to see and treat them as unique individuals.

PSfd may even be different from visit to visit. Therefore, one should adapt one's approach to the person one finds (Sapp, 2001). One cannot use the same pastoral approach for every individual. Pastoral care should be **tailor-made** for the person's specific **needs**. It is therefore essential to have **information** about one's clients.

Obtaining information may also help one understand the person's usual behaviour patterns. It can help individualise care plans to provide a relatively consistent routine, which may help the PSfd stay "calm and feel secure" McCloskey (2004) as cited by Moyle et al. (2008, p. 125).

4.6.3.1 Knowledge about dementia and the experience of the PSfd

To give a PSfd the help they need, first of all, one should have a general understanding of dementia itself. Knowledge about dementia and, more importantly, dementia, specific to the person (Ryan, Martin, & Beaman, 2005) and (Corfield, 2012). Whether they have trouble hearing, how easily they get confused, how they communicate, and in what stage of dementia they are.



Talking too fast or not loud enough, for example, might confuse or frustrate the PSfd. Therefore, one needs to be aware of what the PSfd is going through to adapt how one communicates.

What follows are some examples of how to obtain information about the PSfd's dementia:

- Talk to their 'caretakers' and nurses.
- Read their 'patient file'.
- Talk to their friends or family.
- Observe and be aware of their reactions during a pastoral visit.
- Create individual care plans or use advanced care plans.

According to Corfield (2012), PSfd should be provided with the opportunity of making decisions about their care and treatment.¹⁶ This means that one should talk to them before their ability to communicate declines verbally and document their wishes, likes and how they would like to be treated and cared for. In addition, include information of who they are, personal background information and their disease progression. Finally, at least have a general idea of who the person is with whom one is communicating.

4.6.3.2 Knowledge about the person behind the disease


Knowledge about dementia and the personal progress of the PSfd is essential. Even more important is to know and understand the person behind the disease. The PSfd might feel ashamed and try to hide it (Hudson, 2015). They might feel ignored or excluded from society (Corfield, 2012; Kevern, 2010b) or receive the label disruptive (Moyle et al., 2008), 'difficult', or hard to work with. People having a hard time communicating their wants and needs might even stop trying or withdraw from communication altogether, which means they are stimulated less, causing the process of dementia to accelerate (Kevern, 2010b).

For this reason, it is vital to engage with the person, to get to know them and talk about things they can remember easily. Talk to them about who they were, what they did and what they enjoyed in life instead of talking about everything they have lost (Kirkland, Fortuna, Kelson, & Phinney, 2014). Who they are is of more importance than what they are not or cannot do. Their memories – overlearned behaviour and childhood songs can be easily remembered and might help one connect with them on a deeper level. Try to understand what they want instead of focusing on what they are saying. Do not correct them if they say something wrong. Go with the flow, enter their world (Corfield, 2012) and try to read between the lines. Do not be literal but feel the meaning of their sounds, words, actions and emotions. How they are saying something in a specific context may be more important than **what** they are saying. They can communicate through emotions, and one should try to make use of it. To do that and fully connect with the PSfd, it is essential to be in the moment, the here and now.

4.6.4 Presence / Here and now

Administering worthwhile pastoral care means being present while communicating with a PSfd. Present in the sense that one is not distracted by one's thoughts and busy schedule. Instead, one is entirely in the moment – here and now with the PSfd. Make time for him or her and, for that time, give them one's full attention. Being present and 'in the moment' is of the utmost importance when communicating with PSfd. PSfd get confused easily. One must keep things as simple as possible and continuously show them that our attention is on them and not something else. Because they have a limited concentration span and get distracted easily, it is essential to keep **eye contact** with them. When one writes during a session, one breaks eye contact with the PSfd, which

¹⁶ This is also known as "Advance Directives" (Corfield, 2012, p. 50).



may cause them to lose focus. They might also get confused or forget that you are there for them if one continuously write and break eye contact. It is therefore essential to keep writing to a minimum. Not writing will also help with one's awareness.

One must be aware. Aware of one's feelings, the feelings of the PSfd, the environment and anything and everything that goes on in that moment. When a PSfd rambles on about a particular topic, it is not without reason. We should listen to their ramblings and try to interpret them as they may be meaningful (Morris, 1997). Try to understand, not ignore it, or bring them back to the 'topic at hand' or what one perceives as 'reality' (Moyle, Olorenshaw, Wallis, & Borbasi, 2008). Doing so will only confuse or frustrate them and can be downright cruel (VandeCreek, 2001).

Instead, explore what they are saying and try to understand why they want to talk about it and "validate their experience" (Stolley, Koenig, & Buckwalter, 2001, p. 26). Focus on non-verbal and non-cognitive communication. This requires one to be able to observe what happens, to and with them, but also with oneself. One should understand and feel how what they do or say affects one personally and emotionally.

One may ask oneself: how does one stay in the here and now? How does one connect non-cognitively with another? It all starts by connecting with oneself, one's body. In a conversation with a haptotherapist, Ita van Hilten, it was concluded that one's body is the main feeler of- and dealer with emotions. Not the brain. The brain can make sense of what it is that one is feeling, but one's body is the one that processes whatever it is that one is feeling. Therefore one should observe and fully experience one's feelings and emotions through one's body, rather than ignore them. This might seem strange. However, there is an evergrowing idea in the philosophy of cognition that "cognition is situated, i.e., dependent upon or co-constituted by the body, the environment, and/or the embodied interaction with it" (Stephan, Walter, & Wilutzky, 2014, p. 65). Therefore, by observing and connecting with one's body, to oneself as a whole, one will be able to make better contact with the PSfd.


Although it might take some time to listen, truly listen, to what they have to say, it will be worth it in the end. So take the time to listen to the PSfd. Do not be rushed or pressed for time. Relax and slow down. Take time to be quiet (Mayers & Bursell, 2010) and just be in the same space as them. If they start to ramble, let them ramble and reflect on what is being said. Reflect on what it means for them. Reflect on what it means for oneself, what it does to one emotionally, then connect to those feelings. This should not be just a skill but, something more, a real personal connection—a connection to oneself and the PSfd. One should grant them the time to get used to and get close to the caregiver, and become a familiar face in their lives.

4.6.5 Familiarity

4.6.5.1 *Memory and memories*

Because what is familiar is linked to memory and remembering, it must be discussed how one can trigger memories in a PSfd. As a result of dementia, the cognitive functioning of PSfd is compromised. It is, therefore, essential to make use of their implicit memory and memories.

[Section 1.3](#) explained that there are still some (implicit) memories intact in the PSfd. These memories have proven helpful in making contact with the person and fruitful in conversations. A few things one can do to help bring these memories to the foreground are discussed.



Help them remember or remember for them (Kevern, 2010a). Rather than asking questions about the PSfd's past, which may be difficult for them to answer because of their cognitive disability and their trouble with word-finding (Morris, 1997), help them remember certain past situations by bringing the memories to them (Corfield, 2012). Talk about what one remembers, for example, from one's school days, when one were a child and listen to them as they talk about their experiences. Do not correct rambling (Morris, 1997) or ask difficult questions, just be there and listen to their story. One could also remember *for* them (Bryden & MacKinlay, 2001; Kevern, 2010a) by, for example, telling them things one already know about them.


Make use of "remembering boxes" (Ryan, Martin, & Beaman, 2005, p. 50) or "reminiscence packets" (Wentroble, 2001, p. 21) to jostle their memory. Use or explore memories that mean something to them, attached to emotions, making it effortless for them to retrieve. Make life-story books (Kevern, 2010b) when they can still remember, as it can be of great use at a later stage of dementia by reading it to them and help them bring up fond memories of their past. In other words, talking about or remembering what is familiar to them and getting to know them and their history.

4.6.5.2 Making use of what is familiar

Familiar things could be things they remember from childhood, **overlearned material** (Morris, 1997) like songs, pieces of scripture and even the holy communion (Powers & Watson, 2011). The music they liked listening to, habits or rituals that they grew up with are all things that are easy to remember. It can give them energy and help them make contact. Being present with them and reading well-known pieces of scripture can help them remember memories and even God (Corfield, 2012). Familiarity not only helps them connect with themselves, others and God but also improve "their quality of life" (Walters, 2007, pp. 241-242). Bowlby (1993), as cited by (Wentroble, 2001, p. 11), suggests:

- recalling overlearned and very familiar activities, for example: shaking hands or playing catch
- emphasizing the ability to appreciate sensory experiences such as feeling or smelling
- focussing on overlearned and persistent social skills, such as greeting one another
- emphasizing the ability to participate in gross motor activities, such as dancing or moving to music
- focussing on implicit or remote memories, especially childhood and young-adult memories
 - o providing opportunities for reminiscence
- providing opportunities for active participation, such as singing, humming or clapping with music
- bringing attention to a principal or identifiable purposes they might have
- making use of nonverbal skills, such as responding to music
- providing immediate positive feedback.

Closely linked to familiarity is **consistency** or "continuity" (Miller-Sinclair, 2001, p. 8) and "repetition" (Morris, 1997, p. 196). If one repeats the same thing, they might start to remember (Powers & Watson, 2011) and become comfortable doing it (Kirkland, Fortuna, Kelson, & Phinney, 2014). During an internship, the author of this study had the privilege of experiencing this exact process multiple times. We organised and held 'bible study' evenings for non-cognitive and less cognitive persons. In the beginning, the people were confused about what was happening or reluctant to participate. However, by the third time, their behaviour and mood started to change. The repetition of the same actions time and time again, like playing soft music in the background before the start, the ringing of a chime to symbolise the start of the evening as well as singing the same welcome song every time, people started to become comfortable with what was happening – as they understood what was going on. With each session, they started interacting/communicating with us and the others more and more. Who they are and what they liked started to become apparent through their



participation. By repeating the same ‘ritual’ or set of actions, week in week out, it becomes familiar – it becomes overlearned, a ‘new’ memory that can help one make contact with the PSfd. Themes can also help with structure and familiarity making it easier to remember.

Using **themes** can positively affect engagement and general well-being (Kirkland, Fortuna, Kelson, & Phinney, 2014). Each year specific themes are prevalent. Some examples are hope, childhood, birthdays, peace, Easter and Advent. Tapping into themes relevant to the PSfd brings one a step closer to making a deeper connection with the PSfd. Instead of just talking about the themes, one can use objects to portray the meaning of the theme in a non-cognitive manner. Objects, from plush toys to wooden crosses, any object, can be a trigger to memories and bring up experiences that help one make contact with one’s client.


The literature¹⁷ mentions the following **objects**—Rosary, Candle, Cross, Bible & Clothing, etcetera. A rosary, candle and cross might not be relevant to the PSfd at Het Maanderzand. Some churches frown upon the use of particular objects or might even see it as sinful. It is, therefore, up to the pastoral caregiver to determine which objects can to use and which should be avoided. From personal experience, in a different context, the author saw that the lighting of a candle is full of meaning. People see, smell or feel the flame, and they instantly know that something special is about to happen. They know that they are in the presence of God and, just like a candle fills a room with light and warmth, so does God fill their lives with warmth and light.

On the other hand, the Bible is an object the people at Het Maanderzand grew up with and might be worth using. Use objects the PSfd might be familiar with. For example, reading scripture from the Bible is a well-known activity using a well-known object that can be helpful during pastoral care moments. Using overlearned pieces of scripture or scripture that fits the season and theme will be even better. The PSfd might have a favourite verse that can be read or recited. One could ask the PSfd or their family what it is and, ritualistically, read it every time one visits.

Prayer is also essential (Bryden & MacKinlay, 2001; Powers & Watson, 2011; Dalby, Sperlinger, & Boddington, 2011) as it is part of the ‘ritual’ of the pastoral visit. The whole pastoral visit can be made into a ritual with a particular structure, like always ending with prayer if the PSfd wishes it. Use well-known prayers like the Lord's prayer. One could ask them if there is something specific they would want to pray for, but one should keep it short and straightforward and avoid extempore prayer. Extempore prayer or a prayer made up on the spot might confuse the PSfd and cause one to lose contact with them again because it is “unstructured” (Morris, 1997, p. 205) and relies on the ability to follow reasoning, which the PSfd no longer have. They must be able to understand what is going on without having to overthink. The beautiful thing about prayer is that it can be used by anyone helping or visiting the PSfd, not only the pastoral caregiver. The PSfd might not know the words, but they can experience and communicate without words. Prayer can help bring these feelings and experiences back into the PSfd's life (Ryan, Martin, & Beaman, 2005). Using “lifelong religious practices” (Powers & Watson, 2011, p. 62) is a powerful way of making contact with the PSfd.

Nature, music, rituals, and religious symbols can also help trigger memories in PSfd. It provides “opportunities for them to remember and connect with God” (Corfield, 2012, p. 109). Music is easy to remember or feel, especially if it is the music they know well or grew up listening to. Hymns or old church music has proven to be helpful; people come alive when they hear the music, they might smile, tap their feet or even sing along

¹⁷ (Moyle, Olorenshaw, Wallis, & Borbasi, 2008), (Powers & Watson, 2011), (Kirkland, Fortuna, Kelson, & Phinney, 2014), (Ryan, Mart (Ryan, Martin, & Beaman, 2005), (Walters, 2007), (Corfield, 2012), (Morris, 1997), (VandeCreek, 2001) & (Van der Kaaden-Huttinga, 2006)



(Kirkland, Fortuna, Kelson, & Phinney, 2014). Music has been proven to help PSfd ‘come alive’ or become responsive (Powers & Watson, 2011). This shows that the PSfd can still think – maybe just a bit slower than “normal”. Most importantly, they can still feel and still have emotions, which can bring forth responses and help them make contact with others. Therefore, it is essential to focus on the things they can still do, to try and make contact with them by making use of the capabilities they still have and find easiest.

4.6.6 Focus on what is still working

Instead of focussing on what the PSfd has lost (Kevern, 2010a) or can not do anymore, focus on what they are still capable of or, as Bowlby, as cited by Wentroble, puts it: their “persisting assets” (Wentroble, 2001, p. 6). Ryan et al. suggest “building on enduring capabilities” (Ryan, Martin, & Beaman, 2005, p. 43). Their brains may be deteriorating, but some memories are still functional and intact.¹⁸ Besides the fact that specific memories are retained, the author of this study believes that memories may also be located and stored in the body, similar to cognition.¹⁹ Swinton goes one step further. He believes that memories are something that lives inside of our bodies. According to him, “memory is all that we are” (Swinton, 2014, p. 162).

What then are the memories or abilities that are preserved the longest, and what should one make use of? According to Ryan et al., they are ingrained or implicit memories such as lifetime memories, nonverbal comprehension and expression of emotions, “speech pronunciation [and] grammar” (Ryan, Martin, & Beaman, 2005, p. 45). (VandeCreek, 2001) cites Bowlby (1993): “emotional awareness and emotional memory; sensory appreciation; primary motor function; sociability and social skills; procedural memory/habitual skills; long-term memory; sense of humour”, and Zgola (1987): the “ability to perform overlearned or habitual tasks, primary motor and sensory functions, emotional awareness, remote memory, and the tendency to persevere”.

For these reasons, it is important to use these implicit, long-term or overlearned and bodily memories to help the pastoral caregiver connect with the PSfd. However, when it comes to humour, there is a caveat. One must make sure not to make fun of the PSfd or laugh at them. Instead, laugh with them, focus on what they find amusing and try to find things that make them laugh. Do not use sarcasm or idioms, as this may confuse the PSfd. For example, instead of saying ‘it is raining cats and dogs’, say it is raining heavily.

Focus on their body and help them feel and experience one’s presence and the presence of God instead of only talking about it. Ask their family or care staff what they like or what they are good at. All people, including PSfd, are so much more than their cognitive skills. PSfd are people loved by God and should be loved by us as well.


Using and exploring the preserved memories and functions will require some amount of time and energy for the pastoral caregiver to figure out, but it will be worth it in the long run and should not be overlooked. Luckily, however, a pastoral caregiver does not have to do it all by him or herself.

4.6.7 Multidisciplinary endeavour

Figuring everything out oneself might be an intimidating task. It might even be such a large undertaking that one might think, ‘how am I ever going to get the time to get to actual caregiving’? If it was up to only the pastoral caregiver, it might be an impossible task. Luckily the pastoral caregiver works in a larger setting with other caregivers, nursing staff, families, volunteers and colleagues. It is important to realise or remember that pastoral caregiving is a multidisciplinary undertaking (Moyle, Olorenshaw, Wallis, & Borbasi, 2008).

¹⁸ See [1.3 Explicit and Implicit Memory](#).

¹⁹ See [4.6.5 Presence / Here and now](#)



People who are part of this multidisciplinary team include, but is not limited to the following: Pastoral care providers (professionals & laypersons), nurses and nursing assistants, social workers, recreation and physical therapists, housekeepers, food service workers, administrators, “volunteers” (Powers & Watson, 2011, p. 64), friends, family and music therapists.

Working together is key to giving the best care possible to the PSfd. Work together to ensure a safe and respectable workplace. Ask other staff members to tell one about what they know about the PSfd or how he or she is doing before one goes to visit them. Also, respect one another and ask permission (Morris, 1997) before just entering a room. Viewing the PSfd’s family as a part of the “multidisciplinary team” (Moyle, Olorenshaw, Wallis, & Borbasi, 2008, p. 125) is beneficial for the PSfd. They should be involved in the care process where possible. Generally, the more up to date information one has about the PSfd; the better one can tune in to the feelings of the person one are visiting.

Because there are so many people involved in the care of the person but, only very little may have been trained in pastoral caregiving, it is important to facilitate training for those who want it. Demanding or ‘difficult’ clients may suffer in specific settings because staff or volunteers do not know how to deal with them. Therefore, it may be essential to organise training sessions for other caregivers to help them understand the PSfd better and keep the environment as safe and pleasant as possible. A little knowledge goes a long way.

Make use of all the available resources and ensure that the PSfd is visited frequently. It is important to keep helping them make social interactions instead of limiting them. Social interactions ensure a better quality of life for the PSfd (Kirkland, Fortuna, Kelson, & Phinney, 2014). Social interaction with the multidisciplinary team is not only beneficial for the PSfd, but also for all those involved. Dementia has an impact on everyone involved with the PSfd. It is, therefore, also important to talk to one another to keep up morale. Be there for one another and give one another a shoulder to lean on. Do not try to do everything on your own. Sometimes all one need is a listening ear to help one see the situation in another light.

4.6.8 Worship / Church


Social interactions are fundamental also, or even more so, for the PSfd (Ryan, Martin, & Beaman, 2005; Goodall, 2009). Therefore, one should not exclude PSfd from any social interactions, for example, church worships.

Worship or attending church - for that matter, any social interaction/activity is beneficial for PSfd (Lubbinge, Heij, & Geluk, 2019). Therefore, PSfd should attend church functions for as long as they feel comfortable and have the energy to do so. When, for whatever reason, they are not able/allowed to attend these functions, then the pastoral caregiver can organise or invite them to worship especially created for PSfd.

4.6.8.1 *Traditional cognitive methods*

When creating worship sessions for PSfd, it is crucial to realise that the traditional (cognitively based) methods will not work (Walters, 2007; Corfield, 2012). PSfd usually have trouble focussing for long periods of time. As their cognitive functioning declines due to dementia, they also lose the mental capacity to follow or understand complicated sermons and analogies.

Some say the sermon itself is unnecessary or “unhelpful” (Morris, 1997, p. 205). The author of this paper does not fully agree. The target group of Het Maanderzand consists of older, more conservatively raised people. They grew up going to church every Sunday, where the sermon was a significant part of the church service. Because familiarity plays such a significant role in communicating with PSfd, it might be worthwhile to keep



some form of a homily or sermon as part of the service. It could also be ingrained in their memory and, therefore, should not be excluded. It might be a way to stimulate their implicit memory as, for some, it has become a part of themselves or their lives – ‘the way it has always been done’. Although, it may not be true for every other target group or even every person in our target group. What is certain is that it should be short and simple if one does include the sermon. It should be easy to understand and filled with emotive language – using words that trigger as many senses as possible.

4.6.8.2 *Non-cognitive methods focussing on experiences, multisensory interaction and emotions*

Instead of reading long pieces of scripture, one should focus on one theme (Morris, 1997) and a short piece of scripture applicable to a particular theme. When it comes to PSfd, it might be more important to focus on the experience of a worship service rather than the teaching or explanation of the word or gospel (Van der Kaaden-Huttinga, 2006). In the sermon, one should focus on emotive wording, bringing the word and gospel into the world of the PSfd. Think about how it may apply to them or give examples of how the scripture or God has touched one’s life. The more personal, the better. Speak about things that have to do with emotions, use words that incorporate all the senses – touch, smell, sound, taste and hearing (Wentroble, 2001). The more senses one uses, the more one can help them experience the service, and the better one can make contact with them.²⁰

As an example – suppose the chosen theme is ‘the creation of the earth’. One could use the sound of water when talking about the expansion and splitting of the water or even a light spray of mist in the air – making sure to mention, ‘can you hear/feel the mist/water in the air?’. One can have them touch, look at, smell and maybe even taste different fruits or plants. These are but some of many examples that have proven fruitful when used with elderly/cognitively impaired people at Bartiméus.²¹

Using multiple sensory methods helps them connect with their bodies and emotions – improving their experience and, in turn, help them remember.


4.6.9 *Gestures, rituals and symbols*

Gestures, rituals and symbols make communication easier²². Not a single word is needed for the other person to understand exactly what is meant. For example – personal experience taught the author – that the ‘symbol’ of a suit and tie instantly communicates ‘pastor or preacher’. Without having to say anything, a person instantly and instinctively knows ‘who’ stands before them. ‘*U bent zeker de dominee?*’ a PSfd asked the author upon entering the room wearing my two-piece suit. For example, Corfield mentions symbols “like the Bible, a cross, candles, a crucifix or rosary, picture of Jesus, or other visuals like bread and wine, communion cup, and clerical robes” (Corfield, 2012, p. 101). These items help with recollection, aid in conversations, and help the person connect with God. What items to use is up to the discretion of the pastoral caregiver as not every object may

²⁰ Multiple sensory communication falls under ‘alternative methods of communication’ which is, unfortunately, outside of the scope of the current paper. It is a fascinating topic and something the author would like to explore further. For this paper, however, it is enough to realise that making use of the different senses when communicating with the cognitively impaired or PSfd can help elevate the depth of the connection made.

²¹ Bartiméus cares for people with poor eyesight and cognitive disabilities. The author completed an internship at Bartiméus as a part of his studies. For more information about Bartiméus see <https://www.bartimeus.nl/>.

²² “Symbols which are clear and concrete and **require minimal interpretation may be helpful**. For example, a shepherds staff or the Bread and Wine on the Communion Table” (Morris, 1997, p. 414); “Rather than having to think cognitively, one’s emotions become more apparent. The appearance of a cross, a Star of David, a clerical collar, vestments elicit great emotions. Touching a Bible, a prayer-book or a rosary can also spark emotions that will make connections to religious activities of the past” (Wentroble, 2001, p. 17).



apply to each client. As VandeCreek says, whatever the symbols, they must be congruent with the individual's religious beliefs "and provide comfort and solace" (Stolley, Koenig, & Buckwalter, 2001, p. 22).

Symbols do not always have to be linked to faith or church but can be something as simple as a toy car or a doll. Pictograms, for example, are used to help people unable to speak to communicate their wants and needs. A picture of shoes could mean that the person wishes to go outside. The caregiver could reply by showing the person clouds and rain, indicating that it is raining outside and that they can not go outside at the moment. Using these types of pictures is also a method used to communicate with cognitively impaired people at Bartiméus. A picture tells a thousand words. One is not limited to pictures alone. One client used literal objects (small replicas of the actual objects) to communicate. A small candle, for example, indicated that it was time for the pastoral visit. In similar ways, a bible or a stuffed sheep animal could be used to communicate.

Likewise, a ritual can be seemingly insignificant, like shaking the PSfd's hand before and after a meeting. Shaking hands symbolises the beginning and the end of the meeting. Prayer and reading scripture, or even singing can be incorporated into the ritual tailor-made for the specific client. A ritual is also not something one thinks of and implement on one's own. Any good ritual grows out from the connection made with and the input given by the PSfd. It should thus be different for each client and not just some trick one uses to make contact with the PSfd. Rituals like the holy communion/eucharist and maybe even the reading of the ten commandments and the blessing could be significant as they may have been a part of the PSfd's life since childhood. They will most certainly miss it if it suddenly disappears from their lives. Giving the blessing is also essential – it can be as simple as saying "may the Lord be with you" or "the good word of God is with you" or "God with you".


"Everett, a chaplain in a long term care facility in Alberta, suggests that even the most severely affected individuals can experience God's presence through sensory experiences of life that are richly symbolic; the aroma of freshly baked bread, the smell of the earth on a crisp autumn day or the caress of a warm summer breeze not only stimulate the senses, but celebrate and honour the relationship with God and the universe" (Ryan, Martin, & Beaman, 2005, pp. 53-54).

Symbols do not always have to be objects; they can also be actions, making them gestures. Gestures are, for example, occasionally gently touching or rubbing the shoulders of a resident with genuine affection to draw them into the activity. This gesture can bring a PSfd into the social world of the activity by helping them feel comfortable and included (Kirkland, Fortuna, Kelson, & Phinney, 2014).

4.6.10 Touch

Last but most certainly not least, we start to venture into different methods of communication. As stated earlier, the scope of the study does not allow the discussion of different communication methods in detail. However, touch is included in the new method because it is of the utmost importance to successfully communicating with PSfd. Touch instantly communicates emotions, closeness and vulnerability. When one touches someone, one makes physical, **emotional- and maybe even spiritual** contact. Because the PSfd can still feel and detect emotions, touch is a beautiful way to communicate warmth and positive regard.

Touch helps one make and keep contact with one's clients. It lets them know and feel that one is talking to them, that one are there for them, and that one are willing to listen to them. By touching the person and using their name to alert them, one can gain and hold their attention. It may also help in gaining and maintaining eye contact (Morris, 1997).



In the video, 'Gladys Wilson and Naomi Feil' (Feil, 2009)²³, Naomi Feil, the founder of Validation Therapy, shares a breakthrough moment of communication with Gladys Wilson. In it, she shows how touch can help one 'get through to' the PSfd. One can see Gladys communicating with body, emotion and motions. She progressively starts to communicate more and more and finally even uses words! The change is dramatic and heart-warming.

Maartje intuitively uses touch when communicating with her clients, like placing her hand on the PSfd's shoulder or leg. However, she does have some uncertainties about making use of touch. This is not unfounded, as things in the Netherlands are pretty different from those in other parts of the world. Touching someone is, as far as the author is aware, rather uncommon in the Netherlands. The author is from South Africa, where it is considered normal to give someone a hug or a kiss (on the mouth) when greeting them. In the Netherlands, however, one is lucky if someone wants to hug you. They greet kiss each other on the cheek, but never on the mouth. Personal space seems very important in the Netherlands – so reluctance in using touch when communicating with PSfd is not unwarranted. When it comes to touch, more than in the rest of the method, it should be something that must be explored and tailored to the comfort level of the PSfd. Some clients may allow one to touch them, and some might not appreciate it. Nevertheless, it is something that must be explored and used where and whenever possible.

Forms of touch do not have to be limited to placing one's hand on their leg or shoulder. It can also involve placing one's head against their head. Face against their face or their head on one's shoulder, etcetera. Their bodies and emotions have become their new method of communication, and we need to adapt our way of communication if we ever want to make fruitful contact with them.

Like babies who may die if they do not receive the loving embrace or touch from his/her parents, touch may have a life-sustaining effect on PSfd. "Combing an individual's hair or applying lotion on the hands can be an immeasurable act of love and a powerful method of communication" (Corfield, 2012, p. 99). According to Corfield (2012), touch is instrumental when the PSfd's verbal and cognitive-communication skills decline or disappear entirely, and they start to perceive the world through their senses. A light touch of the hand, arm or a kind look and smile (Goodall, 2009) may be more important in making contact with the PSfd than an abundance of words (Roxburgh, 2000; Corfield, 2012). It has often been reported that the person's body language change when they receive a loving touch (Powers & Watson, 2011). A hug may seem like a small gesture, but it can help someone feel accompanied in their struggle with dementia (Ryan, Martin, & Beaman, 2005). "A gentle human touch can be an effective way to reassure the person. A hug will go further than words" (Corfield, 2012, p. 99).

Furthermore, it is almost common knowledge that about 70%, or even more, of communication happens non-verbally. That is why, as the mental functioning of the PSfd decreases, pastoral care and spiritual wellbeing should progressively shift to non-verbal forms. These include rituals, symbols, music and touch! All of which should be exercised with love. "Spirituality is not always words" (Powers & Watson, 2011, p. 71). Therefore, pastoral care should take on non-verbal forms like:²⁴

- Just sitting in the room, making **physical contact** now and then to let them know one is there.
- **Being present** and spending time with them (without wanting to accomplish something).
- Holding, touching or rubbing their **hands** (with hand lotion).

²³ The author strongly recommend watching the short clip.

²⁴ The following list was adapted from (Corfield, 2012) and (Powers & Watson, 2011).


- Holding or touching their **legs or feet**.
- **Kissing** them gently.
- Giving them loving **hugs**.
- **Combing** the **hair** of the PSfd.
- **Taking** them **outside** to feel the sun on their skin, the wind in their hair, to smell nature and watch or listen to the birds.
- Having a **positive and loving regard** towards them.

“Love is sensed when it is present, and persons with dementia respond to love in any form” (Corfield, 2012, p. 99). Reassuring them of one’s presence and oneness are **powerful** ways to show them **love** and add value to their lives. Do not be afraid to get close to them. During a pastoral visit, sermon or blessing, get close to them, crouch down beside them, include them, show them that they are seen and have value (Kirkland, Fortuna, Kelson, & Phinney, 2014). When one administers the holy supper, get on their level, reach out and touch them. Help them drink the wine and feel the warmth of their hands (Swinton, 2014). Do not be afraid to reach out, as one’s loving touch may be one of the few times in a day that the person feels human touch that has no instrumental end. One’s “embrace contains and reveals” (Swinton, 2014, p. 169) the love of Jesus, as do theirs.

Slow down, be patient and gentle. There is no time for haste when working with PSfd. Pastoral care or ministry has more to do with making the presence of God felt than a lively and productive conversation. Instead, express and experience the grace of God through prayer, touch and loving embrace. Like the woman anointing Jesus (Mt 26:6—13), “no action of love, directed towards a person who embodies the presence of Jesus, is wasted but is remembered in heaven” (Roxburgh, 2000, p. 341).

4.7 Conclusion

The strategies used to administer pastoral care to the PSfd should firstly focus on non-verbal cues and forms of communication. One should be aware of one’s own emotions and the PSfd as they tend to communicate with emotions or behaviour. The pastoral caregiver should have an unconditional positive regard toward the PSfd and ensure a safe environment devoid of distractions and stressors. Building a relationship with the PSfd is essential. It is important to keep in mind that every PSfd is different and need care tailormade to their needs. One should stay in the moment, keep eye contact with the PSfd and take the time to listen to them. Some of the PSfd’s memories might still be intact. Therefore, one should focus on talking about familiar topics, listening to songs from their childhood, and using whatever is familiar to them. Making use of overlearned behaviours can affirm the PSfd’s identity and improve their quality of life. Focus on what they can still do. Caring for the PSfd is a multidiscipline endeavour. Other colleagues and care staff can be vital in helping one establish a connection with the PSfd. Social interactions are fundamental for their wellbeing, include the PSfd in social interactions such as church and worship sessions. Gestures, rituals and symbols which are clear and concrete require minimal interpretation and make communication easier. Finally, touch communicates warmth, emotions, closeness and vulnerability – helping them feel safe and aiding in the communication with the PSfd.




Chapter 5. Summary


The paper refers to people with dementia as ‘people suffering from dementia’ – the person should come first, not the disease. Dementia is a long and arduous disease that causes suffering and heartache for all those involved. There is evidence to suggest that some memories in the PSfd are preserved. Explicit memory requires conscious thought and declines over time, whereas implicit memories are retained and can be retrieved without conscious thought. It might feel useless to administer pastoral care to PSfd as ‘they will only forget about it again, but this misconception has detrimental effects on the care for the PSfd. Spirituality and religion provide a sense of importance, help with stress and improve their general well-being. The PSfd deserve to receive pastoral care because they are still humans who deserve and need love and care. The study used the grounded theory method to analyse different care methods to help create a new method for administering pastoral care to PSfd. The results were discussed, and the study concluded that:


- PSfd can communicate with emotion and behaviour.
- One should stay present and provide a stress-free environment when working with the PSfd.
- One should build a relationship with the PSfd.
- One should have knowledge of the PSfd, focus on familiarity and on what they can still do.
- Pastoral care is a multidisciplinary endeavour.
- Church, worship and rituals are beneficial for the PSfd.
- Touch is a powerful communication method that enhances every aspect of pastoral care.

References

- AbdAleati, N. S., Zaharim, N. M., & Mydin, Y. O. (2016). Religiousness and Mental Health: Systematic Review Study. *Journal of Religion and Health*, Vol. 55, No. 6, 1929–1937.
- Agli, O., Bailly, N., & Ferrand, C. (2014). Spirituality and religion in older adults with dementia: A systematic review. *International Psychogeriatrics*, 1-11.
- Agli, O., Bailly, N., Ferrand, C., & Martinent, G. (2018). Spirituality, quality of life, and depression in older people with dementia. *Journal of Religion, Spirituality & Aging*, Vol. 30, No. 3, 268-278.
- Barclay, A. (2012). Psalm 88: Living with Alzheimer's. *Journal of Religion, Disability & Health*, Vol. 15, No. 1, 88-101.
- Bons-Storm, M. (2016). Where is God when dementia sneaks into our house? Practical theology and the partners of dementia patients. *HTS Teologiese Studies/Theological Studies* 72(4), 1-8.
- Bryden, C., & MacKinlay, E. B. (2001). Dementia—A Spiritual Journey Towards the Divine: A Personal View of Dementia. *Journal of Religious Gerontology* Vol.13.
- Cavanaugh, J. C., & Blanchard-Fields, F. (2015). *Adult development and aging 7th edition*. Stamford: Cengage Learning.
- Charmaz, K., & Thornberg, R. (2021). The pursuit of quality in grounded theory. *Qualitative Research in Psychology* 18:3, 305-327.
- Corfield, R. J. (2012). *Ministry of Memories: Keys to Pastoral Care of Non-Cognitive Persons*. Virginia: Liberty Baptist Theological Seminary.
- Dalby, P., Sperlinger, D. J., & Boddington, S. (2011). The lived experience of spirituality and dementia in older people living with mild to moderate dementia. *Dementia* 11(1), 75–94.
- Duncan, F. E., Que, E. L., Zhang, N., Feinberg, E. C., O'Halloran, T. V., & Woodruff, T. K. (2016, April 26). *The zinc spark is an inorganic signature of human egg activation*. Herwin van Scientific Reports: <https://www.nature.com/articles/srep24737>
- Feil, N. (2009, May 26). *Gladys Wilson and Naomi Feil*. Retrieved from <https://www.youtube.com/watch?v=CrZXz10FcVM>
- Ganzevoort, R. R., & Visser, J. (2014). *Zorg voor het verhaal | Achtergrond, methode en inhoud van pastorale begeleiding*. Zoetermeer: Uitgeverij Meinema.
- Goodall, M. A. (2009). The evaluation of spiritual care in a dementia care setting. *Dementia* vol. 8(2), 167-183.
- Harrison, B. E., Son, G.-R., Kim, J., & Whall, A. L. (2007). Preserved Implicit Memory in Dementia: A Potential Model for Care. *American Journal of Alzheimer's Disease & Other Dementias*, 286–293.
- Hill, T. D. (2006). Religion, Spirituality, and Healthy Cognitive Aging. *Southern Medical Journal*. Vol. 99, No. 10, 1176-1177.

- 
- Hudson, R. (2015). God's Faithfulness and Dementia: Christian Theology in Context. *Journal of Religion Spirituality & Aging* 28(1), 1-18.
- Hull, R. H. (2016). The Art of Nonverbal Communication in Practice. *The Hearing Journal: May 2016 - Volume 69 - Issue 5*, 22-24.
- Kandel, E. R. (2018). Chapter 5. Memory, the storehouse of the self: Dementia. In *The Disordered Mind: What Unusual Brains Tell Us About Ourselves*. London: Little, Brown Book Group.
- Kevern, P. (2010a). Alzheimer's and the Dementia of God. *International Journal of Public Theology* 4, 237–253.
- Kevern, P. (2010b). Sharing the mind of Christ: preliminary thoughts on dementia and the Cross. *New Blackfriars Vol. 91(1034)*, 408-422.
- Kevern, P. (2010c). What Sort of a God is to be Found in dementia?: A Survey of Theological Responses and an Agenda for Their Development. *Theology vol. 133(873)*, 174-182.
- Kevern, P. (2015). The spirituality of people with late-stage dementia: a review of the research literature, a critical analysis and some implications for person-centred spirituality and dementia care. *Mental Health, Religion & Culture, Vol. 18, No. 9*, 765–776.
- Kirkland, K., Fortuna, M. C., Kelson, E., & Phinney, A. (2014). Music Therapy and Spiritual Care for Persons with Dementia: A Mixed-Methods Study. *Canadian Journal of Music Therapy*, 20(1), 10-37.
- Koenig, H. G. (2009). Research on Religion, Spirituality, and Mental Health: A Review. *The Canadian Journal of Psychiatry, Vol. 54, No. 5*, 283-291.
- Lubbinge, H., Heij, L., & Geluk, D. (2019). Cognitieve beperking en Avondmaal. *N.P.*
- Maï-Carmen, R.-K., Marshall, C. R., Bond, R. L., Russell, L. L., Greaves, C., Moore, K. M., . . . Warren, J. D. (2020). Altered Time Awareness in Dementia. Vol 11. *Frontiers in Neurology*, 291.
- Mayers, C. A., & Bursell, J. (2010). Spirituality within dementia care: perceptions of health professionals. *British Journal of Occupational Therapy vol. 73(4)*, 144-151.
- Miller-Sinclair, R. L. (2001). Momma, Oh Momma, I Can't Remember. In L. Van De Creek, *Spiritual Care for Persons with Dementia: Fundamentals for Pastoral Practice* (pp. 1-10). New York: Taylor & Francis Inc.
- Morris, H. M. (1997). *Pastoral Communication with confused elderly people*. Edinburgh: The University of Edinburgh.
- Moyle, W., Olorenshaw, R., Wallis, M., & Borbasi, S. (2008). Best practice for the management of older people with dementia in the acute care setting: a review of the literature. *International Journal of Older People Nursing* 3, 121-130.
- Mukherjee, S. B. (2016). Spirituality and Religion: Elderly's Perception and Understanding. *Indian Journal of Gerontology, Vol. 30, No. 3*, 336-354.

- 
- Pastoral care*. (2021). Retrieved from Mercy Health: <https://health-services.mercyhealth.com.au/service/pastoral-care-mhw/>
- Post, S. G., & Whitehouse, P. J. (2001). Spirituality, Religion, and Alzheimer's Disease. In L. VandeCreek, *Spiritual Care for Persons with Dementia: Fundamentals for Pastoral Practice* (pp. 1-23). New York: Taylor & Francis Inc.
- Powers, B. A., & Watson, N. M. (2011). Spiritual nurturance and support for nursing home residents with dementia. *Dementia vol. 10(1)*, 59-80.
- Rae, S. B. (2009). 5. Abortion and Embryonic Stem Cell Research. In S. B. Rae, *Moral Choices. An Introduction to Ethics*. (pp. 1-27). Grand Rapids, Michigan: Zondervan.
- Roxburgh, K. B. (2000). When Mind and Memory Flee: Pastoral Care and Senile Dementia. *The Expository Times vol. 111(10)*, 338-341.
- Ryan, E. B., Martin, L. S., & Beaman, A. (2005). Communication Strategies to Promote Spiritual Well-being among People with Dementia. *The Journal of Pastoral Care & Counseling, Spring-Summer. Vol. 59*, 43-55.
- Sapp, S. (2001). "To See Things as God Sees Them": Theological Reflections on Pastoral Care to Persons with Dementia. In L. Van De Creek, *Spiritual Care for Persons with Dementia: Fundamentals for Pastoral Practice* (pp. 1-33). New York: Taylor & Francis Inc.
- Snyder, L. (2003). Satisfaction and challenges in spiritual faith and practice for persons with dementia. *Dementia vol. 2(3)*, 299-313.
- Son, G.-R., Therrien, B., & Whall, A. (2004). Implicit Memory and Familiarity Among Elders with Dementia. *Journal of Nursing Scholarship*.
- Spinks, N. (2014). *Grounded Theory*. Retrieved from Semantic Scholar: <https://www.semanticscholar.org/paper/Grounded-Theory-Spinks/6182186784d792ed09c4129924a46f9e88869407>
- Stephan, A., Walter, S., & Wilutzky, W. (2014). Emotions beyond brain and body. *Philosophical Psychology. Vol. 27*, 65-81.
- Stolley, J. M., Koenig, H., & Buckwalter, K. C. (2001). Pastoral Care for the Person with Dementia. In L. Van De Creek, *Spiritual Care for Persons with Dementia: Fundamentals for Pastoral Practice* (pp. 1-31). New York: Taylor & Francis Inc.
- Stuckey, J. C., & Gwyther, L. P. (2003). Dementia, religion, and spirituality. *Dementia vol. 2(3)*, 291-297.
- Swinton, J. (2014). What the Body Remembers: Theological Reflections on Dementia. *Journal of Religion Spirituality & Aging vol. 26(2-3)*, 160-172.
- Van den Brink, G., & Van der Kooi, C. (2012). *Christelijke dogmatiek*. Zoetermeer: Uitgeverij Boekencentrum.



Van der Kaaden-Huttinga, W. (2006). *Geloven ervaren: een belevenis / Een praktisch theologisch onderzoek naar de bemiddeling van christelijk geloven aan mensen met een ernstige meervoudige beperking*. Utrecht: Katholieke Theologische Universiteit.

VandeCreek, L. (2001). *Spiritual Care for Persons with Dementia: Fundamentals for Pastoral Practice*. New York: Taylor & Francis Inc.

Wagner, C., Kawulich, B. B., & Garner, M. (2012). *Doing Social Research A Global Context*. Berkshire: McGraw-Hill Education.

Walters, D. (2007). The effect of multi-sensory ministry on the affect and engagement of women with dementia. *Dementia vol. 6(2)*, 233-234.

Wentrobe, D. P. (2001). Pastoral Care of Problematic Alzheimer's Disease and Dementia Affected Residents in a Long-Term Care Setting. In L. Van De Creek, *Spiritual Care for Persons with Dementia: Fundamentals for Pastoral Practice* (pp. 1-34). New York: Taylor & Francis Inc.



Appendix A: The Pastoral caregiver


If I could give a metaphor for what it means to be a pastoral/spiritual caregiver, I would say that **it is like herding sheep**. Actually, this is a simile, but it is a simile containing a couple of metaphors. Let me explain.

A pastoral caregiver is a shepherd. A shepherd faces the same circumstances as the sheep; warm, cold, hail or snow. A shepherd faces the same dangers as the sheep; getting sick, attacks from predators and exhaustion because of the elements. This means that, although a pastoral caregiver leads people, they lead people by entering the same situation the people are in. They refrain from making judgement calls and coming up with solutions. Instead, they try to get as much information about the situation and what it does with the people. Pastoral caregivers let the case have an emotional effect on them. Although pastoral caregivers are vulnerable to some extent, they do not get absorbed by the problem. They rise above the situation by looking at it from different perspectives. In turn, they help others rise above the situation by finding and exploring new and alternative views. Shepherds train and work with their dogs to help the sheep get to where they are going. Likewise, pastoral caregivers do not work alone. They usually work together with a pastoral team or several volunteers. They must be able to educate, instruct and provide these people with the proper knowledge to ensure that they feel capable of doing what is expected of them.

A pastoral caregiver is the shepherd's dog. Like a dog at his master's side - looking up at him, eagerly awaiting the next command then executing it without a moment of hesitation - a pastoral caregiver should look up at his Master in heaven. A pastoral caregiver should live according to the Word of God (Jesus). They should let themselves be inspired by the Holy Spirit and help people, not in a way they see fit but in the way God instructs them to. Pastoral caregivers should spend time with God, study and get to know Him. Pastoral caregivers should have a close relationship with the living God, talk with Him and learn to hear His voice. Being a pastoral caregiver not only means having theological knowledge about God but also knowledge about the mysteriousness of and about God. They must be able to translate this to everyday life and in their practice.

A pastoral caregiver is a sheep. Pastoral caregivers not only work with a team, but they also work within a community. One might say that they are a part of the community. Sometimes situations do not call for a range of different solutions. Sometimes all that is needed is for a pastoral caregiver to "just be there", to be "beneficially present". Sometimes people do not expect the situation to change, for you to make it better, nor help them. Sometimes people only need someone to be there, share in the experiences they go through, be happy with them, or cry with them. Being as sheep means that a pastoral caregiver is human with other humans. In this way, one shows that other people are worth it, worthy of other people's time. They are not alone in this world – but matter; they are essential and make a difference in the world. I say, "all that is needed", but this can also be the most challenging part of pastoral work. One must be willing to listen to stories you've heard a hundred times or give some of your time to people you'd rather not spend time with. It also means that you must sometimes suffer from or endure the suffering of other people. Sometimes things come to an end, and then it's the task of the pastoral caregiver to be there with and for the people losing something or some part of their lives. Being a sheep means enjoying the good times with others but also facing hard times together.

According to Ganzevoort & Visser (2014), there are four main models of pastoral work. The models are the pastoral caregiver as a witness, helper, companion, and pastoral caregiver as interpreter and guide.



Under the **pastoral caregiver as witness** fall the charismatic-, kerygmatic- and ecclesiastical-sacramental pastorate. A pastoral caregiver represents the revelation and tradition of the church. It emphasises the office and official status of the pastor. The pastoral caregiver knows the word of God and brings a message. The messages may include that we must repent from our sins and that we are all saved by the sacrifice Jesus has made for us all. These messages might be used as encouragement or help with the problems people face.

The **pastoral caregiver as helper** includes therapeutic- and systematic pastoral care. The focus lies on helping the client. How a pastoral caregiver does their job is more important than their official status. The professional conversation with a client is more important than bringing a message or adhering to specific belief systems. Pastoral caregivers are professionals, just like other caregivers. Faith or religion do not always have to come up for discussion.

The **pastoral caregiver as companion** does not primarily act on behalf of God nor the church and is not primarily a professional. It is about making contact with people. The focus lies on making contact with people, being there for them and building a relationship with them. A pastoral caregiver remains responsible whilst seeing people as fellow human beings. It's about being there, being present and showing that someone cares.

The **pastoral caregiver as guide** and interpreter tries to bring the three models mentioned into balance. The pastoral caregiver is always, in one way or another, a witness, helper or companion. The focus here is that of hermeneutics, interpreting the story of someone and helping them make sense of it. It is about exploring options, looking at things from different perspectives and creating a safe environment for people to help them help themselves. It is not only about creating coherence in the story of a person but bring their story together with the story of God.

To me, the nature of pastoral guidance is **about creating a relationship** with the other person. It is about **understanding** the person in their context – but also in the context in the story of God. It is about helping them see, explore and understand their own stories – also in relation to God. Pastoral care is about speaking, thinking, feeling, experiencing and doing. It is about building each other up, not being afraid to speak out and trusting in God to be there for the other, and being there to guide you as the pastor.

On the topic of administering pastoral care to the PSfd - I think that even though listening to the story of the person suffering from dementia may be very difficult or even seem impossible, it does not mean that we should not at least try. Everyone deserves to be loved and cared for. Even though they seem absent or cannot communicate, that does not mean that a pastoral visit isn't beneficial.

Appendix B: What is a person?

I agree with Kirkland et al. (2014). I think the misconceptions we might have about the PSfd can be misleading and harmful to their well-being. It will have a negative effect on their “quality of life” (Goodall, 2009, p. 1). I do not believe that the PSfd lose their personhood. I do not even think that personhood is dependant on cognitive functioning. In an essay I wrote,²⁵ I concluded that a person's personality and personhood starts at conception. At conception, an event called a ‘zinc spark’²⁶ “occurs rapidly following egg activation in the human egg” (Duncan, et al., 2016). It signifies the start of the development of the human being or person and personhood. Rae reports that most philosophers would agree and also states that only a “small minority of thinkers hold that not even the newborn baby possesses personhood” (Rae, 2009, p. 14). At this stage of development, the person does not yet have a brain, nor can it think or reflect. Therefore, I have to reject the assumption that **‘if one lacks the ability to reflect thoughtfully on spirituality, it does not exist’**. I think that most of what we know we’ve learned even before we can reflect on it. The ability to think critically about (your)life only comes later in life, if at all.

The western world tends to think/believe the phrase “I think, therefore I am”. I used to think this as well. Recently – during the writing of this paper – I had a burnout... I couldn't think. When I tried to think or attempted to multitask, I would instantly get a headache, stomach ache, feel extremely ill and become very emotional. This was the worst feeling ever – I thought I was losing my identity, ‘that’ which made me who I am – my personhood... As part of my recovery process, I attended Haptotherapy²⁷. I (re)learned to reconnect with my body – and for the first time in what seems forever, I started to feel like an actual human being. I was present. I felt and communicated without words – without having to rely on my mental capacity. For the first time that I know of, I was able to feel that I’m human. Now I believe that being human is not about thinking. It is not ‘I think therefore I am’ but ‘I feel therefore I am’! Or, at least, something in between... The point is, I felt more human, and not less. I was able to connect better with myself and with others... **To be human is to connect to others through more than just words**. If we reduce people to their mental capabilities or processes, we are demoting humans to being nothing more than an input-output system - a computer or robot.

Furthermore, a person’s implicit memory and, therefore, personality and spirituality²⁸ stay intact very late into the disease. So, even if it were true that the PSfd’s personhood or religion gets lost to the disease, it would still be essential to see and treat them as fellow human beings until the very end. Human beings are more than just memory and intellect. We also have “emotion, relationship, imagination, will, and aesthetic awareness” (Post & Whitehouse, 2001, p. 3). It is almost common knowledge that at least 70% of all communication is nonverbal. According to some, it might even be higher. Hull (2016, p. 22) thinks that it is around 80%. It then does not make sense to say that if someone can't think/reflect, nor communicate (with words), that they aren't human or not worthy of pastoral care. Just because someone is losing their mental capacities does not mean that they are less human, nor does it mean they do not deserve pastoral care.

²⁵ Etiek 2 - Opstel (2018)

²⁶ To see this happening, go to: <https://www.youtube.com/watch?v=VAgtRV0otfA>

²⁷ According to <https://www.blom-haptotherapie.nl/what-is-haptotherapy> Haptotherapy is “a form of treatment which helps you experience being more ‘present’ in body and mind, and guides you in gaining more trust towards your own feelings”.

²⁸ See chapter 1




I've personally seen the effect pastoral care has on people with limited mental capacities. During my internship at Bartiméus, I saw how communication with people steadily increased with regular visits and pastoral care moments. I've seen less cognitive people evolve from being passive and turned inward to communicating and enjoying their time with the pastoral care team and the rest of the group.

I think people suffering from dementia are more than just mere bodies to be cared for. I believe that they are human beings that deserve to be treated as such – with love, dignity and respect. They have a soul that longs for connection with others and with God. As pastoral caregivers, it is our task to help them in their journey with (re)connecting with themselves, others, and God in their journey.

Of course, you should not, only, take my word for it. Next, I will summarise what I've learned from scientific research papers on the relevance of spirituality in the lives of cognitive and non-cognitive people.





Appendix C: Theological-based reasons and benefits of administering pastoral care to the PSfd

They are still human

Our personhood does not lie within ourselves, nor how the community or sciences view the person. It lies with the Creator. They are not less human because of the disease but might become it if they are denied social interactions and spiritual or pastoral care. As humans, we are more than the sum of our parts. We are not our brain or our ability to communicate. What defines us as human beings does not lie within us but within God. God sees us as we are regardless of our ailments. He knows us – better than we know ourselves. He remembers us for who we are, even if we or those around us can't or don't. Having dementia does not take away a person's humanness or dignity (Swinton, 2014). Losing the ability to think or communicate does not devalue the PSfd as a person. They are more than flesh and blood and should receive honour and respect (Corfield, 2012) as well as the spiritual care they want and need. The PSfd should, therefore, still be regarded as a person. A person that is worthy of wants and requires some form of spiritual care. This is not just some abstract theoretical or theological idea. Corfield (2012) wrote about the visible change and joy that could be seen in a PSfd taking part in religious activities²⁹. We cannot deny PSfd pastoral care. Doing so would mean impeding them access to the one that holds their identity. One could say that administering pastoral care to a PSfd keeps them human in a way. By virtue of being human beings, they should receive pastoral care.

Because they are human beings, we should take care of them. We must share in the love of God and take care of each other, no matter our physical or mental condition. They are created in His image, and neglecting them is like neglecting God. A human being is body, mind, spirit, soul, love and the house of God. They should be cared for because:


- They are human beings deserving of love and care,
 - o created in the image of God
 - o have a body inscribed with faith
 - o that contains faith that needs to be lived.
- They are loved by God,
 - o contain the love and Spirit of God and therefore needs to be loved by us.
- They are a house of God that need to be taken care of.

Being human brings with it many motivations and reasons as to why we should take care of the PSfd spiritually or pastorally. These should be enough to administer pastoral care to PSfd, but they are not the only reasons. There are other practical theological reasons to take care of the PSfd.

Their spirituality does not get extinguished

Just as some might believe that the PSfd is no longer a human but an empty shell (Hudson, 2015), some might believe that they no longer need spirituality, faith, religion, spiritual- or pastoral care. Just because someone cannot think or communicate doesn't mean that they are less human or don't have spiritual needs. The notion is quite absurd. As cited by Goodall, Bryden says it is "like saying that a baby is not a human being because it

²⁹ "At religious services, demented residents respond positively to the prayers of their childhoods, reflecting their joy in being able to participate in an experience which still has meaning in their lives" (Corfield, 2012, p. 93).



cannot think abstractly or make and follow conversation... because it's, at that point in time, non-cognitive" (Goodall, 2009, p. 171). Religion, moreover, is about more than (abstractly) thinking about God or what gives life meaning. It also involves emotions, experiences and making connections. It's about the things that give our lives meaning and about helping us connect to those things. In a sense, taking away religious experiences from a person is like taking away what gives their life meaning. To people who grew up religiously, religious activities are essential up until the end of their lives, even more so than other activities³⁰. Therefore, if spirituality and the need for it do not disappear with dementia, it stands to reason that we have a responsibility to administer pastoral care to PSfd.

The appeal to administer pastoral care to PSfd can be strengthened by the fact, as Walters (2007) suggests, that some people believe that they might lose their faith as dementia takes its course. If we do not care for their spiritual needs, their fears may be realised. We need to help them remember, feel and experience their faith and help them connect with others and God. On the other hand, another PSfd believes that their faith grows as their cognition decreases (Bryden & MacKinlay, 2001). In both cases, the need for spirituality and connection is present in the PSfd, and it is vital to help the PSfd "spend their last days on earth in communion with their creator" (Corfield, 2012, p. 76).

Kirkland et al. (2014) report PSfd verbally confirming their need for spiritual care. "One participant said, 'I need the spirituality of the whole group. . . . You need this connection to strengthen your own faith.' A second participant felt that being part of the group was 'spiritually fulfilling' to him. A third participant said emphatically, 'This was needed in my life— I wouldn't miss it for anything'" (Kirkland, Fortuna, Kelson, & Phinney, 2014, p. 27).

Not administering pastoral care to the PSfd robs them of meaningful experiences. There is a growing consensus that pastoral care is needed in the life of the PSfd³¹, because the spiritual part of a person may become the only way for them to communicate and have exchanges that are meaningful, which gives their lives hope, value and meaning. "Without the opportunity to experience these moments, the person with dementia is likely to fall further into isolation or despair" (Stuckey & Gwyther, 2003, p. 295).


Benefits of receiving pastoral care as a PSfd

Clearly, the spiritual needs of PSfd do not go away, but they do get harder to see, realise and understand. However, that does not mean that we should not try and help them with it. From a practical theological perspective administering pastoral care to PSfd has proven to be beneficial to them in many ways. According to a PSfd, spirituality gives life meaning, empowers the PSfd and helps others connect with them (Mayers & Bursell, 2010). Like these benefits, there are many others. What follows next are summaries of benefits according to different authors.

³⁰ "People with a lifelong history of religious faith and practice often consider spiritual activity to be more meaningful than any other activity. Adelsber (1995) and Richards (1990) asserted that if spiritual faith and practice were once important to a person, cognitive deficits did not erase the need to engage in meaningful spiritual activity. When interviewed, many dementia sufferers reported that religion continued to bring them comfort. Some informants expressed fear that as their dementia worsened they would be unable to remember God's promises (Snyder, 2003).

Stuckey and other professionals who participated in a 1998 dialogue believed that even deep into dementia, people retained the capacity for meaningful spiritual experiences" (Walters, 2007, pp. 1-2).

³¹ "We join a growing list of colleagues (Richards, 1990; Kitwood, 1997; Sapp, 1997; McFadden et al., 2000; Bell & Troxel, 2001; Smith & Harkness, 2002) who call for a holistic approach to dementia care that considers the religious and spiritual elements alongside the cognitive, physical, and emotional" (Stuckey & Gwyther, 2003, p. 295).



According to Mayers & Bursell, spiritual care provides emotional support, dignity, comfort, hope, value and meaning in life. It helps meet the spiritual needs of the PSfd by attending church services, going outside to enjoy the sun and nature. Providing them with end-of-life care, quiet time and space. Listening to the PSfd, helping them fulfil their wishes, and providing helpful multisensory activities like listening to music (Mayers & Bursell, 2010).


Kirkland et al. note that it helps people feel connected by means of providing them with meaningful social interactions and community, paying attention to the individual and focussing on their life story. Building their self-worth by exploring past roles, relationships and experiences (Kirkland, Fortuna, Kelson, & Phinney, 2014).

PSfd wants to keep their spirituality and sense of self for as long as possible. According to Dalby et al., not being able to socialise with loved ones and feeling socially isolated are very real fears PSfd go through. Receiving pastoral care can help combat the fears becoming a reality. Being able to talk and be listened to in an open and non-judgmental way is beneficial for the PSfd. Being part of or staying involved in their existing communities are of importance. Pastoral care can be helpful by providing the PSfd with the opportunity to attend “prayer groups, Bible or scripture readings, religious storytelling and general participation in the life of the spiritual community” (Dalby, Sperlinger, & Boddington, 2011, p. 92). It is also crucial for the PSfd to feel helpful as it will help them attach meaning and value to their lives. Spiritual activity can assist them in helping others through prayer, charity, relationships, being there for other PSfd, and by being able to make use of other remaining skills they might still have.

Similarly, Ryan et al. are of the opinion that spiritual well-being is essential and that one should help the PSfd maintain meaningful social activities whilst emphasising their individuality. Affirming the personhood of the PSfd will help reaffirm their sense of self, others, environment and God. This and participating in activities with symbolic meaning help them feel valued and loved. Spiritual care can help the PSfd “feel accompanied on their journey through life while refreshing their own spirit” (Ryan, Martin, & Beaman, 2005, p. 55).

To Corfield, the most important thing a pastoral caregiver can do is to listen. Listening to the PSfd improves their self-esteem as well as validates who they are. In turn, it creates opportunities for sharing profound spiritual moments. Pastoral care can ease mental suffering through prayer, scripture, meditation and sacred music. When making use of symbols, they can touch, hear, see, or smell can help PSfd experience and feel the warmth, care and love of God. It helps them stay in touch with the religious activities they practices throughout their lifetime. By listening to the stories of their past and by using nature, music, rituals, and religious symbols, the pastoral caregiver can help the PSfd remember past memories and facilitate them remembering and connecting with God. Spirituality and religion help PSfd find peace and comfort as well as a way of coping with what they are dealing with (Corfield, 2012).

Practising religion and participating in religious activities are linked to better health. Administering pastoral care to the PSfd could improve their quality of life, not only because of the health benefits but also because it helps with meaning-making. Pastoral care helps the PSfd find meaning in life, hold onto what they find important in faith and gives them inner strength. Pastoral care provides access to group activities that are beneficial to the PSfd. It provides a feeling of belonging, a setting for socialisation and social behaviour. It enables them to mean something for or support others like them. Religious activities offer support, reassurance and help the PSfd cope with the stress associated with dementia. It allows the PSfd to express their emotions and spirituality. The familiarity of the activities is reassuring and essential to holistic treatment. Because the



activities have been practised their whole life, it is easy to understand or follow. It can be a helpful way of communicating with the PSfd when they are not able to do so verbally (VandeCreek, 2001).

Stuckey & Gwyther notes that PSfd has the same value as a healthy human being. They respond to holistic care that includes all aspects of life, including spirituality. "Alzheimer's disease may strip away the memories that help construct a person's identity, but it does not strip away that person's intrinsic value or the right to dignity and respect" (Stuckey & Gwyther, 2003, p. 292). Spirituality may help with coping with the disease. Religion and spirituality can also help find meaning in all the turmoil they are undergoing. It may help them rebuild their identity and be the foundation for the person they will become because of the disease. This also has implications for the quality of life for the PSfd. "The extent to which individuals have the opportunity to participate in religious events is directly related to their perceptions of overall quality of life" (Stuckey & Gwyther, 2003, p. 293).


Snyder lists the different ways it may help and have helped PSfd cope with the disease. Spirituality and religion:

- "gives hope, strength, guidance, or something to hold onto;
- specifically provides hope in an afterlife;
- helps with acceptance; and
- relieves fears or anxiety" (Snyder, 2003, p. 304).



Appendix D: Preliminary method list based on data from 25 scholarly articles

1. Dementia is an individual (client-based) process
 - a. Life Story
 - i. Obtain information
 - About client
 - About dementia
2. Presence / Here and now
 - a. Awareness
 - i. Observe
 - ii. Acceptance
 - iii. Listen
 - Make time
 - Silence
 - Don't correct rambling
 - iv. Reflect – On yourself, how they feel and everything – know yourself
3. Familiarity
 - a. Consistency and repetition
 - b. Themes
 - c. The use of objects
 - i. Rosary
 - ii. Candle
 - iii. Cross
 - iv. Bible
 - v. Clothing
 - d. Scripture
 - e. Prayer
 - i. Well known
 - ii. The lord's prayer
 - iii. Extempore prayer
 - f. Music
 - i. (Old) Hymns
4. Focus on what is still working
5. Multidisciplinary endeavour
 - a. Young people and children/layperson/family
 - b. The impact of AD on the care setting
 - c. Train other caregivers
6. Worship / Church
 - a. Traditional **cognitive** methods do not work
 - i. Traditional as in **familiar** does work
 - Sermon / Homily

- 
- b. Tips/Advice
 - c. Neglected
 - d. Visual aids and drama
 - 7. Memory
 - a. Memories
 - i. Help them remember / Remember for them
 - ii. Stories about people remembering
 - iii. Things that help them remember
 - b. Memory aids
 - i. Remembering Boxes
 - 8. Relationships
 - a. Empathy
 - 9. Symbols / Symbolism
 - a. Rituals
 - i. Holy Communion / Eucharist
 - ii. Gestures
 - iii. Blessing
 - iv. Sacraments
 - 10. Environment
 - a. Reduction in stressors
 - 11. Touch
 - 12. Cognitive vs non-Cognitive
 - a. Experience(s)
 - b. Reasoning
 - 13. Eye Contact
 - a. Get down to their level
 - 14. Humour
 - a. Laughter
 - 15. Reality orientation
 - a. Introduce yourself
 - 16. Being aware of your good practice



Appendix E: Final list of codes for the new method

This list can also be used as a shorthand for the method.

1. Environment
 - a. Stress reduction
 - b. Reality orientation
 - i. Introduce yourself clearly
 - ii. Don't correct rambling
2. Relationships
3. Dementia differs from person to person
 - a. Obtain knowledge about dementia and the experience of the PSfd
 - b. Obtain knowledge about the person behind the disease
4. Presence / Here and now
 - a. Keep eye contact
 - b. Be present and aware
 - i. Slow down
 - ii. Make time to listen
5. Familiarity
 - a. Memory and memories
 - i. Childhood
 - b. Make use of what is familiar
 - i. Overlearned activities
 - ii. Consistency
 - iii. Themes
 - iv. Objects
 - v. Music
 - vi. Rituals
6. Focus on what is still working
7. Multidisciplinary endeavour
8. Worship / Church
 - a. Traditional cognitive methods
 - b. Non-cognitive methods
 - i. Experiences
 - ii. Multisensory interaction
 - iii. Emotions
9. Gestures, rituals and symbols
 - a. Candle
 - b. Cross
 - c. Bible
 - d. Clothing
10. Touch



Appendix F: New method

1. Environment

Ensure that the environment is quiet and free from distractions. If the room is not free of distractions, move to another room. Ensure a quiet place to sit, whether inside or outside, but choose a place where the caregiver and client can be alone (with God).

Do not sit in **front of a window or close the curtain**. Choose a well-lit room so that the PSfd can see one's face clearly. Speak loud and clear. Pronounce words clearly so that the PSfd can understand what is being said.

Remove as many stressors from the meetings as possible – **stress reduction**. Turn off cell phones, alarm clocks, TV, radio and anything that can interfere and cause undue stress. Ensure the PSfd is comfortable as unmet needs, including physical, social and emotional needs, can act as a stressor and lead to anxious, dysfunctional, or confused states.

All behaviour has meaning and cause.

- Ensure safe functioning by supporting them in areas of loss, like providing cues to compensate for memory loss.
- Give the PSfd unconditional positive regard. That means accepting the PSfd as they are.
- Use behaviour linked to anxiety and avoidance to determine when the PSfd is comfortable or has had enough.
- Teach others to listen to the PSfd. Help them learn how to evaluate verbal and nonverbal responses.
- Modify the environment to support losses and enhance safety.
- Provide ongoing support, care and problem solving for caregivers.

The room used and the atmosphere one creates should become a safe place where the PSfd can be free to talk/communicate, feel, and be him/herself. The room and atmosphere can help orient them to what they are doing. One should not constantly 'be forced' to bring them back to reality or orient them to 'reality' personally. That is the purpose of the room and the atmosphere one creates. It should help them remember what they are doing. For these reasons, it is also applicable to discuss reality orientation next.

1.1 Reality orientation


Reality orientation can be constructive but, at the same time, very destructive.

Do:

- Wear recognisable clothing or clothing pieces.
- Introduce yourself **clearly**
 - o Touch the person while saying **their name** clearly to get their attention.
 - o Clearly state your name and whom you work for.
 - o Let them see or touch significant religious symbols like a Bible.

Do not:

- correct rambling
- correct them if they remember one's name incorrectly
- constantly bring them back to (one's own) reality
- remind them of what they have lost – loved ones, capabilities or otherwise.



PSfd do not perceive time as being linear anymore, resulting in a different perception of reality. They might experience events as if they are currently happening. Validate their experiences, focusing on the emotional overtones, rather than correcting them and only use information needed for safe functioning.

Consider the environment and safety of the other residents. If concerns that entering a room full of people might disturb the other residents or cause a commotion/confusion, ask the staff at hand if they would be so kind as to escort the PSfd to the hall where one can take over.

2. Relationships

Understand the PSfd's life story and gather as much information about their past lives as possible. It can provide a glimpse of who the PSfd is and help affirm their sense of identity.

The best way to get through to PSfd is by understanding them, getting to know them and respecting them as fellow human beings. In other words, not seeing them as just (another) client or as someone who needs help - but to make an effort to build a relationship with them. They should become a part of one's life, respected and loved. Someone one would like to spend time with or simply be with - someone to whom one gives a piece of oneself.

Building a relationship will enable one to show more than sympathy. One will learn to feel empathy for the PSfd. What moves them should move one as well. One can be human together through feelings or emotions, and more profound connections can be established than would be possible through words alone.

Building and maintaining a relationship with the person is essential. Every person is unique and should be treated as such, people with an identity, their own problems, wants, and needs.

3. Dementia differs from person to person

Every person has his or her personality, way of dealing with things, lifestyle and quirks. Every person is unique. The same is true for PSfd.

PSfd may even be different from visit to visit. Therefore, one should adapt one's approach to the person one finds. Do not use the same pastoral approach for every individual. Pastoral care should be **tailor-made** for the person's specific **needs**.

Obtain information about the PSfd and their dementia.


3.1 Knowledge about dementia and the experience of the PSfd

Gather knowledge about dementia and, more importantly, dementia, specific to the person. Whether they have trouble hearing, how easily they get confused, how they communicate, and in what stage of dementia they are.

Talking too fast or not loud enough, for example, might confuse or frustrate the PSfd. Therefore, one needs to be aware of what the PSfd is going through to adapt how one communicates with the person.

Obtain information about the PSfd's dementia by:

- Talking to their 'caretakers' and nurses.
- Reading their 'patient file'.
- Talking to their friends or family.

- 
- Observing and being aware of their reactions during a pastoral visit.
 - Creating individual care plans or use advanced care plans.

Provide the PSfd with the opportunity of making decisions about their care and treatment. Talk to them before their ability to communicate declines verbally—document their wishes, likes and how they would like to be treated and cared for. In addition, include information of who they are, personal background information and their disease progression.

3.2 Knowledge about the person behind the disease

Know and understand the person behind the disease. The PSfd might feel ashamed and try to hide their dementia. They might feel ignored or excluded from society. People having a hard time communicating their wants and needs might stop trying or withdraw from communication altogether.

For this reason, it is vital to engage with the person, to get to know them and talk about things they can remember easily. Who they are is of more importance than what they are not or cannot do. Their memories – overlearned behaviour and childhood songs can be easily remembered and might help one connect with them on a deeper level.

Try to understand what they want instead of focusing on what they are saying. Do not correct PSfd if they say something wrong. Go with the flow, enter their world and try to read between the lines. Do not be literal but feel the meaning of their sounds, words, actions and emotions. They communicate through emotions, try to make use of it.

4. Presence / Here and now

Make time for the PSfd. Be present and ‘in the moment’ when communicating with PSfd. PSfd get confused easily. Keep things as simple as possible and continuously show them that they have your attention. They have limited concentration and get distracted easily. Therefore, keep **eye contact** with them and do not write.

Be aware of your feelings, the feelings of the PSfd, the environment and anything and everything that goes on in that moment. When a PSfd rambles on about a particular topic, it is not without reason. Listen to their ramblings and try to interpret them. Do not constantly bring them back to the ‘topic at hand’.


Validate their experience and focus on non-verbal and non-cognitive communication. Observe the environment, their body language and what is happening within you. By observing and connecting with one’s body, to oneself as a whole, will enable one to make better contact with the PSfd.

Take the time to listen, truly listen, to what they have to say. Relax and slow down. Take time to be quiet and just be in the same space as them. If they start to ramble, let them ramble. Grant them the time to get used to and get close to the caregiver and become a familiar face in their lives.

5. Familiarity

5.1 Memory and memories

Use the memories that are still intact in the PSfd to help them remember or remember for them. For example, help them remember certain past situations by bringing the memories to them. Talk about, for example, school days, when they were childer and listen to them as they talk about their experiences. Do not correct rambling



or ask too many questions, just be there and listen to their story. One could also remember *for* them by telling them things one already know about them.

Make use of “remembering boxes” or “reminiscence packets”. Use or explore memories that mean something to them, attached to emotions, making it effortless for them to retrieve. Make life-story books to read back to them at later stages.

5.2 Make use of what is familiar

Familiar things could be things they remember from childhood, **overlearned material** like songs, pieces of scripture and even the holy communion. The music they liked listening to, habits or rituals that they grew up with are easy to remember.

Improve their quality of life by:

- recalling overlearned and very familiar activities, for example: shaking hands or playing catch
- emphasizing the ability to appreciate sensory experiences such as feeling or smelling
- focussing on overlearned and persistent social skills, such as greeting one another
- emphasizing the ability to participate in gross motor activities, such as dancing or moving to music
- focussing on implicit or remote memories, especially childhood and young-adult memories
 - o providing opportunities for reminiscence
- providing opportunities for active participation, such as singing, humming or clapping with music
- bringing attention to a principal or identifiable purposes they might have
- making use of nonverbal skills, such as responding to music
- providing immediate positive feedback.

Be consistent – this helps them remember. Use familiar themes, objects and rituals to trigger memories and bring up experiences that help one make contact. For example, listen to their favourite music with them and move with their body as they start to remember.


6. Focus on what is still working

Focus on what they can still do and build on enduring capabilities instead of focussing on what the PSfd has lost or can not do anymore.

Focus on ingrained or implicit memories such as:

- lifetime memories,
- nonverbal comprehension,
- expression of emotions,
- emotional awareness,
- emotional memory,
- sensory appreciation,
- primary motor function,
- sociability and social skills,
- procedural memory/habitual skills,
- long-term memory,
- sense of humour.

Long-term or overlearned and bodily memories can help the pastoral caregiver connect with the PSfd. However, when it comes to humour, there is a caveat. Do not to make fun of the PSfd or laugh at them. Instead,



laugh with them, focus on what they find amusing and try to find things that make them laugh. Do not use sarcasm or idioms, as this may confuse the PSfd.

7. Multidisciplinary endeavour

Do not try to figure everything out by yourself. Pastoral caregiving is a multidisciplinary undertaking that includes other caregivers, nursing staff, families, volunteers, colleagues and more.

Work together to giving the best care possible to the PSfd. Work together to ensure a safe and respectable workplace. Ask other staff members to tell one about what they know about the PSfd or how he or she is doing before one goes to visit them. Also, respect one another and ask permission before just entering a room. The PSfd's family is a part of the "multidisciplinary team". Involved them in the care process where possible.

Train and facilitate training for those who want it. Demanding or 'difficult' clients may suffer in specific settings because staff or volunteers do not know how to deal with them. Help others understand the PSfd and dementia to keep the environment as safe and pleasant as possible. A little knowledge goes a long way.

Make use of all the available resources and ensure that the PSfd is visited frequently. It is important to keep helping them make social interactions instead of limiting them. Social interactions ensure a better quality of life for the PSfd.

8. Worship / Church

Do not exclude PSfd from any social interactions, for example, church worships.

The PSfd should attend church functions for as long as they feel comfortable and have the energy to do so. When, for whatever reason, they are not able/allowed to attend these functions, then the pastoral caregiver can organise or invite them to worship especially created for PSfd.

8.1 Traditional cognitive methods

Traditional (cognitively based) methods will not work. PSfd usually have trouble focussing for long periods of time. As their cognitive functioning declines due to dementia, they also lose the mental capacity to follow or understand complicated sermons and analogies.


Keep sermons short and straightforward. Use easy to understand, emotive language – words that trigger as many senses as possible.

8.2 Non-cognitive methods focussing on experiences, multisensory interaction and emotions

Focus on one theme and a short piece of scripture applicable to a particular theme. Focus on the experience of a worship service rather than the teaching or explaining the word or gospel.

Focus on emotive wording, bringing the word and gospel into the world of the PSfd. Think about how it may apply to them or give examples of how the scripture or God has touched one's life. The more personal, the better.

Speak about things that have to do with emotions, use words that incorporate all the senses – touch, smell, sound, taste and hearing. The more senses one uses, the more one can help them experience the service, and the better one can make contact with them.



Use multiple sensory methods and help them connect with their bodies and emotions – improving their experience and, in turn, help them remember.

9. Gestures, rituals and symbols

Use gestures, rituals and symbols because they make communication easier. Use symbolic items, for example, the Bible, a cross, candles, a crucifix, a picture of Jesus, or other visuals like bread and wine and communion cup. These items help with recollection, aid in conversations, and help the person connect with God.

Symbols do not always have to be linked to faith or church but can be something as simple as a toy car or a baby doll. Pictograms, for example, are used to help people unable to speak to communicate their wants and needs.

Use rituals like shaking the PSfd's hand before and after a meeting. Shaking hands symbolises the beginning and the end of the meeting. Prayer and reading scripture, or even singing can be incorporated into the ritual tailor-made for the specific client. A ritual is also not something one thinks of and implement on one's own. Any good ritual grows out from the connection made with and the input given by the PSfd. It should thus be different for each client and not just some trick one uses to make contact with the PSfd. Rituals like the holy communion/eucharist and maybe even the reading of the ten commandments and the blessing could be significant as it may have been a part of the PSfd's life since childhood.

Symbols can also be actions, making them gestures. Gestures are, for example, occasionally gently touching or rubbing the shoulders of a resident with genuine affection to draw them into the activity. This brings the PSfd into the social world of the activity by helping them feel comfortable and included

10. Touch

Touch is one of the most powerful methods of communication when it comes to communicating with people with cognitive disabilities. Touch instantly communicates emotions, closeness and vulnerability. When one touches someone, one makes physical, **emotional- and maybe even spiritual** contact. Because the PSfd can still feel and detect emotions, touch is a beautiful way to communicate warmth and positive regard.

Touch helps one make and keep contact with one's clients. It lets them know and feel that one is talking to them, that one are there for them, and that one are willing to listen to them. In addition, by touching the person and using their name to alert them, one can gain and hold their attention.

Not all PSfd like to be touched. Be careful and always ask for permission first. Having background knowledge of the PSfd can help one decide when to use touch.

Forms of touch do not have to be limited to placing one's hand on their leg or shoulder. It can also involve placing one's head against their head. Face against their face or their head on one's shoulder, etcetera. Their bodies and emotions have become their new method of communication, and we need to adapt our way of communication if we ever want to make fruitful contact with them.

Like babies who may die if they do not receive the loving embrace or touch from his/her parents, touch may have a life-sustaining effect on PSfd. Touch is vital when the PSfd's verbal and cognitive-communication skills decline or disappear entirely, and they start to perceive the world through their senses. Use a gentle touch to reassure the PSfd. Hugs mean more than thousands of words.



70%, or even more, of communication happens non-verbally. That is why, as the mental functioning of the PSfd decreases, pastoral care and spiritual wellbeing should progressively shift to non-verbal forms. Therefore, pastoral care should take on non-verbal forms like:

- Just sitting in the room, making **physical contact** now and then to let them know one is there.
- **Being present** and spending time with them (without wanting to accomplish something).
- Holding, touching or rubbing their **hands** (with hand lotion).
- Holding or touching their **legs or feet**.
- **Kissing** them gently.
- Giving them loving **hugs**.
- **Combing** the **hair** of the PSfd.
- **Taking** them **outside** to feel the sun on their skin, the wind in their hair, to smell nature and watch or listen to the birds.
- Having a **positive and loving regard** towards them.

