

Discussing Dementia 2: On Caring @ St. Peter's Tamworth – Summary (Online)

4th & 5th May 2018

Discussing



Dementia

A. Introduction

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Blessed are they

Found in the Booth Memorial Hospital Cape Town, S. Africa

Blessed are they who understand
My faltering steps and palsied hands,
Blessed are they who know that my ears today
Must strain to catch the things they say;
Blessed are they who seem to know
That my eyes are dim and my wits are slow;
Blessed are they that look away
When coffee spilled at the table today;
Blessed are they with a cheery smile
Who stop to chat for a little while;
Blessed are they who never say
You've told me that story twice today.
Blessed are they who know the ways
To bring back memories of yesterdays;
Blessed are they who make it known
That I'm loved, respected and not alone;
Blessed are they who know I'm at a loss
To find the strength to carry the cross;
Blessed are they who ease the days
On my journey home in loving ways.

B. “Discussing Dementia 1: An Overview” – Recap

See separate Handout. **INSERT.**

C. On Caring

- C.1** Who is the most important person? The person living with dementia or their carer?
The carer! “You can’t pour from an empty cup”.
- C.2** We will explore:
- How do we best care for persons living with dementia (PLWD*)?
 - How do carers best care for themselves?
 - How do we helpfully care for the carers?
- C.3** Terminology: Dementia Australia “Dementia Language Guidelines”.
<https://www.dementia.org.au/resources/dementia-language-guidelines>.
- C.4** Story: Why continue to visit your wife living with dementia?
Because I still know who she is! **INSERT**
- C.5** A Carer’s story.

D. Organisations and Individuals

D.1 Dementia Australia

- a) **Doing Stuff Together**: (**INSERT** video on my Blog). Handout **INSERT**
- b) **Website**: www.dementia.org.au.
- c) **Dementia Daily** (<https://www.dementiadaily.org.au/>)
e.g. Imelda Gilmore: “Someone to come alongside” 19.4.2018. **INSERT**
- d) **HELP** Sheets.
- e) **Dementia-Friendly Communities**: www.dementiafriendly.org.au.

D.2 Carers Australia

- Website: www.carersaustralia.com.au.
- An article: Carers flag respite shortage, Australian Ageing Agenda Apr-May 2018
INSERT.

D.3 Carer Gateway (Federal Government)

- www.caregateway.gov.au

D.4 Kate Swaffer

- Reader’s Digest article (February 2017): Life beyond dementia. **INSERT**
- Book: “What the hell happened to my brain?”
- Sheet: “20 things not to say or do”. **INSERT**

D.5 Christine Bryden

- **Before I forget: Christine Bryden’s struggle with early-onset dementia**
22/12/2015: ‘The Doctor said, “You’ve got about five years until you are demented, and then another until you die.” ‘It was,’ Bryden says, ‘just unbelievably cruel.’
INSERT
- Books:
Who will I be before I die?
Dancing with dementia
Will I still be me?
“Nothing about us, without us! 20 years of dementia advocacy”.

E. The five griefs of dementia

Grief is a natural (God-given) response to loss and death.

The 5 griefs of dementia:

1. When the person's symptoms first begin.
2. When the person is first diagnosed with dementia.
3. When the person enters residential care.
4. When the person is dying and dies.
5. When the carer loses their role as carer.



Story: "Her heart remembered" by Lynne Walter Budnik. **INSERT**

F. Film: "10 Glorious seconds"

See <http://www.tengloriousseconds.com>

G. Where is God in dementia?

G.1 Parable of the Good Samaritan (Luke 10:25-37) - Rephrased

G.2 Jesus' Great Commandments

Jesus' two great Commandments: "Love the Lord your God with all your heart, mind, soul and strength. Love your neighbour as yourself". **Explanation**: Heart = body. Mind = brain. Soul = Spirit. So we are Body + Brain + Spirit.

G.3 The breath of life

"the LORD God formed the man from the dust of the ground and breathed into his nostrils the breath of life, and the man became a living being" (Genesis 2:7).

G.4 Spiritual renewal

Our God-given spirit does NOT suffer from ageing or dementia. It remains whole, well and strong. *"Therefore we do not lose heart. Even though our outward man is perishing, yet the inward man is being renewed day by day"* (2 Cor. 4:16).

G.5 Spiritual Glory: Charles Wesley's hymn *"Love divine, all loves excelling"* (verse 3): **changed from glory into glory!**

G.6 Psalm 139: Our Daily Bread 22/10/2014. **INSERT**

G.7 Dementia-Friendly Worship

- Book of Common Prayer article (9/10/2016) **INSERT**
- "Meaningful Ageing": Dementia-Specific Christian Worship Service Handbook <https://meaningfulageing.org.au>.

G.8 John Swinton

- Paper: "Gentle Discipleship. **INSERT**
- Book: "Dementia – Living in the Memories of God"

G.9 Hammond Care: Faith for Life

- <http://www.hammond.com.au/shop/faith-for-life>.

G.10 Teepa Snow and Lin Possell

- <http://teepasnow.com/>
- The gift of those living with dementia: they live in the present moment!
- Book: “Dementia Guide for Faith Communities and Leaders”. Excerpt: “I am living with dementia” pp.69-70. **INSERT**
- Videos e.g. Spirituality in Dementia Care.

G.11 A Carer’s Story #2

H. Dementia and Technology

H.1 Is there an App for that?

- BPSD / Care4Dementia / Cultura / The Dementia Friendly Home / Google Earth / Photo Booth / Sound Hound / YouTube / amuseIT
- My compilation: *Is there an App for that?* (See my Blog).

H.2 EDIE (Educational Dementia Immersive Experience)

<https://www.dementia.org.au/learning/centre-for-dementia-learning/edie-educational-dementia-immersive-experience>.

H.3 Centre for Cultural Diversity and Ageing

- <http://www.culturaldiversity.com.au/>
- Site was recommended in the ‘Australian Ageing Agenda’ Mar-Apr 2018 p.56. **INSERT.**

H.4 My Aged Care (Federal Government): <https://www.myagedcare.gov.au/>

I. TIPS

I.1 Sense of humour: Keep a sense of humour! “Don’t take yourself too seriously!”

I.2 Respite

- Respite is a form of self-care. The dementia journey is a marathon.
- “Respite care can support you and your carer with a break for a short period of time. This gives carers the chance to get to everyday activities or go on a planned break. Respite care may be given informally by family, friends or neighbours, or by formal respite care services” (myagedcare).
- Give your children the opportunity to care!
- Search the Dementia Australia & My Aged Care websites.

I.3 Driving

- Dementia Australia has 2 Help sheets (one for the driver and one for the carer). See also <https://www.dementia.org.au/resources/dementia-and-driving>.
- NRMA and Dementia Australia brochure: Staying on the move with dementia: <https://www.dementia.org.au/sites/default/files/NSW-Staying-on-th-move-with-dementia-booklet.pdf>

I.4 UTAS: <https://mooc.utas.edu.au/courses>

- Understanding Dementia Massive Open Online Course (MOOC)
- Preventing Dementia MOOC
- Bachelor of Dementia Care

I.5 Risk Factors for Dementia

- **The Lancet** (Dec. 2017) – Can dementia be prevented? See [Blog](#): “On Caring 2”.
- **Alzheimer’s Research UK** – Reducing your risk of dementia. See the site <https://www.alzheimersresearchuk.org/about-dementia/helpful-information/reducing-the-risk/>.

J. Resources

J.1 Project We Forgot (21.4.2018) - Living the long goodbye with my grandpa and dementia. See <https://projectweforgot.com/your-aid/country/canada/living-the-long-goodbye-with-my-grandpa-and-dementia/>. **INSERT**

J.2 Films e.g. Still Alice / The Iron Lady / The Notebook

J.3 TV: Mother & Son

J.4 Radio e.g. ABC “All in the mind”.
<http://www.abc.net.au/radionational/programs/allinthemind/>

J.5 Printed material

- Caregiver’s 10 Commandments. **INSERT**
- Answering the same questions over and over **INSERT**
- Caring for a Dad with dementia, blindness and hearing loss **INSERT**
- Early signs and symptoms of Alzheimer’s **INSERT**
- What to do if you think that a loved one has dementia **INSERT**

J.6 Young Onset Dementia

- **Book** by Hilda Hayo and others: “Young Onset Dementia: A Guide to Recognition, Diagnosis, and Supporting Individuals with Dementia and their Families”.
 - Table of Contents: **Chapter 5:** The Impact ... on Family Relationships.
- <https://www.jkp.com/uk/young-onset-dementia-2.html>

J.7 Sally Magnusson

- **Book:** “where memories go”.

K. Final Questions and Answers

L. Conclusion

- “**God still remembers me**” by Paul Hornback.
- <http://www.faithfulfoggyliving.com/new-devotional-book/>

D.1(a) Dementia Australia: *Doing Stuff Together*

Understanding to engage

- history
- interests
- ability
- importance of non-verbal communication

Planning to engage

- try not to take over the activity
- choose an activity that has a sense of purpose
- ensure the activity meets the ability
- go from simple tasks to more complex
- break down tasks into steps
- being in the moment is important, not the outcome

Really engaging

- invite the person to participate
- offer choices where possible and communicate these clearly
- re-establish eye contact, gently touch their hand, invite them to help
- end the activity “Did you enjoy doing this?”
- be prepared
- don’t correct mistakes

Benefits of engaging

- spending quality time with the person
- reducing distressing behaviours
- maintaining dignity
- improving the person’s well-being
- providing a meaningful and enjoyable experience

20 things NOT to say or do to a person with dementia

1. Don't say, 'but don't look or sound like you have dementia'
2. Don't tell us we are wrong
3. Don't argue with us or correct trivial things
4. Don't say 'remember when...'
5. Don't call us 'sufferers' or 'victims'
6. Don't refer to us as suffering, sufferers, demented, dementing illness, vacant dement, demented sufferer, an empty shell, fading away, disappearing, or that it is the longest goodbye, the saddest goodbye, stealing us away (we are always still here), afflicted
7. Don't say you are 'living with dementia' unless you are diagnosed with dementia
8. Don't remind us of the death of a loved one or pet
9. Don't blame the person for the changes in behaviour or personality
10. We have a form or type of dementia, not an 'affliction'
11. Don't call me honey, love or anything other than my preferred name
12. Don't refer to us as 'aggressives, 'wanderers', 'poor feeders', 'wetters', 'attention-seekers', 'non-communicators' or as 'obstructive' – we are still human beings
13. Don't assume because we can't tell you, your words or actions don't hurt our feelings
14. Don't assume I can't answer for myself
15. Don't talk about me to someone else, in front of me
16. Don't assume we can't communicate even if I we can't speak
17. Don't say, 'but I've just told you that' or 'you've asked me that already'
18. Don't think we can't feel pain, or have emotions
19. Don't assume we don't understand just because we are silent
20. Don't assume anything; it makes an ass out of u and me

J.5 Caregiver's 10 Commandments

CAREGIVER'S 10 COMMANDMENTS

AGREE Never Argue

REDIRECT Never Reason

DISTRACT Never Shame

REASSURE Never Lecture

REMINISCE Never say "Remember"

REPEAT Never say, "I already told you"

SAY "DO WHAT YOU CAN" Never say "You can't"

ASK Never Command

ENCOURAGE & PRAISE Never condescend

REINFORCE Never Force



www.dementiasupport.org.uk