

# AJDC Journal Club

DISCUSSION GUIDE 5

Vol 8 No 1 February/March 2019


## Welcome

Welcome to the **AJDC Journal Club! The Australian Journal of Dementia Care (AJDC) Journal Club** is – like the Journal itself – aimed at all staff working with people with dementia in your service, facility or centre.

The purpose of the **AJDC Journal Club** is to offer an opportunity to step back from the day-to-day pressures of work, reflect on practice and to consider whether any of the ideas shared in the AJDC could be useful in your service.

We hope that you find the AJDC a valuable resource and will use these questions to stimulate discussion on the needs of people with dementia and care practice at weekly or fortnightly team meetings within your service or organisation.

## Scan our QR Codes!



We have added Quick Response (QR) codes next to all our useful resources and additional readings. Scan the QR codes with your internet enabled device e.g. smartphone, to open the URL.

No scanner? Download a free App in your store e.g. QR Reader for iPhone

## Some tips for your AJDC Journal Club

Work out ahead of time who will take a lead in organising and facilitating the discussion and distributing copies of the articles to be discussed.

Discuss 1 article / set of questions per meeting (say, every fortnight).

We have suggested 4-5 questions per article. If this seems too many (given time constraints), or some are not applicable to your service, pick 2 or 3 and focus on these.

Ideally all participants will have read each article before the group discussion. In practice, this may be unrealistic or impossible – so the questions have been written in such a way that people should still be able to contribute, even if they haven't read all the articles completely.

If possible, ask one of the participants to write brief notes during the discussion. These can be distributed to colleagues who attended as well as those unable to make it.

This **AJDC Journal Club** initiative is supported by Dementia Training Australia.

**dta.com.au**

Download the **Journal Club Discussion Guides** at [dta.com.au/journalclub](http://dta.com.au/journalclub)

## ARTICLE 1

### Meeting Centres: an Australian trial

by Dragana Bozinovski and Amal Madani

Australian Journal of Dementia Care,  
Feb/Mar 2019, Vol 8, No 1, pp 8-10



Pages 8-10

#### QUESTIONS

1. What sort of help is available to people who have recently been diagnosed with dementia to adjust to the changes of living with dementia? In an ideal world, what sorts of things might a post-diagnostic support plan include?
2. What do you think are some particular strengths of the Meeting Centres Support Program?
3. What benefits may come from involving researchers from the start of this pilot program? What challenges?
4. Can you suggest ways that aged care services could build in more support for family carers alongside support for the person with dementia?
5. How can care facilities involve people with dementia in regular meal preparation and eating together? How feasible do you think this is?

#### Useful resources and additional reading

##### Meeting Centres Support Programme UK: Overview, Evidence And Getting Started

This booklet explains the history of the Meeting Centres Support Program in the Netherlands, reports on progress to implement it in the UK and other countries, and sets out information about how to get started with developing a MCSP.

<http://bit.ly/meetingcentres-JC>



##### Supporting Independence And Function In People Living With Dementia

This HammondCare resource explains the programs that might assist a person newly diagnosed with dementia to keep up with everyday living activities, mobility and physical functioning, and cognition and communication.

<http://bit.ly/supportresource-JC>

**Allied Health Professionals And You: A Guide  
For People Living With Dementia And Their  
Carers** This guide explains the role that allied health professionals can play in supporting people with dementia.

<http://bit.ly/acihealth-JC>



**Running Self-Help Groups In Sheltered And  
Extra Care Accommodation For People Who  
Live With Dementia** This UK resource has lots of content that is relevant in the Australian context, for example on how to get peer support groups up and running, how to sustain and evaluate them, and a long list of engaging activities for such a group situation.

<http://bit.ly/helpgroups-JC>



## ARTICLE 2

### Toilets: no laughing matter

by Mary Marshall

Australian Journal of Dementia Care,  
Feb/Mar 2019, Vol 8, No 1, pp 12-13



Pages 12-13

#### QUESTIONS

1. Can you share an example of a time when you saw that the design of a bathroom was causing practical problems for a person with dementia?
2. What issues might family members and friends face when trying to support a person with dementia to use public toilet facilities?
3. How could the campaign for dementia-friendly communities help with promoting improvements in public facilities?
4. Can you suggest some practical strategies that might help a person with dementia who is becoming increasingly anxious about using public toilet facilities?

#### Useful resources and additional reading

##### Promoting Continence For People Living With Dementia And Long-Term Conditions

This easy-read guide presents five ways to support a person with dementia with managing continence (one of which relates to the environment), and lists simple, practical ways to achieve this.

<http://bit.ly/continenceguide-JC>



**Dementia-Friendly Community – Environmental  
Assessment Tool** This Dementia Training Australia resource can be used in collaboration with a group of people with dementia to review a facility and examine how 'dementia-friendly' it is.

<http://bit.ly/DFCTool-JC>

##### Is This INSIDE Public Space Dementia-inclusive?

Innovations in Dementia, the University of Edinburgh and HammondCare developed this simple checklist for use by dementia advocacy groups, which includes a section on 'Is it easy to find and use a toilet?'.

<http://bit.ly/inclusivecheck-JC>



**Dementia Enabling Environments Project  
(DEEP)** The DEEP website looks at settings in detail (homes, apartments, care homes, public buildings and gardens), and considers how to best support people with dementia via colour, signage, lighting and so on. It includes links to resources, tools and checklists.

<http://bit.ly/enabling-JC>



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## ARTICLE 3

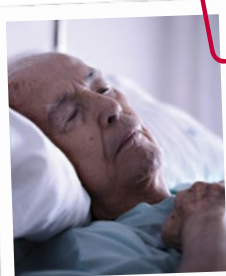
# Death and dying in dementia care: a good end?

by Rosalie Hudson

Australian Journal of Dementia Care,  
Feb/Mar 2019, Vol 8, No 1, pp 24-27

## QUESTIONS

1. How important do you think it is to clarify whether a person has formally been given a diagnosis of dementia, and to find out which type of dementia they have?
2. Can you think of an example of when a relative showed you a better or deeper way to approach or understand dementia?
3. How has talking about death and dying with people with dementia and their family carers affected you?
4. How can you support family carers and relatives to learn more about end-of-life care in dementia? What resources could you distribute or promote?
5. The author says care providers need to be clear about who is responsible for speaking with the family of a person with dementia about death and dying: "Who will speak with the family, and when?" If this is not clear in your organisation, how can it be improved?



Pages 24-27

## Useful resources and additional reading

**Talking About Dementia And Dying: A Discussion Tool For Residential Aged Care Facility Staff** Guidance on communicating about death and dying with people with dementia and their family and friends, from The Wicking Dementia Research and Education Centre. <http://bit.ly/talking-JC>



**Asking Questions About Dementia Can Help** This Alzheimer's Australia and Palliative Care NSW booklet lists questions that a person with dementia and/or their family members may want to ask of health professionals about or during the advanced stages of dementia (eg pain relief, medication and nutrition). <http://bit.ly/askingquestions-JC>

**Future Planning And Advance Care Planning** The Cognitive Decline Partnership Centre and HammondCare conducted this 2016 review of research and interviews with 80 practitioners on advanced care planning for people with dementia, in order to work towards a national model. <http://bit.ly/futureplanning-JC>



**Palliative Care And Dementia** Guidance on end-of-life care for people with dementia, covering topics such as prognosis, symptom management, advance care planning, personal comfort measures and grief and bereavement support. Available at: <http://bit.ly/palliatiivedem-JC>

## ARTICLE 4

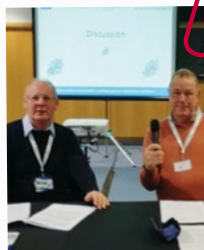
# Frontotemporal dementia: the real lived experience

by Reinhard Guss, Chris Norris, Chris Ryan, Morgan-Wallis Egremont and Megan Roby

Australian Journal of Dementia Care,  
Feb/Mar 2019, Vol 8, No 1, pp 31-33

## QUESTIONS

1. How much contact have you had with people who have been diagnosed with behavioural variant frontotemporal dementia (bvFTD)? Do you think the experience of people with bvFTD can tell us something about the experience of people with other forms of dementia?
2. The authors say that family carers' perspectives have been given more weight in earlier research, compared with the views of people living with dementia. Why do you think this has happened?
3. Chris Norris writes that he and the other interviewee, Chris Ryan, both have insight, on the majority of occasions, and are also able to reflect on difficult situations afterwards. What do you think about this? What are some implications of this?
4. The research involved listening to the experiences of people living with dementia and valuing what they say. How can care organisations make sure that they regularly, routinely listen to people living with dementia?



Pages 31-33

## Useful resources and additional reading

**The FTD Toolkit** This website from the Eastern Cognitive Disorders Clinic in Melbourne has information on frontotemporal dementia (FTD), covering what it is, diagnosis, caring approaches, assessment and management, younger onset aspects and links to other resources. <http://bit.ly/theftdtoolkit-JC>



**FTD Talk** This website was developed by scientists at University College London with the aim of making frontotemporal dementia (FTD) easy to understand. The site includes a dozen factsheets related to various sub-types of FTD, available to download for free. <http://bit.ly/ftdtalk-JC>

### Managing Triggers

This practical guide is written by and aimed at people in the earlier stages of dementia, to help them identify and reflect on 'triggers' in their life: what situations or environments cause distress and how to prepare and anticipate these challenges. <http://bit.ly/managingtriggers-JC>



**Diagnostic Dementia Tests** The Frontier research team at the University of Sydney's Brain and Mind Centre focuses on FTD and has developed a range of FTD-specific diagnostic tests which can be downloaded. <http://bit.ly/dementiatest-JC>

### **Australian Journal of** **DementiaCare**

#### **The Australian Journal of Dementia Care (AJDC)**

The Australian Journal of Dementia Care is a subscription-only multidisciplinary journal for all professional staff working with people with dementia, in aged care homes, hospitals, day units and the community. The journal is committed to improving the quality of care provided for people with dementia, by keeping readers abreast of news and views, research, developments, practice and training issues. The Australian Journal of Dementia Care is grounded firmly in practice and provides a lively forum for ideas and opinions. We also welcome submissions of articles and letters to the editor from people involved in the dementia care sector.

**[journalofdementiacare.com](http://journalofdementiacare.com)**



#### **Dementia Training Australia (DTA)**

DTA is funded by the Federal Government to provide high-quality dementia education, training and services to aged and health care staff, managers and other professionals across Australia. It combines the dementia expertise of five universities and Dementia Australia to deliver a coordinated national approach to dementia training for individuals and organisations. The consortium members are: the University of Wollongong, Dementia Australia, La Trobe University, Queensland University of Technology, the University of Western Australia, and the Wicking Dementia Research and Education Centre (University of Tasmania).

**[dta.com.au](http://dta.com.au)**

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