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# Limitation of care orders: Making an informed choice

▶ **An education resource for health professionals**



Produced by the Victoria and Tasmania Dementia Training Study Centre  
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## **Limitation of care orders: Making an informed choice**

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#### **Important note**

This resource is intended for use by health educators as a component of a structured education session.

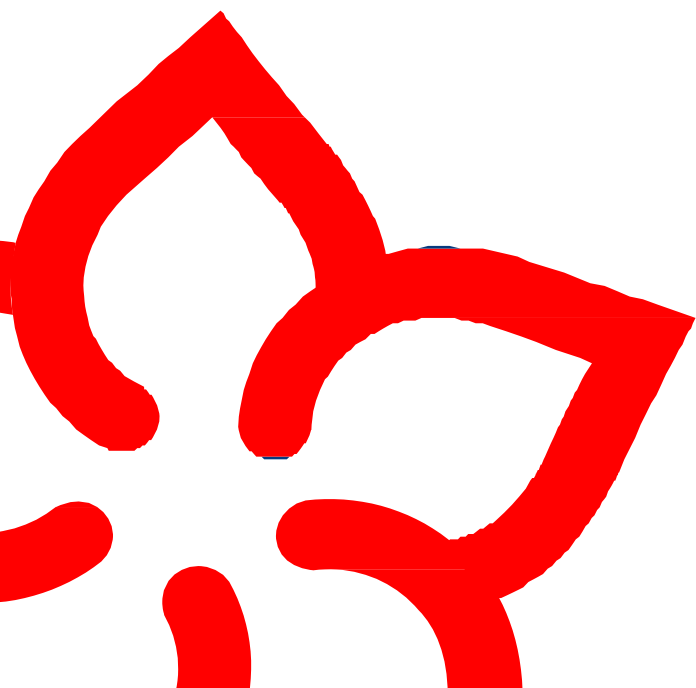
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## **Authorship**

**Professor Joseph E Ibrahim MBBS, Grad Cert HE, PhD, FRACP, FAFPHM**

CRE-Patient Safety, Department of Epidemiology & Preventive Medicine

& Prevention Research Unit, Department of Forensic Medicine, School of Public Health and

Preventive Medicine, Monash University

Department of Epidemiology & Preventive Medicine, The Alfred Centre,

& Department of Forensic Medicine, Victorian Institute of Forensic Medicine

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Victoria and Tasmania Dementia Training Study Centre

Dr Prateek Bandopadhyay

Mr. Jeremy Ley

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## **About the resource**

This education resource was developed by Professor Ibrahim to raise awareness of the important issues around limitation of care orders and cardiopulmonary resuscitation in persons with dementia, a sensitive and often contentious matter. People with dementia deserve the same opportunities as everyone else to be involved in making decisions about their treatment and lives and care should be exercised by others when presuming a certain quality of life for the person living with dementia.

The resource consists of:

- Context and background information
- An animated video presenting the issues and dilemmas
- Key questions for health educators to prompt discussion
- Key questions for people living with dementia and their family

The purpose of the resource is to raise awareness of the important and complex issues surrounding limitation of care orders and cardiopulmonary resuscitation in persons with dementia, a sensitive and often contentious matter.

The resource promotes a balanced and empathetic approach to decision-making in these circumstances which takes an individualised approach, recognising the complex legal, ethical and clinical issues.

The video is intended for viewing in a structured education session, ideally facilitated by a health educator who is able to explain, discuss and debate the key issues.

The resource is designed primarily for an audience of medical practitioners and other health professionals. The content may also be of interest to the general public to help inform their discussions with health professionals.

### **Important Note**

**This Resource Does Not Provide Medical Advice**

## Context and background

### Why this resource?

In the acute hospital setting, limitation of care orders, appear to be underused in patients with dementia. Limitation of care orders are intended to prevent unnecessary suffering and inappropriate use of healthcare resources when life-prolonging treatments are likely to be ineffective, harmful or are not in accordance with the patients' preferences. One form of these therapies, cardiopulmonary resuscitation, has been criticised for causing suffering with a low likelihood of benefit.

There is controversy and concerns from patients, families and the public about limitation of care orders. The effective use of limitation of care orders is one of the most difficult skills to master in clinical medicine. Although dementia is the fourth leading cause of death in high-income countries most limitation of care orders policies and guidelines do not specifically consider what to do if a person has dementia.

The result of this, combined with limited discussion of death and dementia means we remain unprepared for these important decisions. Most persons living with dementia die of acute illness and many are hospitalised at the end of life. Dementia is under-recognised as a serious condition and patients with dementia have very poor outcomes following resuscitation<sup>1,2</sup>.

A person with dementia is often incorrectly assumed to lack the capacity to make decisions about limitation of care orders. This assumption occurs frequently and as a result, patients are denied information and participation in end-of-life care decision-making. Patients with mild-to-moderate dementia often retain the capacity for some clinical care decisions and should be given the opportunity to participate.

A balanced and empathetic approach to decision-making requires an individualised approach and recognition of the complex legal, ethical and clinical issues.

Another important aspect is that persons with dementia usually rate their quality of life more favourably than their caregivers. Medical practitioners also tend to underestimate quality of life in patients with dementia. The law does not permit clinicians to make treatment limitation decisions based on quality of life judgments. However, in practice these judgments do influence treatment. The recent UK High Court decision mandates that 'not for resuscitation must be discussed with patients or proxies unless compelling circumstances are demonstrated'<sup>3</sup>.

In Australia and throughout the Western world, systems and processes for obtaining and documenting limitation of care orders need improvement at the individual, organisational and societal level. One obvious area is to redress the current lack of information about dementia as a clinical condition in the training curricula of many medical specialties, and in limitation of care orders policy and guidelines.

A greater debate is required around the topic of 'who and how we determine the assessments of quality of life and treatment abatement decisions'. These are usually viewed in law and ethics as needing to be made only by the person concerned.

Does this approach need to be strengthened to prepare for a world with more people with

dementia? Or does it need to be challenged in a world with resource limitations?

## Using the resource

We recommend the resource be used within the context of a structured education session ideally facilitated by a health educator who is able to explain, discuss and debate the key issues.

Ideally the session should be structured as follows:

### 1. Introduction to the topic

An introduction to the topic - this should be tailored to the needs of the specific audience and considers their learning needs by providing background information about:

- Dementia (see [Alzheimer's Australia](#) website; [Dementia Training Study Centre](#) website)
- Use of 'not for resuscitation orders' in health care (see [Resuscitation Council UK](#) website)
- Shared decision-making (see [Australian Commission on Safety and Quality in Healthcare website](#))
- Pertinent laws that apply in the jurisdiction (for example in Victoria, Australia see the website of Office of the Public Advocate <http://www.publicadvocate.vic.gov.au/>)
- Advance Care Planning See [Palliative Care Australia's Advance Care Planning Resources](#) website

### 2. Animated video

Help Prof Joe decide what to do by [watching the video](#)

### 3. Facilitated discussion on the key issues

- We suggest a small group of about 7 to 10 people
- We suggest using the questions listed below to promote discussion
- This is a sensitive issue, and there is no single correct answer; each individual needs to decide with their medical practitioner and loved ones what they wish to choose. We raise the topic to highlight the need for a greater breadth and depth of discussion and we do not advocate a particular viewpoint on this topic.

## **Key questions for discussion by health educators and health professionals**

- What would you do in this situation? Why?
- How do we determine a person's quality of life? How would you describe your own quality of life and what factors would inform this assessment? Is this a fair approach?
- How do we determine an intervention is clinically justified? Is this a reasonable approach?
- How do we ascertain a patient's preference? Are you confident this reflects their true wishes?
- What could we do better to prepare for this situation? As an individual, as a profession, as a community?
- How would you determine who has authority to make these decisions on behalf of a patient who is unable to do so for themselves?
- Who could you refer a patient to for further assistance around Advance Care Plans, Powers of Attorney and Guardianship and information and support about dementia? [Alzheimer's Australia Vic.](#) for information about dementia, counselling and support, assistance to consider legal, financial and ACP planning.

## **Questions for people living with dementia and their family or carers**

Whilst the resource is designed primarily for an audience of medical practitioners and other health professionals we acknowledge the content may also be of interest to the general public. We would advise these viewers to identify the questions of concern to them to then discuss these with their general practitioner or an allied health professional. [Alzheimer's Australia](#) in all Australian States and Territories have professional staff and counsellors who can assist people living with dementia and their family or carers to discuss these kinds of issues and consider planning ahead for such circumstances.

Some questions the video may raise are:

- Why do you think people avoid discussing this topic?
- What would you want to happen if you or a loved one was in this situation? Why?
- What information would you need to help in making a decision? Explain.
- What could we do better to prepare for this situation? As an individual and as a community?
- Write a list of questions that you want answered?

- Keep this list with you and ask your general practitioner or other health professional at your next visit.

## References

1. Morrison RS, Siu AL. Survival in end-stage dementia following acute illness. JAMA: The Journal Of The American Medical Association. 2000;284(1):47-52.
2. Sachs GA, Shega JW, Cox-Hayley D. Barriers to excellent end-of-life care for patients with dementia. 2004;19(10):1057-63.
3. Royal Courts of Justice, UK. The Queen on the application of David Tracey (Personally and on behalf of the Estate of Janet Tracey- Deceased) 2014. Accessed August 2014 from <http://www.judiciary.gov.uk/wp-content/uploads/2014/06/tracey-approved.pdf>

## Useful resources

[Alzheimer's Australia](#)

[Australian Commission on Safety and Quality in Healthcare](#)

[Australian Resuscitation Council](#)

[Palliative Care Australia](#)

Pertinent laws that apply in the jurisdiction (for example in Victoria, Australia see the website of Office of the Public Advocate)

Your Professional College or organisation

## Contacts

**Professor Joseph E Ibrahim**

Tel: 0407 760 087

Email: [joseph.ibrahim@monash.edu](mailto:joseph.ibrahim@monash.edu)

**Dr Margaret Winbolt**

Director Victoria and Tasmania Dementia Training Study Centre

Tel: (03) 9479-5983

Email: [Margaret.winbolt@latrobe.edu.au](mailto:Margaret.winbolt@latrobe.edu.au)





**We value your feedback; questions for facilitators**

**Limitation of care orders: Making an informed choice**

Your role/position title		
Session/s participants were:	Doctors	<input type="checkbox"/>
	Nurses	<input type="checkbox"/>
	Allied Health Professionals	<input type="checkbox"/>
	Other	<input type="checkbox"/>
	Specify.....	
What worked well in the session/s?		
What changes would you make next time?		
What advice do you have for others who are facilitating a similar session?"		
Other comments		

**Thank you. Please email completed form to: [margaret.winbolt@latrobe.edu.au](mailto:margaret.winbolt@latrobe.edu.au)**

## We value your feedback; questions for health professionals

### Limitation of care orders: Making an informed choice

I am a:	Doctor	<input type="checkbox"/>
	Nurse	<input type="checkbox"/>
	Allied Health Professional	<input type="checkbox"/>
	Other	<input type="checkbox"/>
Specify.....		
My reason for attending the session was:		
What worked well in the session/s?		
What changes would you make next time?		
What advice do you have for others who are facilitating a similar session?"		
Other comments		

Thank you. Please return completed form to your session facilitator or email to:  
[margaret.winbolt@latrobe.edu.au](mailto:margaret.winbolt@latrobe.edu.au)