



Limitation of care orders: Making an informed choice

▷ An education resource for health professionals



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The entire contents of this resource are intended for information purposes only. We want to promote a broader understanding and knowledge of complex health care topics. We do not intend this to be a substitute for professional medical advice. Always seek the advice of your medical practitioner or other qualified health care professional with any questions or concerns you may have. Never disregard professional medical advice or delay in seeking it because of something you have read in this resource

Important note

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

The information in the film and this guide does not constitute medical advice.

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Authorship

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Acknowledgements

Dementia Training Australia

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Mr. Jeremy Ley

This education resource was developed by Professor Joseph E Ibrahim to raise awareness of the important issues surrounding limitation of care orders and cardiopulmonary resuscitation in persons with dementia. It is a sensitive and often contentious matter.

People with dementia deserve the same opportunities as everyone else. This includes to be involved in making decisions about their life and any treatment. 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 film 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 film 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

Fast facts in Australia

- 500,000 people live with dementia
- 1,500,000 people involved in their care
- Dementia is the second most common cause of death
- People with dementia have very poor outcomes following cardiopulmonary resuscitation
- A person with dementia is often incorrectly assumed to lack the capacity to make their own decisions

Why this resource?

It is curious that not so long ago, everyone was marvelling at the advances in medical science leading to a universal requirement or expectation to provide cardiopulmonary resuscitation.

This was the 1970's, a time when Intensive Care and Coronary Care Units were becoming widely established. Twenty years later, in the 1990s, we recognised that sometimes interventions could be futile and that setting limits around life-sustaining therapy was a reasonable concept. Another twenty years on, in the 2010's we see models of shared decision-making with patients and residents, the introduction of advance care planning and National Standards for acute care hospitals to ensure goals-of-care are identified

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 a patient's preferences. One form of these therapies, cardiopulmonary resuscitation, has been criticised for causing suffering with a low likelihood of benefit. *While the term 'limitations of care' is commonly used it often projects the notion 'that care is being limited' rather than the intent which is that non-beneficial or harmful treatments are being avoided.*

There is controversy and concerns from patients, families and the public about limitation of care orders. The effective use of limitation of care orders in clinical medicine is a difficult skill to master. 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. In Australia, dementia is now the overall second

leading cause of death (2017) the most common cause of death for women and the third most common cause for men.

The results of this combined with patchy discussions around death and dementia means clinicians remain unprepared for these important decisions. Most persons living with dementia die of an 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^{1,2}.

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'³.

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 assessments of quality of life and treatment abatement decisions are made'. In the fields of law and ethics these decisions are usually viewed being made by the person concerned only. This view is not always possible to adhere to when involving persons with dementia.

The approach to end of life care and decisions around limitations of care need to be debated and clarified to prepare for a world with many more people living with dementia.

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 Dementia Australia website(<https://www.dementia.org.au/>) and the Dementia Training Australia (<https://www.dta.com.au/>) website)
- Use of ‘not for resuscitation orders’ in health care (see Resuscitation Council United Kingdom website <https://www.resus.org.uk/dnacpr/>)
- Shared decision-making (see Australian Commission on Safety and Quality in Healthcare <https://www.safetyandquality.gov.au/our-work/partnering-consumers/shared-decision-making>)
- 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 Australia* is a national program that provides information and resources to individuals, care workers and healthcare professionals on this subject. (<https://www.advancecareplanning.org.au/>)
- There are additional fact sheets specifically for people with dementia: <https://www.advancecareplanning.org.au/for-health-and-care-workers/in-various-settings/advance-care-planning-in-dementia>

2. Animated film

Help Prof Joe decide what to do, by [watching the film](https://www.youtube.com/watch?v=tOaEt5WJGkM&feature=youtu.be) (<https://www.youtube.com/watch?v=tOaEt5WJGkM&feature=youtu.be>)

Prof Joe wants your help. He's sitting having a tea when the medical emergency code sounds - a patient has collapsed in the hallway... his patient! Prof rushes to the scene to find that the person who has collapsed is Mr Rupert Jones, a man with dementia. The ICU doctor wants to know how advanced Mr Jones' dementia is and whether or not they should stand down the medical emergency code. Should they attempt to resuscitate Mr Jones?

3. Facilitated discussion on the key issues

- We suggest small groups comprising of 7 to 12 people being the ideal size
- Quiet room
- Round table discussion or set-up the room in a U-shape with facilitator at the top of the 'U'
- We suggest promoting discussion using the questions listed below
- 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?
- For information about dementia, counselling and support, assistance to consider legal, financial and Advance Care Planning.

<https://www.dementia.org.au/services/programs>

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.

Dementia Australia (<https://www.dementia.org.au/>) 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 film may raise:

- 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. *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>

This examines a case where a patient was not informed of a medical practitioners' clinical decision not to attempt to resuscitate. The court determined there was a duty on the doctor to consult with the patient about whether or not to treat.

4. Ibrahim JE., Davis MC., Availability of education and training for medical specialists about the impact of dementia on comorbid disease management. *Educational Gerontology* 2013 39 (12):925-941.

The dementia-related content of specialist medical training curricula and dementia-related information published in high-impact medical journals between 2000–2012 was reviewed. Dementia-related education was found to be absent from the training curricula for 14 of the medical specialties within Australia. And less than 0.10% (1,921 articles) of the more than two million articles published in the 138 journals assessed were dementia related.

5. Ehlenbach WJ, Barnato AE, Curtis JR, Kreuter W, Koepsell TD, Deyo RA, Stapleton RD. Epidemiologic study of in-hospital cardiopulmonary resuscitation in the elderly. *N Engl J Med.* 2009. 361(1):22-31

This very large study from the United States of America examined patients from 1992 through 2005 who underwent in-hospital CPR. The researchers identified 433,985 patients who had CPR in-hospital and found 18.3% survived to discharge. What is surprising is the rate of survival did not change over the years. Survival was lower among those who were male, older, with more coexisting illnesses, or were admitted from a skilled-nursing facility.

Useful resources

- Dementia Australia: <https://www.dementia.org.au/>
- Australian Commission on Safety and Quality in Healthcare. Information on shared decision making is available at <https://www.safetyandquality.gov.au/our-work/partnering-consumers/shared-decision-making>
- Australian Resuscitation Council: <https://resus.org.au/>
A short film promoting the importance of cardiopulmonary resuscitation (CPR) in the community featuring the actor Richard Roxburgh is available at Information <https://resus.org.au/shock-verdict/>
- Palliative Care Australia: <https://palliativecare.org.au/>
- Pertinent laws around medical care differ between states and territories in Australia. Important to identify those that apply in the jurisdiction this resource is being used. For example, in Victoria, Australia, it is the Office of the Public Advocate: <https://www.publicadvocate.vic.gov.au/>
 - Information about medical decisions is available at <https://www.publicadvocate.vic.gov.au/medical-consent>
This section provides useful information about medical decisions when an adult patient cannot consent. The Medical Treatment Planning and Decisions Act 2016 allows people to complete an advance care directive, appoint a medical treatment decision maker and appoint a support person. The Act also sets out the process for health practitioners when a patient does not have decision-making capacity to consent to medical treatment. Flow chart available at <https://www.publicadvocate.vic.gov.au/our-services/publications-forms/medical-consent/flowchart-1/341-can-your-adult-patient-consent-flowchart>
- Professional Medical or Health Professional Colleges
- Department of Health, Western Australia. Advance CPR decision-making in the hospital setting Teaching Resource. Perth: WA Cancer & Palliative Care Network, Department of Health, Western Australia 2015
https://ww2.health.wa.gov.au/~/_media/Files/Corporate/general%20documents/Palliative/CPR%20decision%20making/12862-advanced-cpr-decision-making.pdf

Useful resources from our team

1. Ibrahim JE, MacPhail A, Winbolt M, Grano P. Limitations of care orders in patients with a diagnosis of dementia. *Resuscitation*: 2016 Jan;98:118-24.
doi: 10.1016/j.resuscitation.2015.03.014. Epub 2015 Mar 26.
This is a comprehensive article discussing the issues of limitation of care orders in patients with dementia. It describes the need for systems and processes for obtaining and documenting LCO to be improved at the individual, organisational and societal level. The issue is controversial amongst the public and poorly understood by clinicians. Balanced and empathetic decision-making requires an individualised approach and recognition of the complexities (legal, ethical and clinical) of this issue. The article examines the domains of: (a) treatment effectiveness, (b) burden of care and quality of life and (c) patient autonomy and capacity.
2. Residential Aged Care Communique Vol 9 Iss 4 and Supplements Dec 2014
This periodical presents cases investigated by the coroner and these two issues cover the complex topics, goals-of-care and end-of-life in Residential Aged Care Services. Together with the supplement four cases, four commentaries and a detailed list of resources are presented. The cases highlight different aspects of care at the end-of-life and some of the challenges around discussing these matters. The expert commentaries cover a range of experiences. Three of the commentaries are written by medical practitioners, two are specialists in palliative care, one is a general practitioner and the final commentary is from a nurse academic in aged care.
3. Lovell JJ., MacPhail A., Cunningham N., Winbolt M., Young C., Pham T., Ibrahim JE., Junior doctors and limitation-of-care orders: perspectives, experiences and the challenge of dealing with persons with dementia. *European Journal for Person Centered Healthcare* 2017 Vol 5 Issue 3 pp 373-388.
This article highlights that junior doctors were frequently involved in discussion and decision-making around treatment limitations and end-of-life care. It identified that junior doctors described inconsistent support, a lack of preparedness, a vague understanding of related hospital policies and inadequate knowledge and experience when it came to completing the limitation-of-care orders. Most acknowledged the additional nuances of capacity and prognosis assessment for patients with dementia, they did not feel that the processes for completing limitation-of-care orders were significantly different for these persons. Many also recognised that decisions were often made without adequate consultation with the relevant stakeholders in this patient group.
4. Ibrahim JE, Anderson LJ, MacPhail A, Lovell JJ, Davis MC, Winbolt M: Chronic disease self-management support for persons with dementia, in a clinical setting. *Journal of Multidisciplinary Healthcare* 01/2017; Volume 10:49-58,
DOI:10.2147/JMDH.S121626
A framework is presented that describes how impairment in cognitive domains (attention and information processing, language, visuospatial ability and praxis, learning and memory and executive function) impacts on the five key processes of chronic disease self-management.
Patients with dementia require individually tailored strategies that accommodate and adjust to the individual and the cognitive domains that are impaired, to optimize their capacity for self-management. Management strategies for clinicians to counter poor self-management due to differentially impaired cognitive domains are also detailed in the presented framework. Clinicians should work in collaboration with patients and care givers to assess a patient's current capabilities, identify potential barriers to successful self-management and make efforts to adjust the provision of information according to the patient's skill set.

5. Yoong J, MacPhail A, Trytel G, Rajendram P, Winbolt M, Ibrahim JE: Completion of Limitation of Medical Treatment forms by junior doctors for patients with dementia: clinical, medicolegal and education perspectives. *Australian Health Review*:.10/2016; DOI:10.1071/AH16116
Current policy and practice are not at the desired level to deliver appropriate end-of-life care with regard to Limitation of Medical Treatment (LMT) orders, especially for patients with dementia. Greater involvement of executives and senior clinicians is required to improve both practice at the bed side and the training and support of junior doctors, as well as creating more robust policy.

Contacts

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We value your feedback; session evaluation questions for facilitators

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Limitation of care orders: Making an informed choice

Facilitator Feedback

Name:		Usual role:	
Estimated number of participants:			
Type of participants (<i>estimate numbers</i>)			
Medical practitioner		Allied Health Professional	
Medical practitioner in training		Educator and trainer	
Registered nurse		Manager	
Enrolled nurse		<i>Other</i>	
The NFR film was well received during this session?			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly agree	Agree	Unsure	Disagree Strongly disagree
The resources in this guide provided sufficient content to address participants questions?			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly agree	Agree	Unsure	Disagree Strongly disagree
Would you recommend this film and resource guide to other colleagues?			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Definitely YES	Probably YES	Unsure	Probably NO Definitely NO
What worked well in facilitating this session?			
What aspects of this session could be improved? <i>Consider location, duration, setting, information given to participants prior to session etc</i>			
What advice do you have for others who are facilitating a similar session?			
Any other comments			
Thank you			

Please return completed form to your session facilitator or email to:

margaret.winbolt@latrobe.edu.au

We value your feedback; session evaluation questions for participating health professionals

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Limitation of care orders making an informed choice: evaluation of session

Participant Feedback

I am a:	<input type="checkbox"/> Medical practitioner <input type="checkbox"/> Medical practitioner in training <input type="checkbox"/> Registered nurse <input type="checkbox"/> Enrolled nurse	<input type="checkbox"/> Allied Health Professional <input type="checkbox"/> Educator and trainer <input type="checkbox"/> Manager <input type="checkbox"/> <i>Other</i> _____		
This session raised issues that I would not otherwise be aware?				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly agree	Agree	Unsure	Disagree	Strongly disagree
This session provided an opportunity to review & reflect on your practice?				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly agree	Agree	Unsure	Disagree	Strongly disagree
Would you recommend this workshop to colleagues?				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Definitely YES	Probably YES	Unsure	Probably NO	Definitely NO
Overall I was satisfied with the quality of this session?				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very interesting	Interesting	Average	Poor	Very Poor
My reason for attending the session:				
What were the best aspects of this session?				
What aspects of this session could be improved?				
Any other comments				
Thank you				

Please return completed form to your session facilitator or email to:

margaret.winbolt@latrobe.edu.au