JCECC: End-of-Life Care in RCHE

Professional Seminar on End-of-Life Care in Advanced Dementia

Advances in Advance Care Planning with Dementia Patients and Carers

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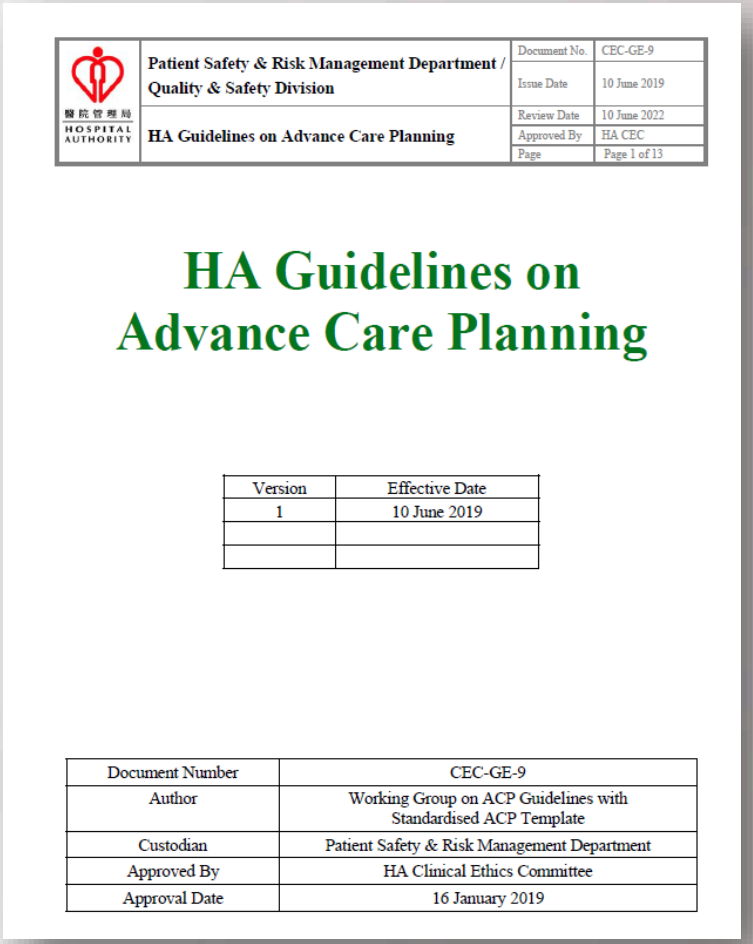
Advance Care Planning (ACP)

ACP is an overarching process of **proactive communication** regarding **end-of-life care**. Through this process of communication, a **patient with advanced progressive disease**, his/her **health care providers**, and his/her **family members** and **caregivers** can consider ahead of time **what kind of care is appropriate** when the patient can no longer make a decision.



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HA Guidelines on Advance Care Planning

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1	10 June 2019

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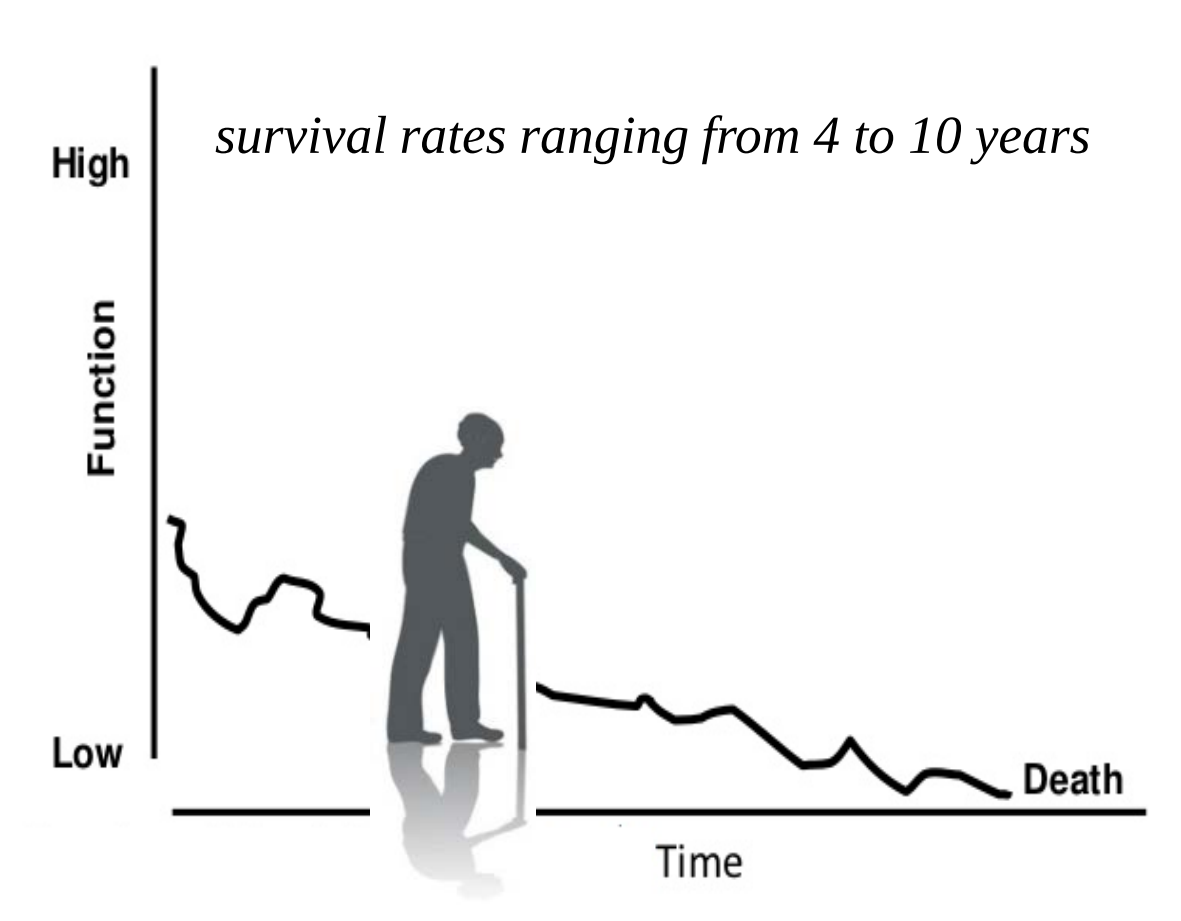
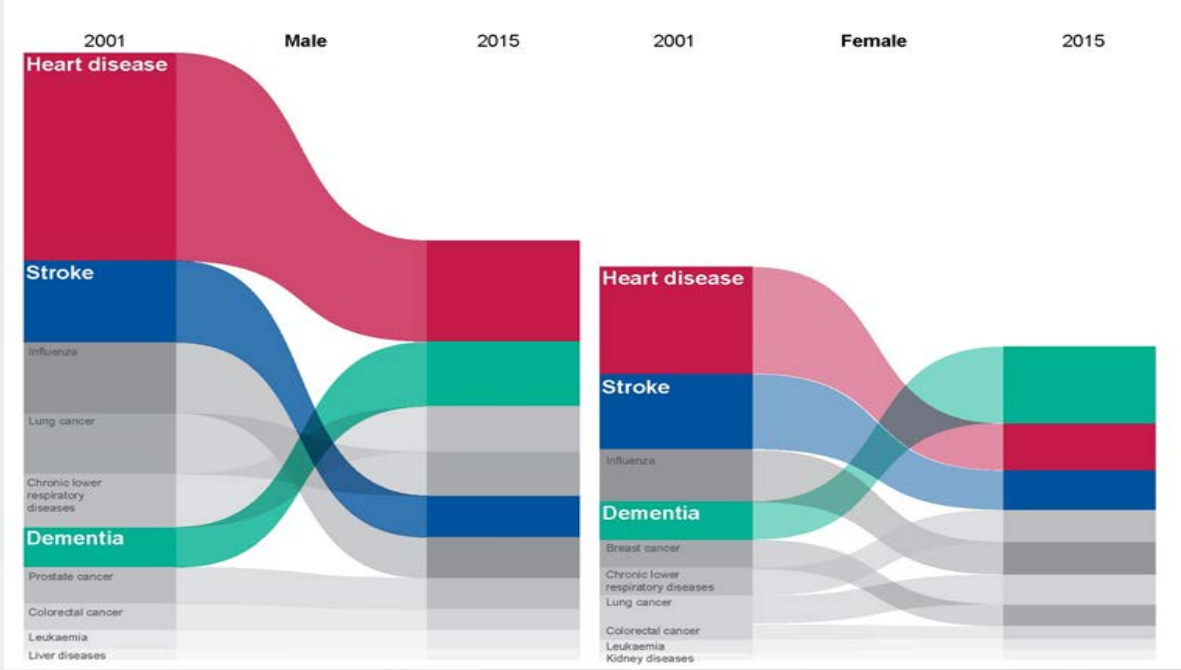
Approved By	HA Clinical Ethics Committee
Approval Date	16 January 2019

Relevance to Dementia



survival rates ranging from 4 to 10 years

ALZHEIMER'S DISEASE IS THE 6TH LEADING CAUSE OF DEATH IN THE UNITED STATES



(Health Profile for England, 2017)

End-of-life care for dementia

TOO MUCH intervention with little benefit (tube feeding and laboratory tests, use of restraint and IV medication)

TOO LITTLE (poor pain control, dehydration and malnutrition, emotional and social neglect, absence of spiritual care and support for family caregivers)

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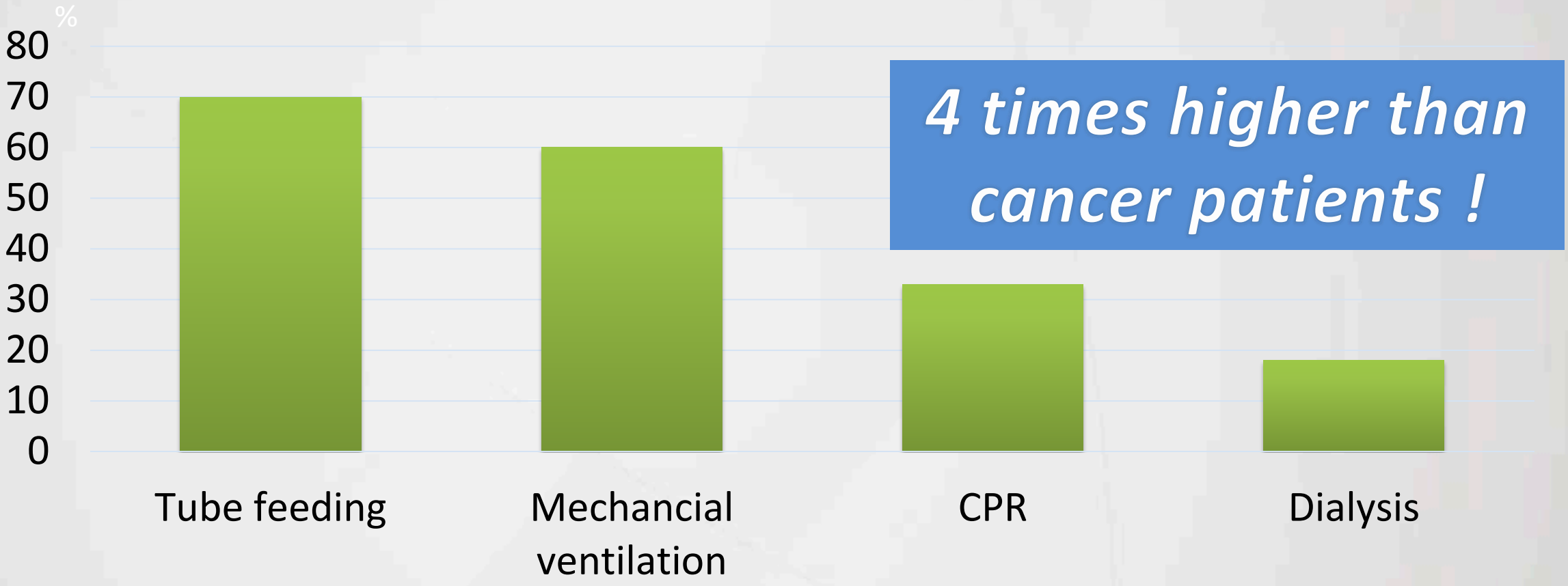
World Health Organization (2011). Palliative care for older people.

Use of life-sustaining treatment in advanced dementia in Taiwan



(Geriatrics & Gerontology International)

Challenges of ACP for persons with dementia

- Lack of knowledge about dementia/ACP
- Questionable mental capacity
- Organizational barriers
- Lack of training/skills

(Yeung & Chan)

Recommendations

Piers et al. BMC Palliative Care (2018) 17:88
https://doi.org/10.1186/s12904-018-0332-2

BMC Palliative Care

RESEARCH ARTICLE Open Access

Advance care planning in dementia: recommendations for healthcare professionals

Ruth Piers[1,2], Gwenda Albers[3], Joni Gilissen[2,9*], Jan De Lepeleire[4], Jan Steyaert[5,6], Wouter Van Mechelen[4], Els Steeman[7], Let Dillen[8], Paul Vanden Berghe[3] and Lieve Van den Block[2,9*]

1. Initiation of ACP,
2. Evaluation of mental capacity,
3. Holding ACP conversations,
4. The role and importance of those close to the person with dementia,
5. ACP when it is difficult or no longer possible to communicate verbally,
6. Documentation of wishes and preferences, including information transfer,
7. End-of-life decision-making &
8. Preconditions for optimal implementation

1. Initiation of ACP

- Start ACP as early as possible and integrate ACP into the daily care of people living with dementia.
- Key moments
  - Period around diagnosis;
  - While discussing the overall general care plan; and/or
  - when changes occur in health status, place of residence or financial situation
- Be alert for triggers and opportunities to start ACP and make use of any opportunity to talk about ACP
- The healthcare professional should initiate ACP conversations if the person with dementia and/or those close to them do not do this themselves

2. Evaluation of mental capacity

- Always assume maximal mental capacity
- Consider mental capacity as a fluctuating rather than static condition
- Judge mental capacity task-specifically i.e. for a certain decision at a particular moment in time
- Always stay in contact with the person him/herself and ensure their maximum participation

2. Evaluation of mental capacity

- Assess mental capacity through formal clinical assessment:
  - where there is doubt or disagreement between healthcare professionals and/or family
  - when the decisions can have far-reaching consequences
  - preferably by a multidisciplinary or interdisciplinary team with experience in dementia

3. Performing ACP conversations

- Adjust conversation style and content to the person's level and rhythm
- Explore who the significant people in their life are and who can be involved in the ACP conversations
- Lead the conversation but do not force it to become too formulaic or phased
- Explore the person's disease awareness and their expectations, ideas and possible misconceptions concerning the disease trajectory
- Do not insist where someone lacks disease awareness or is reluctant to talk about ACP
- Held on several occasions and over a longer period of time

Who should be targeted to?

Chan, H.Y.L. & Pang, S.M.C. (2011). Readiness of Chinese frail old age home residents to end-of-life care decision making. Journal of Clinical Nursing, 20, 1454-1461.

Illness trajectory

EAPC ONLUS
European Association for Palliative Care
Non Governmental Organisation (NGO) recognised by the Council of Europe

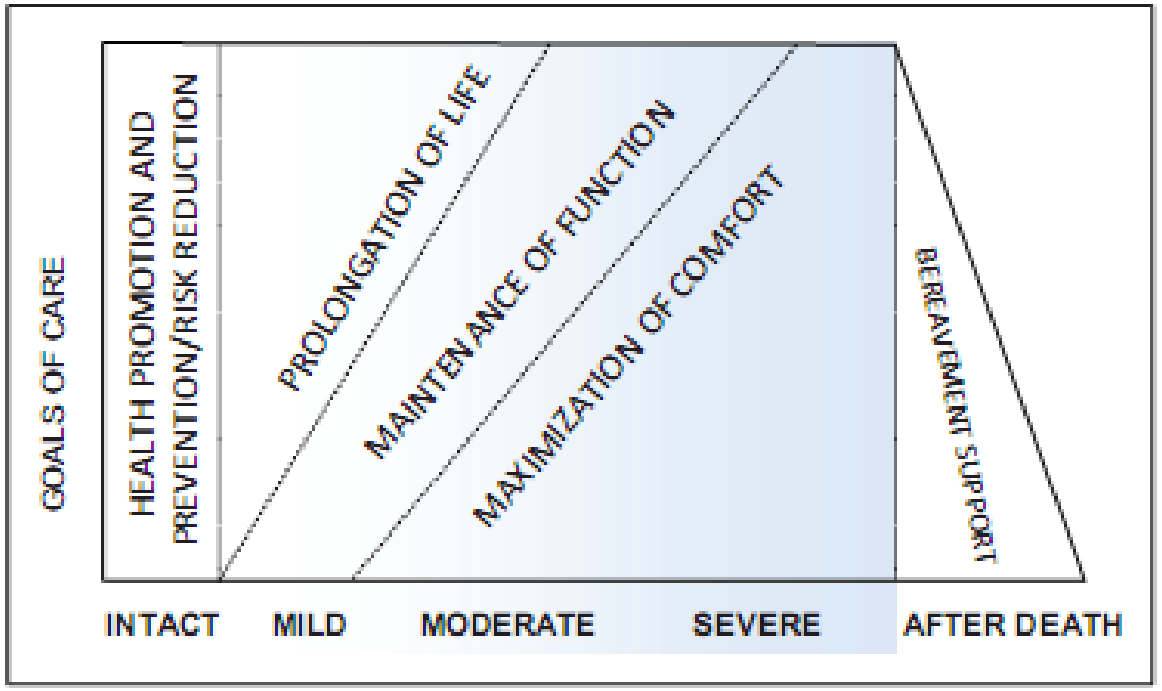
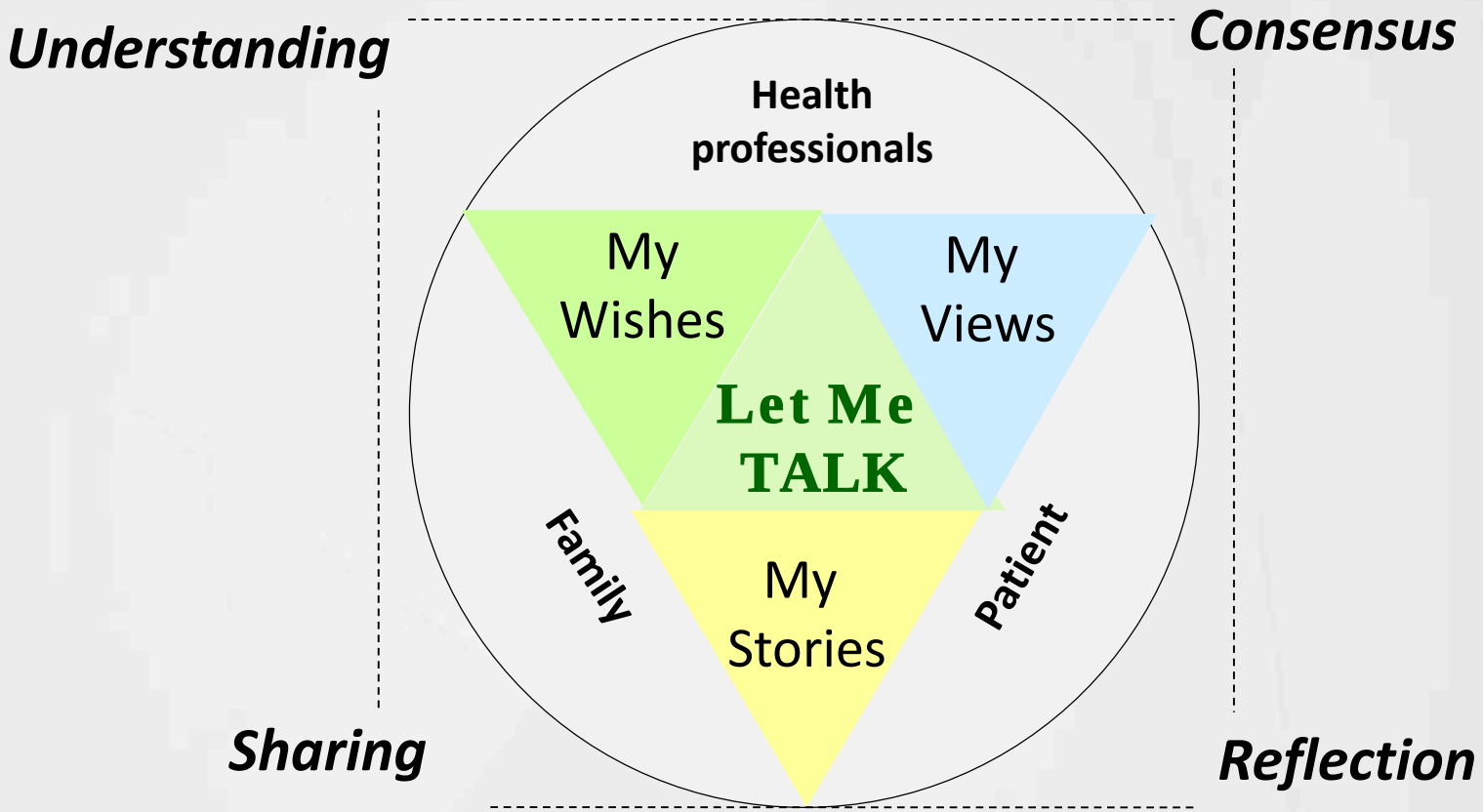


Figure 1. Dementia progression and suggested prioritizing of care goals.

3. Performing ACP conversations

- Cover several different topics such as the broader values of the person, their fears and concerns about the future and the end of life, their future care goals
- Try to understand the whole person living with dementia, explore their *life story, important values, norms, beliefs and preferences*
- Explore the person's current experiences; ask what is the perception of the person living with dementia of their quality of life?
- If possible and desirable, guide the person in formulating their care goals, specific wishes concerning EOL care
- Explore whether the person would like to have a written advance directive

Let Me Talk ACP programme



Chan HYL. Pang SMC. Let Me Talk – an advance care planning programme for frail nursing home residents. J Clini Nurs. 2010;19:3073-3084.

4. The role and importance of those close to them

- Involve family or significant others
- Inform them about the role of a surrogate decision-maker
- Evaluate their disease awareness
- Inform them about the expected disease trajectory and possible end-of-life decisions
- Pay attention to their perceptions during the ACP process

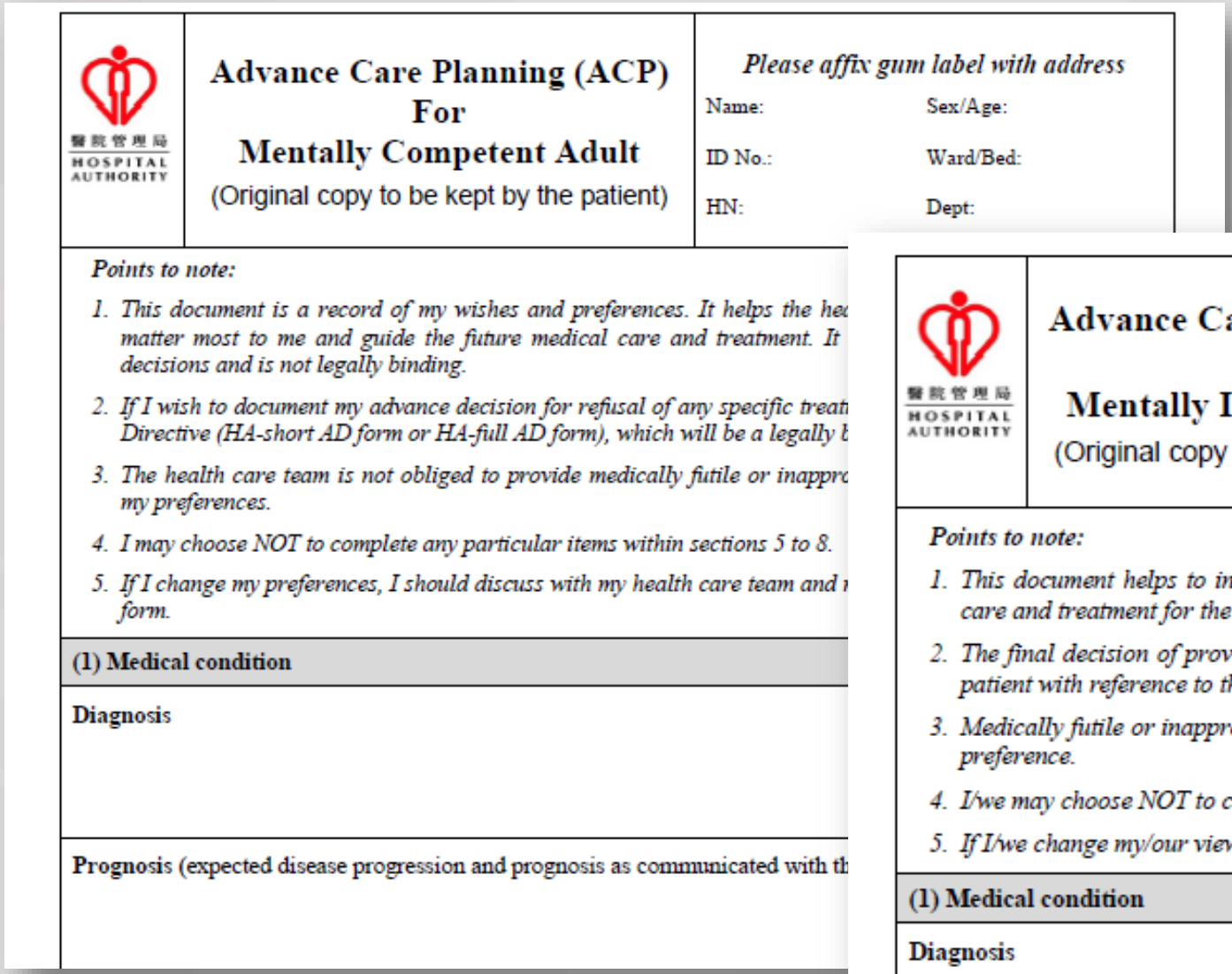
5. ACP when it is difficult or no longer possible to communicate verbally

- Keep connected with the person living with dementia and ensure their maximum participation
  - Respond to their emotions,
  - Attend to non-verbal communication and
  - Observe their behaviour to know more about their current quality of life, fears and desires

6. Documentation of wishes and preferences, including information transfer

- Write down in the medical/care files of the person with dementia
  - the outcomes of the ACP process,
  - their values, preferences and care goals, and
  - if applicable, the advance directive and legal representative
- Regularly re-evaluate as part of the ACP process
- Communicate the outcomes of the ACP process within the care team

HA ACP forms



醫院管理局
HOSPITAL AUTHORITY

Advance Care Planning (ACP)
For
Mentally Competent Adult
(Original copy to be kept by the patient)

Please affix gum label with address

Name: Sex/Age:

ID No.: Ward/Bed:

HN: Dept:

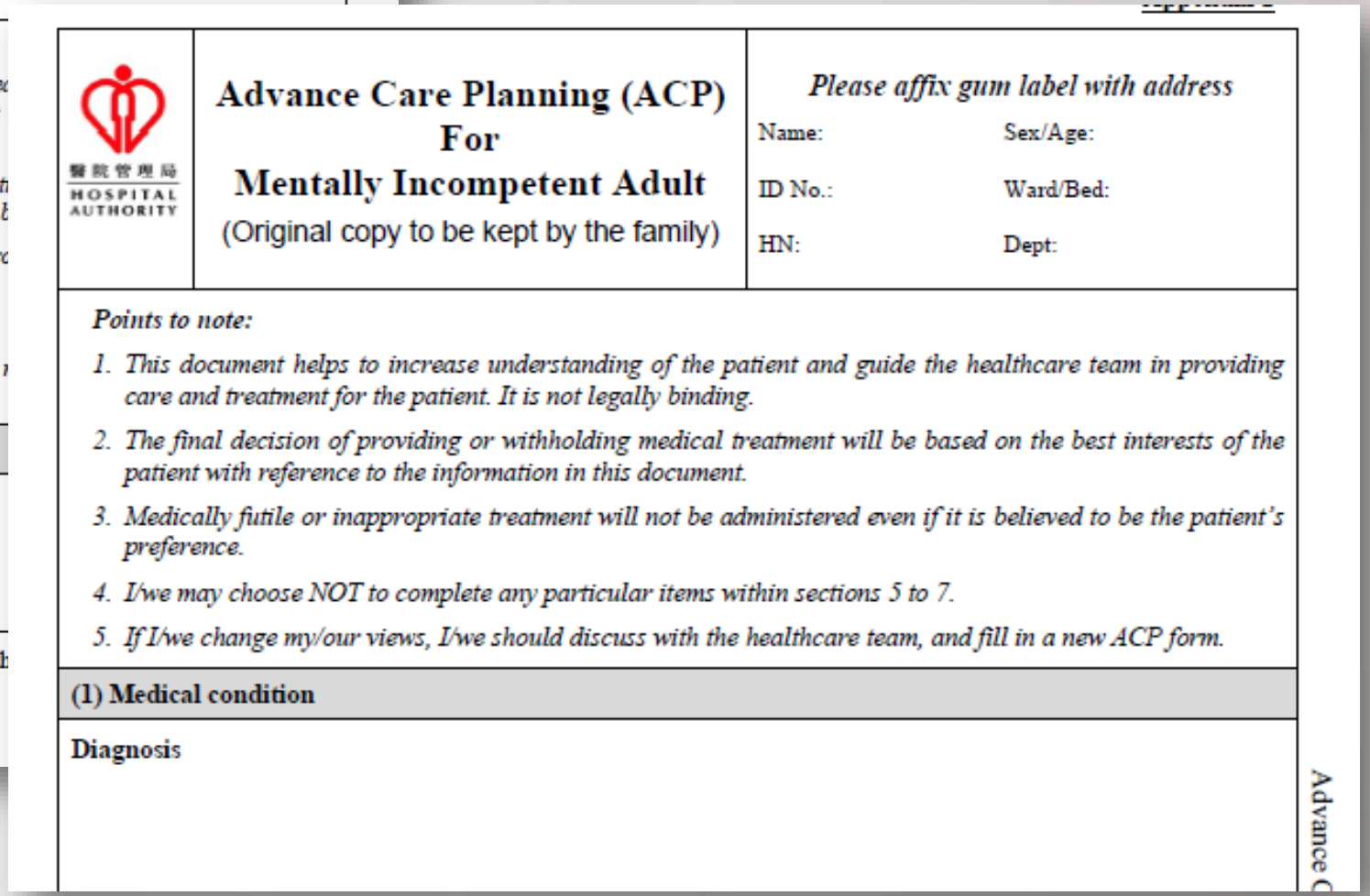
Points to note:

1. *This document is a record of my wishes and preferences. It helps the hea matter most to me and guide the future medical care and treatment. It decisions and is not legally binding.*
2. *If I wish to document my advance decision for refusal of any specific treat Directive (HA-short AD form or HA-full AD form), which will be a legally b*
3. *The health care team is not obliged to provide medically futile or inappro my preferences.*
4. *I may choose NOT to complete any particular items within sections 5 to 8.*
5. *If I change my preferences, I should discuss with my health care team and form.*

(1) Medical condition

Diagnosis

Prognosis (expected disease progression and prognosis as communicated with th



醫院管理局
HOSPITAL AUTHORITY

Advance Care Planning (ACP)
For
Mentally Incompetent Adult
(Original copy to be kept by the family)

Please affix gum label with address

Name: Sex/Age:

ID No.: Ward/Bed:

HN: Dept:

Points to note:

1. *This document helps to increase understanding of the patient and guide the healthcare team in providing care and treatment for the patient. It is not legally binding.*
2. *The final decision of providing or withholding medical treatment will be based on the best interests of the patient with reference to the information in this document.*
3. *Medically futile or inappropriate treatment will not be administered even if it is believed to be the patient's preference.*
4. *I/we may choose NOT to complete any particular items within sections 5 to 7.*
5. *If I/we change my/our views, I/we should discuss with the healthcare team, and fill in a new ACP form.*

(1) Medical condition

Diagnosis

Advance C

7. End-of-life decision-making

- Carefully weigh the wishes (expressed and/or written down earlier) against the current best interest of the person with dementia
- in consultation with those close to them and the healthcare professionals involved

8. Preconditions for optimal implementation of ACP

- Provide enough training opportunities for healthcare professionals to learn how to conduct ACP conversations
- Integrate ACP into the mission and policy of the organization and embed it in the organizational culture

Timing

4.2 The appropriate time for triggering the ACP discussion for patients with progressive disease depends on the state of the disease and the readiness of the patients. ACP is voluntary and should not be initiated simply as a routine procedure.

4.3 Discussions may be appropriately initiated in a range of situations including: [6]

- Following the diagnosis of a life limiting condition with a more rapid downhill course e.g. advanced cancer, motor neuron disease. It should be noted that some patients may not be ready to discuss ACP immediately after such a diagnosis. Thus, the approach should be individualized.
- Early cognitive decline in dementia
- Significant disease progression in terms of functional decline, biochemical parameters, symptom burden, deteriorating quality of life
- Discontinuation of disease targeted treatments
- Transition to palliative care
- Recovery from an acute severe episode of a chronic disease
- Following multiple hospital admissions
- Patient becomes institutionalized

Overseas experiences

DementiaUK

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You are here: Home / Understanding dementia / Information leaflets / Planning for the future / Planning now for your future – Advance Care Planning

Planning now for your future – Advance Care Planning

Content below is reflective of the PDF leaflet.

When you are thinking about your future care, it is important to discuss your wishes wi
family, friends and healthcare professionals.

Planning ahead will help those close to you, and healthcare professionals looking after
understand what is most important to you, when you may be unable to make your wis
preferences known.

What is an Advance Care Plan?

An Advance Care Plan helps you plan and record your decisions about future care. It wi
you identify your preferences about treatment and end of life care, to be considered ir
when you may not be able to communicate your wishes.

Planning now for your future – Advance

Alzheimer Society CANADA

About dementia | Living with dementia | We can help

Home > Living with dementia > Caring for someone > Dementia and end-of-life care > Advance care planning

Advance care planning

Advance care planning is the process of planning for a person's future health-care based on conversations about their values and beliefs. Developing a clear plan in advance can reduce family distress and help ensure that the person receives the end-of-life care that they want.

"The window of opportunity to include the person in end-of-life decisions is well before they are gone. I started having these discussions with my parents as they were aging and getting more frail. I asked, 'what would you like us to do?' I believe in being proactive because it helps in the end." – *Rachael Mierke, a caregiver in Winnipeg*

What should be discussed?

COGNITIVE DECLINE PARTNERSHIP CENTRE

UNDERSTAND EDUCATE ALZHEIMER'S AUSTRALIA FIGHTDEMENTIA.ORG.AU

Start2Talk

A QUICK GUIDE TO PLANNING AHEAD

Start2Talk is a website of Alzheimer's Australia. This Quick Guide – using material from the website – was developed by the Cognitive Decline Partnership Centre to assist all adults to plan ahead.

NHS England

My future wishes

Advance Care Planning (ACP) for people with dementia in all care settings

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Alzheimer's Society

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The Chinese University of Hong Kong

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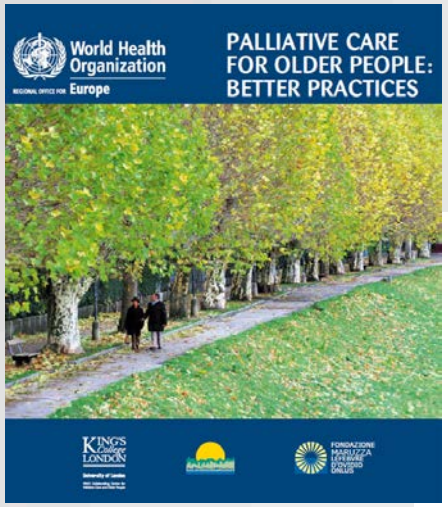
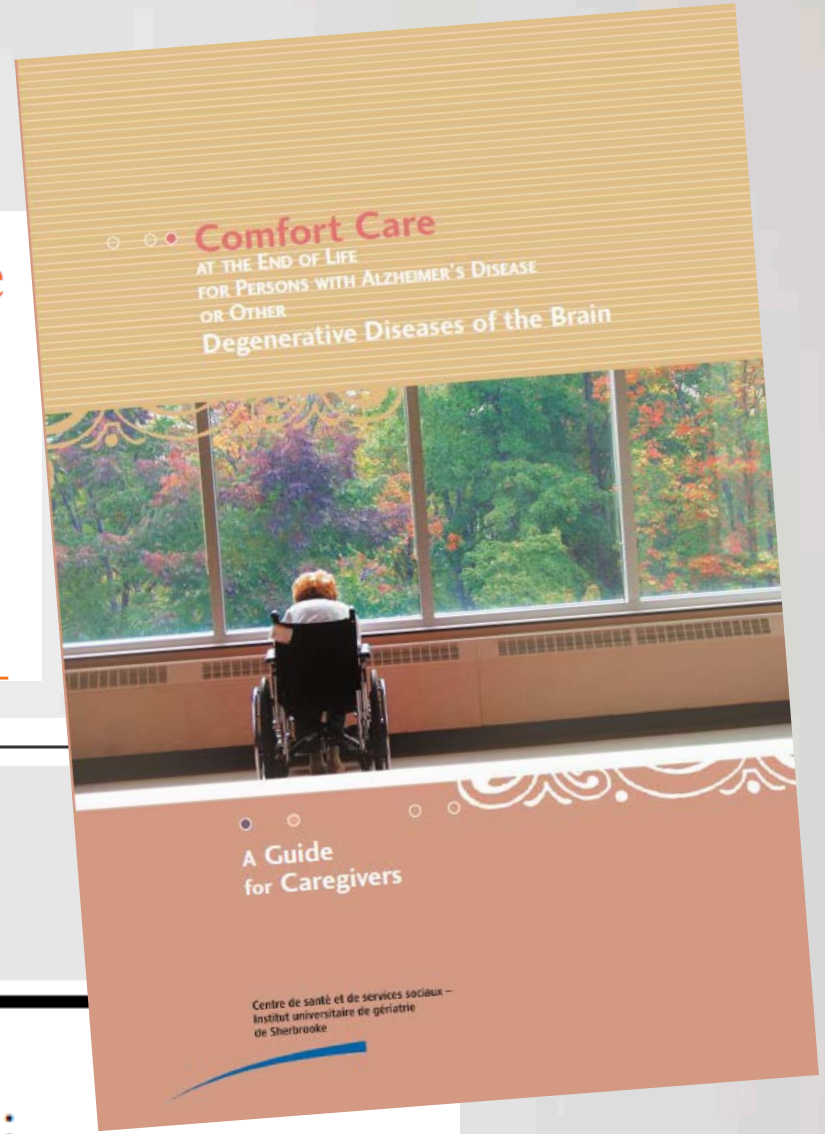


Educating families about end-of-life care in advanced dementia: acceptability of a Canadian family booklet to nurses from Canada, France, and Japan

Marcel Arcand, Kevin Brazil, Miharu Nakanishi, Taeko Nakashima, Michel Alix, Jean-François Desson, Rémy Morello, Louise Belzile, Marie Beaulieu, Cees MPM Hertogh, Franco Toscani, Jenny T van der Steen



ELSEVIER

JAMDA

journal homepage: www.jamda.com

Original Study

A Family Booklet About Comfort Care in Advanced Dementia: Three-Country Evaluation

My experiences

http://acpe.cuhk.edu.hk

UGC Research Grant Council 2018-19

- ACP for people with early dementia and their family member

Reviewer 1:

The project :

Scientific/scholarly merit	Excellent ◉
Duration Proposed	Too Long ○
Impact of Research	High ◉

The principal investigator :

Ability to undertake the proposal	Excellent ◉
Track record in field	Excellent ◉

Reviewer 2:

The project :

Scientific/scholarly merit	Excellent ○	Very Good ○	Good ◉
Duration Proposed	Too Long ○	Appropriate ◉	Too Short ○
Impact of Research	High ○	Moderate ○	Low ◉

The principal investigator :

Ability to undertake the proposal	Excellent ◉	Very Good	Good
Track record in field	Excellent ◉		

REJECTED

- *"The participants are to have been diagnosed as early-onset dementia patients; they may not be demented as we know it - they may have a reversible delirium."*
- *"Forward-planning people, the type who make long-term plans, are using anticipation; they have a highly internal locus of control. Many will not have this way of adapting."*

"This may not be a very importa… problem. Demented people have their control taken from them over time as a matter of course. High-level health care interventions are not often thought of as appropriate for, say, an Alzheimer's patient who is nearing the end of life."

Review Panel:

Potential Research Impact Comment:

The proposed project addresses a very important but neglected ageing research topic and has the potential to advance knowledge and influence policy and practice.

How to move forward?

- Can we be more proactive?

Raise public awareness

Bottom-up approach

- Can we collaborate?

- Can we provide evidence on the effects of ACP on persons with dementia and their family carers?

Research

Thank you!

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