ACT Government | Canberra Health Services

Clare Holland House

Insights into Improving Palliative Care in Hospitals and Residential Aged Care

…and how ELDAC can help!

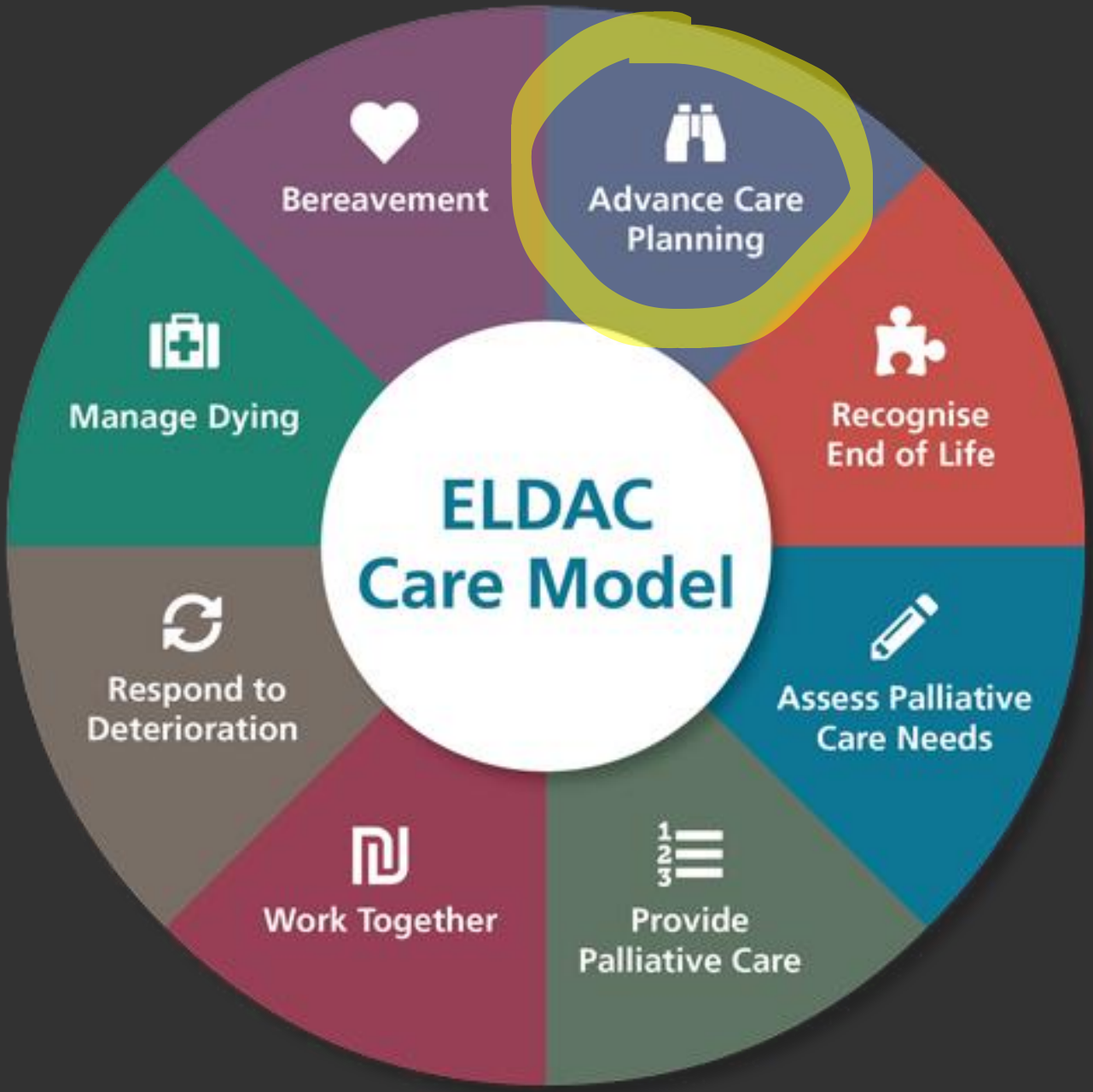
Peter Jenkin
Nurse Practitioner
Clare Holland House
Canberra ACT

ACT Government | Canberra Health Services

Clare Holland House

or...
Advance Care Planning,
Are we barking up the wrong tree?

Peter Jenkin
Nurse Practitioner
Clare Holland House
Canberra ACT


Bereavement
Advance Care Planning
Recognise End of Life
Assess Palliative Care Needs
Provide Palliative Care
Work Together
Respond to Deterioration
Manage Dying
ELDAC Care Model

Advance Care Planning

Advance care planning is the process of planning for your current and future health care.

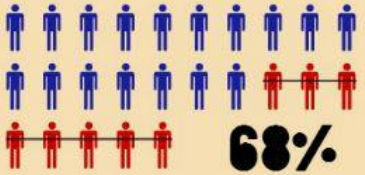
It involves **talking about your values, beliefs and preferences** with your loved ones and doctors. This helps them make decisions about your care when you can't.

People **may also formalise their plan with an advance care directive**.

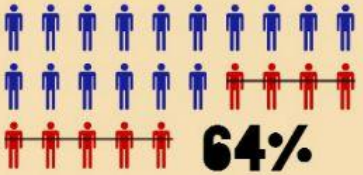
https://www.huffpost.com/entry/how-hospitals-kill-our-loved-ones-and-conceal-it_b_58cbd60fe4b07112b6472c7d

CPR SURVIVAL RATES: ON SCREEN VS. REAL LIFE

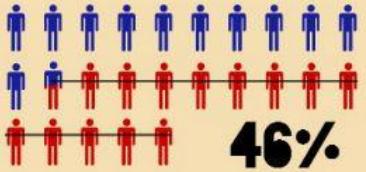
ER



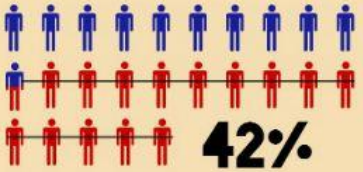
CHICAGO HOPE



GREY'S ANATOMY



CASUALTY



IN REAL LIFE...

12%

IN THE REAL WORLD, CPR SAVES JUST ONE IN EIGHT HOSPITAL PATIENTS.

White Coat, Black Art with Dr. Brian Goldman

Piktochart make information beautiful

“For every complex problem there is an answer that is clear, simple, and wrong."

H.L.Mencken

JOURNAL OF PALLIATIVE MEDICINE
Volume XX, Number XX, 2020

DOI: 10.1089/jpm.2020.0272

Advance Directives/Care Planning: Clear, Simple, and Wrong

"For

I HAVE BEEN THINKING a
prophetic words of the earl
satirist, H.L. Mencken, in the
19 pandemic.[1] As I read W
"Impact of Advance Directiv
in Elderly Trauma Patients" i
liative Medicine, I could not
biting satire again—quoted at
again, 30 years after the Patie
1991, we have a report that do
of adults (this time trauma pat

VIEWPOINT

R. Sean Morrison, MD
Brookdale Department of Geriatrics and Palliative Medicine, Icahn School of Medicine at Mount Sinai, New York, New York; and James J. Peters VA Medical Center, Bronx, New York.

Diane E. Meier, MD
Brookdale Department of Geriatrics and Palliative Medicine, Icahn School of Medicine at Mount Sinai, New York, New York.

Robert M. Arnold, MD
Section of Palliative Care and Medical Ethics, University of Pittsburgh Medical Center, Pittsburgh, Pennsylvania.

What's Wrong With Advance Care Planning?

Advance care planning (ACP) has emerged during the last 30 years as a potential response to the problem of low-value end-of-life care. The assumption that ACP will result in goal-concordant end-of-life care led to widespread public initiatives promoting its use, physician reimbursement for ACP discussions, and use as a quality measure by the Centers for Medicare & Medicaid Services, commercial payers, and others. However, the scientific data do not support this assumption. ACP does not improve end-of-life care, nor does its documentation serve as a reliable and valid quality indicator of an end-of-life discussion.

What Is ACP?

The purpose of ACP is to ensure goal-concordant care near the end of life for patients who lack decisional capacity. It is a process to support adults in understanding and sharing their values, goals, and preferences regarding future potential medical care decisions; choosing and preparing a trusted person(s) to make medical decisions; and documenting these wishes so that they can be acted on when future medical decisions need to be made. Most approaches to ACP encourage all adults to participate in the process regardless of their health status. Advance care planning goal-concordant care or patient quality of life. Additionally, these reviews found no association of ACP with subsequent health care use, including emergency department visits, hospitalizations, and critical care. Subsequently, 5 large multisite randomized clinical trials that enrolled patients with cancer (1117 patients at 23 hospital cancer centers),[3] nursing home residents (12 479 residents from 360 nursing homes),[4] older adults in primary care (759 patients from 8 primary care practices),[5] adults with serious illness (515 patients from 20 outpatient clinics),[6] and patients with heart failure (282 patients from 2 heart failure centers)[7] could not identify meaningful differences in health care use, patient quality of life, or goal-concordant care between those randomly assigned to receive either ACP or usual care.

Why Does ACP Not Achieve Its Desired Outcomes?

The inability of ACP to achieve its desired outcomes represents the gap between hypothetical scenarios and the decision-making process in clinical practice settings. The success of ACP depends on 8 steps: (1) patients can articulate their values and goals and identify which treatments would align with those goals in hypothetical future scenarios; (2) clinicians can elicit these values and preferences; (3) preferences are documented; (4) directives or surro-
gates are available to guide clinical deci-

Advance Care Planning Australia

Advance care planning involves planning for your future health care. It enables you to make some decisions now about the health care you would or would not like to receive if you were to become seriously ill and unable to communicate your preferences or make treatment decisions.

Advance care planning helps to ensure your loved ones and health providers know what matters most to you and respect your treatment preferences.

Advance Care Planning Australia™ is funded by the Australian Government.

Learn more about advance care planning

National Advance Care Planning Support Service

For free advice or to request a printed starter pack, call us on 1300 208 582 from 9am - 5pm (AEST/AEDT) Monday to Friday. You can also refer a patient or client to the Support Service.

Contact us

Advance Care Planning Improvement (ACPI) Toolkit

The ACPI Toolkit provides health and aged care services with resources to support organisational advance care planning uptake, performance monitoring, and quality improvement.

Find out more

Prevalence of advance care planning documentation in Australian health and residential aged care services

2020

Advance Care Planning Australia

BE OPEN | BE READY | BE HEARD

Buck K, Detering KM, Sellars M, Sinclair C, White B, Kelly H and Nolte L. 2019. Prevalence of advance care planning documentation in Australian health and residential aged care services. Advance Care Planning Australia, Austin Health, Melbourne.


25.3%
Of audited records contained at least one statutory or non-statutory advance care directive


5.9%
Statutory advance care directives: preferences for care
12.2%
Statutory advance care directives: substitute decision-maker
11.5%
Non-statutory advance care directives


My Health Record
0 of 249
Statutory advance care directives: preferences for care
1 of 511
Statutory advance care directives: substitute decision-maker
15 of 480
Non-statutory advance care directives

Advance Care Planning is the most researched topic BY FAR in palliative care.

If we can just do the 'right' study we can prove it works…

2018 review[1] of **80 systematic reviews** (including 1600 original articles) **found no evidence** that ACP was associated with

- influencing medical decision-making at the end of life, enhancing the likelihood of goal-concordant care, or improving patients' or families' perceptions of the quality of care received

2020 scoping review[2] including 62 recent high-quality articles also demonstrated **no link between ACP and occurrence of goal-concordant care or patient quality of life**.

Also, **no association of ACP with subsequent health care use, including emergency department visits, hospitalizations, and critical care…**

NB: this is international, not Australian context

1. Jimenez G, Tan WS, Virk AK, Low CK, Car J, Ho AHY. Overview of systematic reviews of advance care planning: summary of evidence and global lessons.J Pain Symptom Manage. 2018;56(3):436-459.e25. doi:10.1016/j.jpainsymman.2018.05.016
2. 2. 2. McMahan RD, Tellez I, Sudore RL. Deconstructing the complexities of advance care planning outcomes: what do we know and where do we go? a scoping review.J Am Geriatr Soc. 2021; 69(1):234-244. doi:10.1111/jgs.16801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VIEWPOINT

Shifting to Serious Illness Communication

Juliet Jacobsen, MD
Harvard Medical School, Boston, Massachusetts; and Lund University Institute for Palliative Care, Lund, Sweden.

Rachelle Bernacki, MD
Harvard Medical School, Boston, Massachusetts; and Dana-Farber Cancer Institute, Brigham and Women's Hospital, Boston, Massachusetts.

Joanna Paladino, MD
Serious Illness Care Program, Ariadne Labs, Boston, Massachusetts; and Harvard Medical School, Brigham and Women's Hospital, Boston, Massachusetts.

Although the research evidence for advance care planning has been debated,[1] the underlying need remains. Every day, patients and families engaged in medical decisions toward the end of life experience distress that could have been lessened or even prevented through communication.

Advance care planning originally focused on the completion of advance directives and tries to address this need by preparing patients for decision-making. Advance care planning is now considered to be a "process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care."[2] There is significant face validity to this person-centered approach: the only way for clinicians to know and honor patients' values and goals is to ask about them. Yet research questions remain about which patients, which clinicians, when to start, and the key elements that lead to benefit.

This Viewpoint focuses on a related emerging construct and promising intervention, serious illness communication, and describes its components, presents evidence supporting the approach, and discusses areas for further research.

Components of Serious Illness Communication

Serious illness is a "health condition that carries a high risk of mortality and either negatively impacts a person's daily function or quality of life, or excessively strains their caregivers."[3]

a source of strength as patients try to live as normally as possible, an important priority for many.

Serious illness communication also helps patients engage with the psychological and existential work of serious illness. This means slowly learning to cope with the illness and prognosis by finding a way to balance hopes for the future and a perspective of life engagement with a growing awareness of the possibility of experiencing advanced disease and illness or dying. To do so, patients need to develop some understanding of the illness and prognosis. Clinicians might discuss how much time remains. Although clinicians' time-based prognostic estimates are uncertain, many patients appreciate and expect these discussions, which are needed for planning.[6]

However, because many patients are ambivalent about time-based prognostic information, serious illness communication need not include specific disclosures about time. It can instead focus on information about the uncertainty of future health or anticipated function, such as explaining that the patient may find it more difficult to perform daily tasks than previously. This less explicit framing may be all that is needed to foster prognostic awareness. Such conversations are often emotional and require that clinicians help patients process feelings and grieve. With such opportunities to reflect, patients may reprioritize their goals. For example, a patient with a serious illness may take a trip with family soon rather than wait until next year or might work to mend an estranged relationship. A patient with serious, advanced illness might

•Jacobsen J, Bernacki R, Paladino J. Shifting to Serious Illness Cummunication. JAMA. 2022;327(4):321-322
DOI: 10.1001/jama.2021.23695

What Matters Most
Discussion Starter

Supporting older people to work out what is right for them

dyingtotalk.org.au

A *Dying to Talk* initiative through Palliative Care Australia

This project was funded by the Australian Government through the Dementia and Aged Care Services Fund

PalliativeCare AUSTRALIA

About you

This section is about you. It has questions about what is important to you.

The questions in this section can be the hardest ones to answ
take some time to thi
before you write anyt
answer one or two at

Some important thi

- There are no right
this is about what y
want.
- You can change yo
time.

About your health

This section is about your health. It has questions about what you would like to know and what you would like your carer
ut your health. It may
ople make decisions in

or wrong answers.
ur answers at any

answer all of the

me questions now and
nother time.
ers may help those
what you would
nt, if you could not

About what you want at the end of your life

This section is about what you might want at the end of your life.

It can be difficult to know what you might want. You may take some time to think about the questions before you write anything down or only answer one or two questions at a time. You may also want to look at our 'What Matters Most' cards to help you identify what is important to you. The cards are available on the website dyingtotalk.org.au.

Remember:

- There are no right or wrong answers.
- You can change your answers at any time.
- You do not have to answer all of the questions.
- You can answer some questions now and some questions another time.
- Sharing your answers may help those around you know what you would and would not want, if you could not tell them.
- It is important to know that being given the Discussion Starter doesn't mean you are about to die.

THE UNIVERSITY of EDINBURGH

Supportive and Palliative Care Indicators Tool (SPICT-4ALL™)

The SPICT™ helps us to look for people who are less well with one or more health problems. These people need more help and care now, and a plan for care in the future. Ask these questions:

Does this person have signs of poor or worsening health?

- Unplanned (emergency) admission(s) to hospital.
- General health is poor or getting worse; the person never quite recovers from being more unwell. (This can mean the person is less able to manage and often stays in bed or in a chair for more than half the day)
- Needs help from others for care due to increasing physical and/ or mental health problems.
- The person's carer needs more help and support.
- Has lost a noticeable amount of weight over the last few months; or stays underweight.
- Has troublesome symptoms most of the time despite good treatment of their health problems.
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Does this person have any of these health problems?

Cancer

Less able to manage usual activities and getting worse.

Not well enough for cancer treatment or treatment is to help with symptoms.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Has lost control of bladder and bowel.

Not able to communicate by speaking; not responding much to other people.

Frequent falls; fractured hip.

Frequent infections; pneumonia.

Nervous system problems

(eg Parkinson's, MS, stroke, motor neurone disease)

Physical and mental health are getting worse.

More problems with speaking and communicating; swallowing is getting worse.

Chest infections or pneumonia; breathing problems.

Severe stroke with loss of movement and ongoing disability.

Heart or circulation problems

Heart failure or has bad attacks of chest pain. Short of breath when resting, moving or walking a few steps.

Very poor circulation in the legs; surgery is not possible.

Lung problems

Unwell with long term lung problems. Short of breath when resting, moving or walking a few steps even when the chest is at its best.

Needs to use oxygen for most of the day and night.

Has needed treatment with a breathing machine in the hospital.

Kidney problems

Kidneys are failing and general health is getting poorer.

Stopping kidney dialysis or choosing supportive care instead of starting dialysis.

Liver problems

Worsening liver problems in the past year with complications like:

- fluid building up in the belly
- being confused at times
- kidneys not working well
- infections
- bleeding from the gullet

A liver transplant is not possible.

Other conditions

People who are less well and may die from other health problems or complications. There is no treatment available or it will not work well.

What we can do to help this person and their family.

- Start talking with the person and their family about why making plans for care is important.
- Ask for help and advice from a nurse, doctor or other professional who can assess the person and their family and help plan care.
- We can look at the person's medicines and other treatments to make sure we are giving them the best care or get advice from a specialist if problems are complicated or hard to manage.
- We need to plan early if the person might not be able to decide things in the future.
- We make a record of the care plan and share it with people who need to see it.

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT-4ALL™, June 2017

Use this to help develop an understanding of clinical change/frailty and consideration of a palliative approach

https://www.spict.org.uk/spict-4all/

https://youtu.be/45b2QZxDd_o

What do you know about your condition?

(How much do you want to know?)

What are your fears/worries?

What are your goals for the future?

What would you be willing to sacrifice or endure to reach those goals?

What would a ‘’Good Day’ look like for you?

IN SUMMARY

Little evidence for *efficacy* of advance care planning (directives)

Appointing a health proxy (substitute decision maker) much more important in terms of outcomes.

So long as they know what the persons values and goals are…

The DISCUSSIONS are the key

Q: should we consider diverting resources from ACP to increasing capacity of health care professionals to have meaningful empathic 'in the moment' decision making conversations?

Thank you

Peter Jenkin

peter.jenkin@act.gov.au

ACT Government | Canberra Health Services

Acknowledgement of Country

Canberra Health Services acknowledges the Ngunnawal people as traditional custodians of the ACT and recognises any other people or families with connection to the lands of the ACT and region. We acknowledge and respect their continuing culture and contribution to the life of this region.

Accessibility
Call (02) 5124 0000
Call 131 450

canberrahealthservices.act.gov.au/accessibility