Goals of Patient Care (GOPC) and Advance Care Planning (ACP)

GP Engage Event

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I respectfully acknowledge the past and present traditional owners of this land on which we are meeting, the Noongar people. It is a privilege to be standing on Noongar country.

I also acknowledge that the Aboriginal population in the South Metropolitan Health Service is diverse and includes Aboriginal people from many communities across Australia.

I also acknowledge the contributions of Aboriginal Australians and non-Aboriginal Australians to the health and well-being of all people in this country we all live in and share together –

Western Australia.

Maude

- 83 yr old ex social worker
- Lives alone, no current partner, no children
- Peripheral Vascular Disease (PVD) – angioplasty x 2
- External Radiation Therapy (XRT) for Non-Hodgkin's lymphoma (NHL) 35 years ago.
- Slowly progressive Bronchiectasis
- Depression
- Osteoporosis
  - Distal radial fracture
  - L3 crush
- Prolonged hospitalisation after bilat provoked PE/retroperitoneal haematoma/IVC filter

- Yoga teacher
- Has active interest in Buddhism
- 3 cats, 1 old dog and several turtles she hand feeds
- Swims every morning at South Beach
- Has a bike as her main form of transport
- Main supports are her neighbours, and her niece (Victoria Park)

Outline of today's talk

- Background regarding GOPC, ACP, Advanced Health Directive (AHD)
- Substitute decisions makers and hierarchy of decision makers in WA
- SPICT tool/Surprise question/Frailty scale
- Brief overview of frailty
- Outcomes of CPR in frailty
- Services available: Metropolitan Palliative Care Consultancy Service (MPaCCS), Residential Care Line (RCL), other initiatives

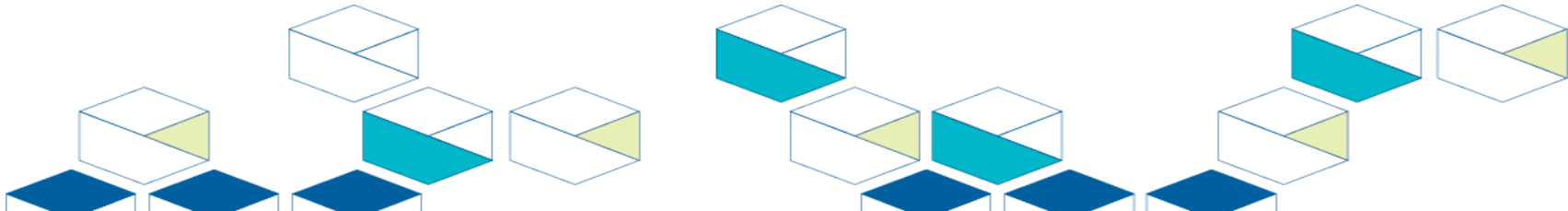
GOPC, ACP & ADH

- GOPC is one component of Advance Care Planning (ACP)
  - Generally applicable for current episode of care (can be extended to 12 months with Consultant approval)
- ACP is a document outlining the patient's values, beliefs and preferences and usually discussed when the patient is well.
- AHD is a legally binding document describing the patient's plans for future care.

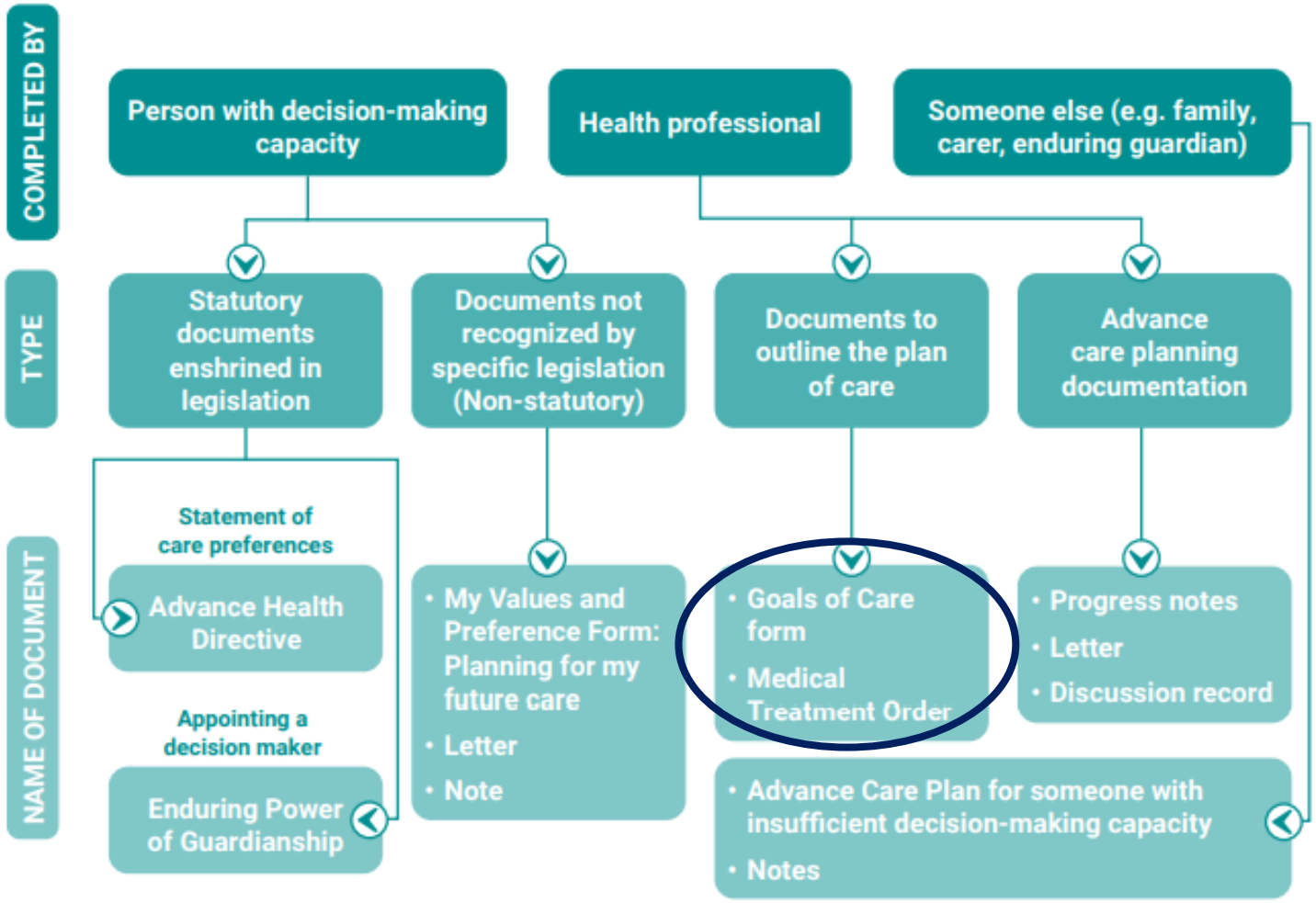
Source:

https://www.advancecareplanning.org.au

https://www.publicadvocate.wa.gov.au



ACP documentation flowchart for WA



Source: Health Professional Guide to Advance Care Planning in Western Australia

Role of health professionals in ACP

1. Think

Encourage people to consider advance care planning by:

- identifying and acting on opportunities to have discussions about advance care planning
- raising the topic of advance care planning
- describing the benefits of advance care planning.

2. Talk

Support people to talk about advance care planning by:

- using open conversation starters
- actively listening and responding positively
- planning and making time to continue the conversation
- identify whether a person has an advance care planning document(s) (by asking the person or their family, or by checking their record).

Patient centred care that aligns with an individual's values, beliefs, preferences and treatment decisions

- Enact and follow advance care planning documents when a person loses capacity.
- Revisit advance care planning conversations regularly and encourage review of decisions and documents when there are major changes to a person's condition or health.

3. Write

Support people to make their wishes known in writing by:

- familiarising yourself with different types of advance care planning documents
- informing people about documents relevant to them
- advising people about how to complete advance care planning documents, including Advance Health Directives
- referring to advance care planning documents and Goals of Patient Care forms where appropriate to ensure they are current and align.

4. Share

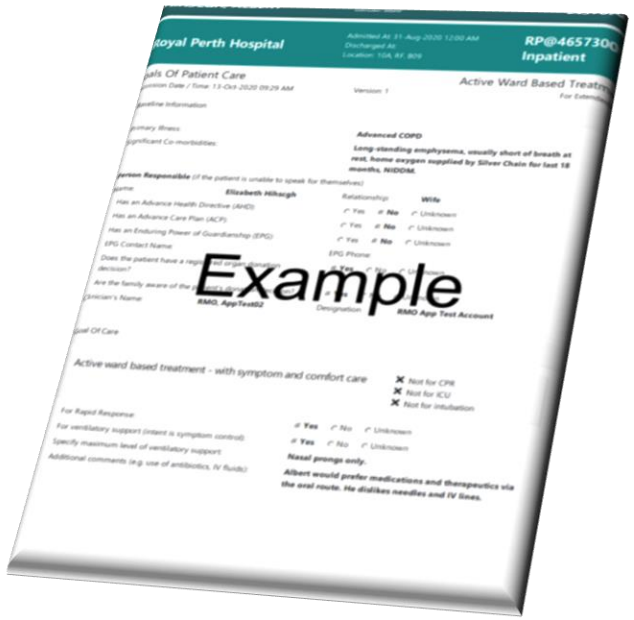
Ensure appropriate sharing and storage of advance care planning documents by:

- advising people on how to share their advance care planning documents with those involved in their care
- following organisational policies on recording discussions and documents
- assisting people to upload relevant advance care planning documents to My Health Record.

Source:

Health Professional Guide to Advance Care Planning in Western Australia

Why change from Decision Rationale (DNR) to Goals of Patient Care?



Patient preferences (needs, values and wishes): _____

Decision rationale for agreed **Goals of Patient Care** (please tick one only):

☐ Medically-driven decision ☐ Patient wishes ☐ Shared decision-maki

Other information:

Focusing on **Values** and **Preferences**

Difficult decisions to limit a patient's treatment tend to occur during crisis situations especially during MET calls

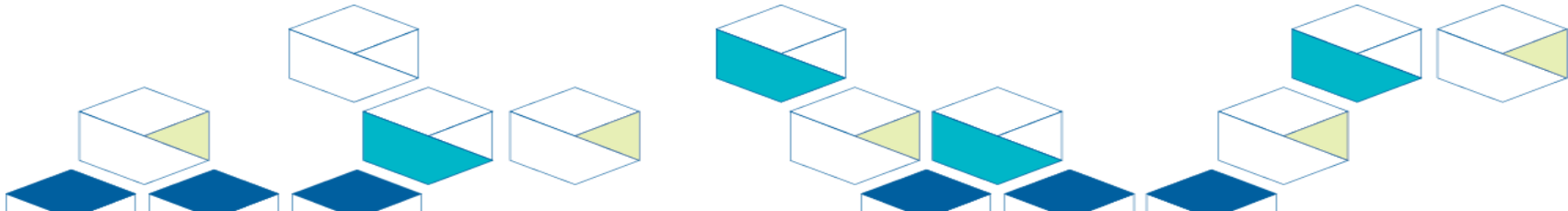
This will encourage shared decision making between patients, family, and doctors, and will ensure appropriate care in the event of a patient's clinical deterioration

The GOPC process

- Facilitates proactive shared decision making between clinicians, and patients and/or family, to ensure treatment is aligned with patient preferences, needs, values and wishes.

- Establishes and documents the most medically appropriate agreed GoPC that will apply in the event of the patient's clinical presentation and/or deterioration.

- Ensures a clear escalation plan which may include treatment ceilings or limitations to treatment.



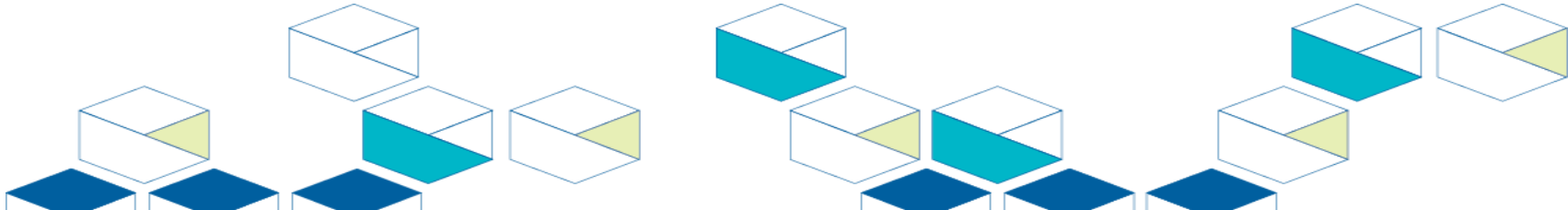
GOPC options include:

- **All life sustaining treatment**
  All treatments including care within an ICU will be considered.

- **Life extended intensive treatment – with treatment ceiling**
  Care within an ICU will be considered but not all treatments will be used e.g. the person does not wish to have blood products.

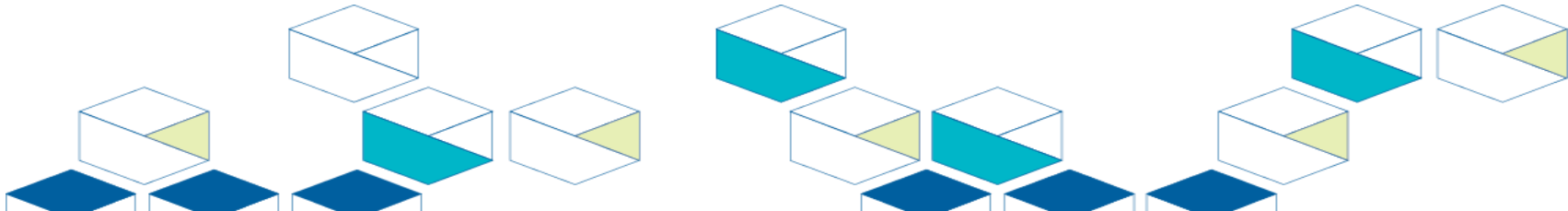
- **Active ward-based treatment – with symptoms and comfort care**
  The persons treatment will be given within a hospital ward their care will not be transferred to an Intensive Care Unit. There will be an emphasis on quality of life and on treatments that will improve comfort.

- **Optimal comfort treatment – including care of the dying person**
  The aim of all treatment will be to provide comfort and prevent and relieve suffering.



Benefits of GOPC

- Improved quality of communication
- Care consistent with patient preferences
- Reductions in patient harm
- Reduced Intensive Care Utilisation
- Decreased non-beneficial medical care near death



My Health Record

- As part of the Collaborative, WA Health hospitals upload both the Digital Medical Record (DMR) GoPC and the iCM GoPC eForms to My Health Record.
- These documents can only be uploaded to My Health Record with the patient's consent.
- This allows GP's and private providers to understand the types of discussions that have occurred between the patient and their healthcare team about their goals of care and treatment preferences.
- This can then be used to prompt discussions with other people involved in their care.

SECTION 1 BASELINE INFORMATION

Primary illness: Extensive PE

Significant co-morbidities: Bronchiectasis/Retroperitoneal Bleed

In the event that the patient is unable to speak for themselves, who would they wish to speak for them? This is known as the **'Person responsible'**

Name: Kelsey Smythe Relationship: Neice

Does the patient have?:

* Advance Health Directive (AHD) ☐ Yes ☒ No
* Advance Care Plan (ACP) ☐ Yes ☒ No
* Enduring Power of Guardianship (EPG) ☐ Yes ☒ No

EPG contact name: _____ Phone: _____

* Does the patient have a registered organ donation decision? ☐ Yes ☒ No
* Are the family aware of the patient's donation decision? ☐ Yes ☒ No

Clinician's Name (please print): Alicia Massarotto Designation: _____

Date: ___/___/___ Time: _____ Signature: _____

SECTION 2 GOAL OF CARE

Please tick one only and complete section 3 over the page to be valid. In discussion with the clinician, patient, person responsible and/or family/carer(s), please select the most medically appropriate agreed goal of patient care that will apply in the event of clinical deterioration.

☐ **All life sustaining treatment**

* For Rapid Response (MER/MET Calls)
* For CPR
* For ICU

☒ **Life extending intensive treatment – with treatment ceiling**

* Not for CPR

* For Rapid Response ☒ Yes ☐ No
* For ventilatory support, including intubation ☐ Yes ☒ No
* Specify maximum level of support .....
* For ICU/HDU admission ☒ Yes ☐ No
* *Additional comments (e.g. use of inotropes, NIV, dialysis)* ..... FOR HDU for trial of Inotropes

☐ **Active ward based treatment – with symptom and comfort care**

* Not for CPR
* Not for ICU
* Not for intubation

* For Rapid Response ☐ Yes ☐ No
* For ventilatory support (intent is symptom control) ☐ Yes ☐ No
* Specify maximum level of support .....
* *Additional comments (e.g. use of antibiotics, IV fluids)* .....

☐ **Optimal comfort treatment – including care of the dying person**

* Not for Rapid Response
* Not for CPR
* Not for intubation
* Not for ICU

* For ongoing review to identify transition to the terminal phase
* Ensure timely commencement of the *Care Plan for the Dying Person*

SECTION 3 SUMMARY OF DISCUSSION(S)

Goals of Patient Care has been discussed with: Date: ___/___/___ Time: _____

Patient: ☒ Yes ☐ No Person Responsible: ☐ Yes ☐ No Family/carer(s): ☐ Yes ☐ No

Name(s) of those present at this discussion: _____

Is the patient able to fully participate in this discussion? ☒ Yes ☐ No

Comments: _____

What is the patient's likely response to CPR and critical intervention? poor - increasing frailty

Patient preferences (needs, values and wishes): Loves her community - would not want to be dependant on others. Hopeful she can keep looking after her animals and teaching Yoga. If unable to do these things, quality of life would be decreased to the point that active treatment would be against her wishes

Decision rationale for agreed **Goals of Patient Care** (please tick one only):

☐ Medically-driven decision ☐ Patient wishes ☒ Shared decision-making

Other information:

Doctor's name (please print): _____ Designation: _____

Signature: _____ Date: ___/___/___ Time: _____

Consultant review completed: Name (please print): _____

Signature: _____ Date: ___/___/___ Time: _____

SECTION 4 EXTENDED USE

Consultant endorsement for extended use beyond this admission for 12 months or until ___/___/___

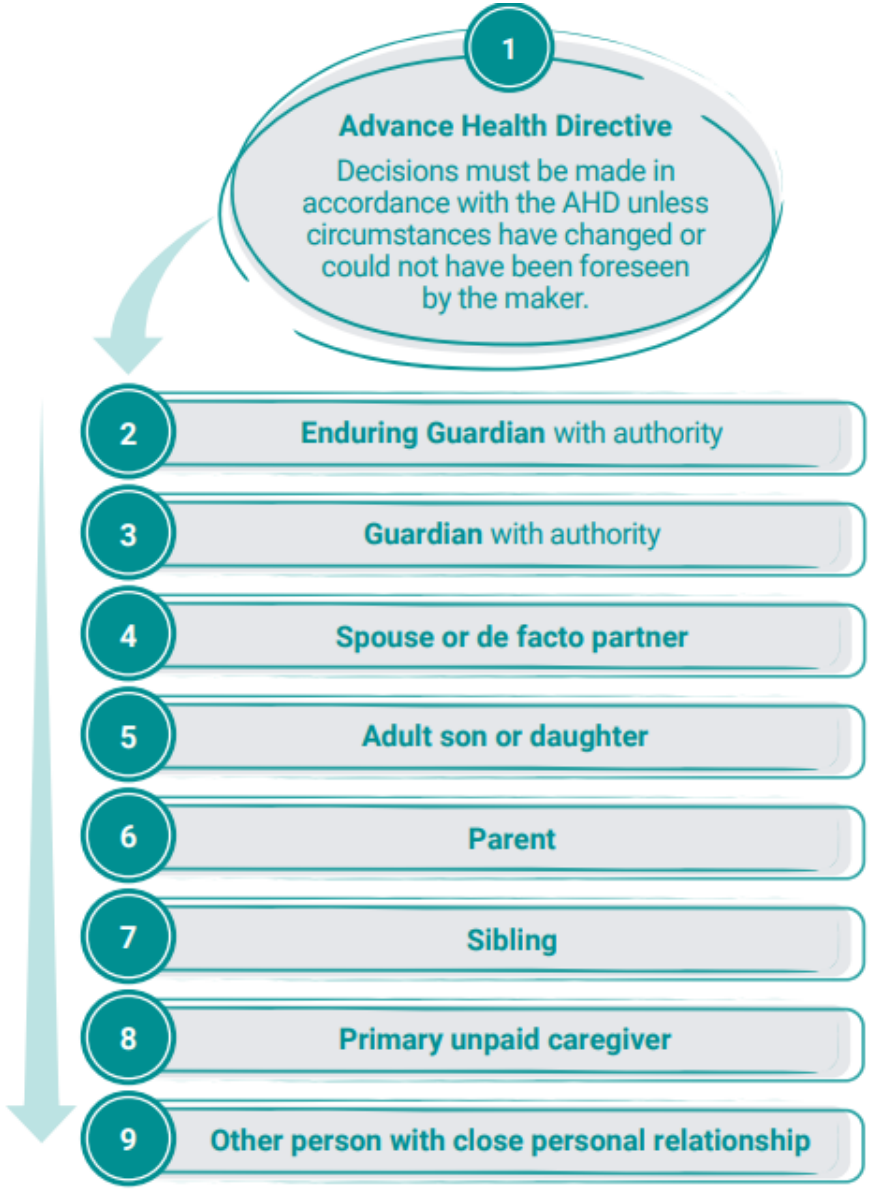
This includes patient transportation to another facility or home following the current admission.

Consultant's comments: patient is clear these are her long term wishes and will be discussing these issues with the GP to complete an ACP

Consultant's name (please print): Massarotto Signature: _____

Specialty: _____ Date: ___/___/___ Time: _____

Hierarchy of Treatment Decision makers



Maude becoming frail – comes to see GP

- Deconditioned despite 4/52 with Rehabilitation in the House (RITH)
- Seems much slower in your clinic.
- Needs assistance with shopping – can’t ride her bike
- Had a fall after trying to hang her sheets out independently
- Has reluctantly agreed for a Common Health Support Program (CHSP) for transport and shopping
- Not sure she will ever get back to teaching Yoga

Clinical Frailty Scale*

1 **Very Fit** – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2 **Well** – People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.

3 **Managing Well** – People whose **medical problems are well controlled,** but are **not regularly active** beyond routine walking.

4 **Vulnerable** – While **not dependent** on others for daily help, often **symptoms limit activities.** A common complaint is being "slowed up", and/or being tired during the day.

5 **Mildly Frail** – These people often have **more evident slowing,** and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6 **Moderately Frail** – People need help with **all outside activities** and with **keeping house**. Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.

7 **Severely Frail** – **Completely dependent for personal care**, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8 **Very Severely Frail** – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9. **Terminally Ill** - Approaching the end of life. This category applies to people with **a life expectancy <6 months**, who are **not otherwise evidently frail.**

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

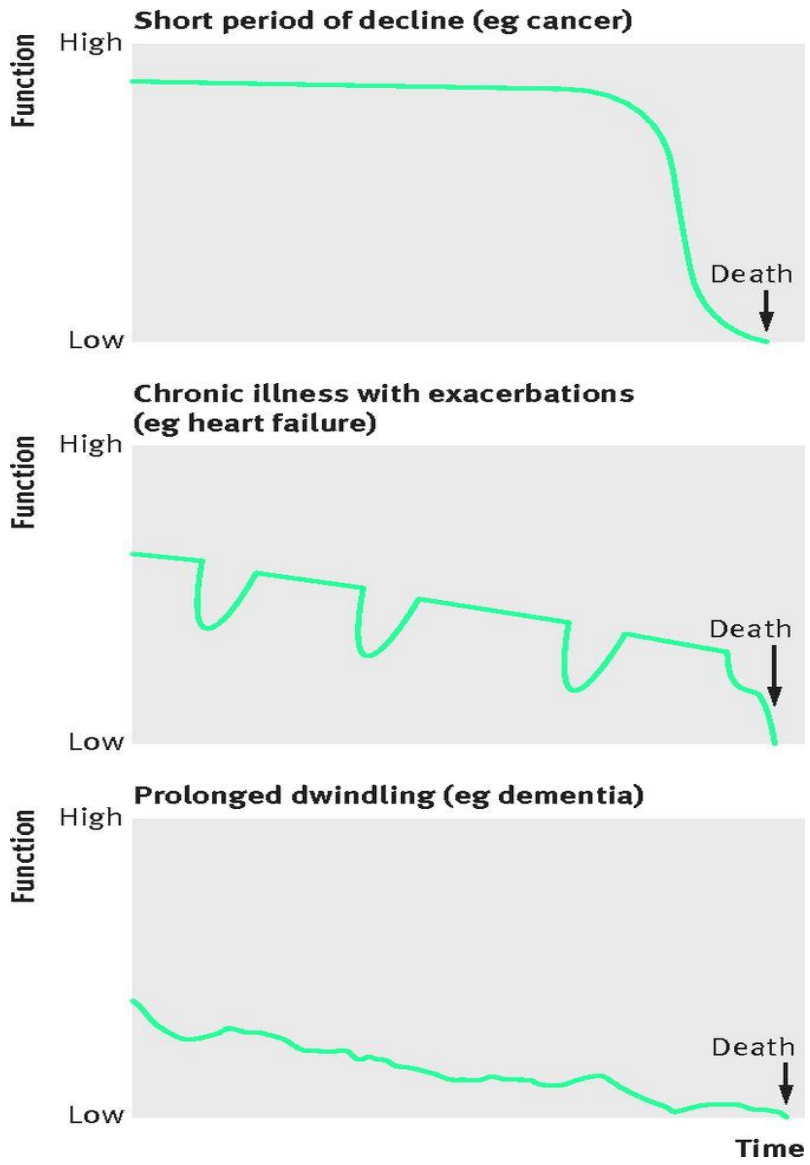
In **severe dementia**, they cannot do personal care without help.

* 1. Canadian Study on Health & Aging, Revised 2008.
2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.

DALHOUSIE UNIVERSITY
Inspiring Minds

[Source: British Geriatrics Society - Clinical Frailty Scale]

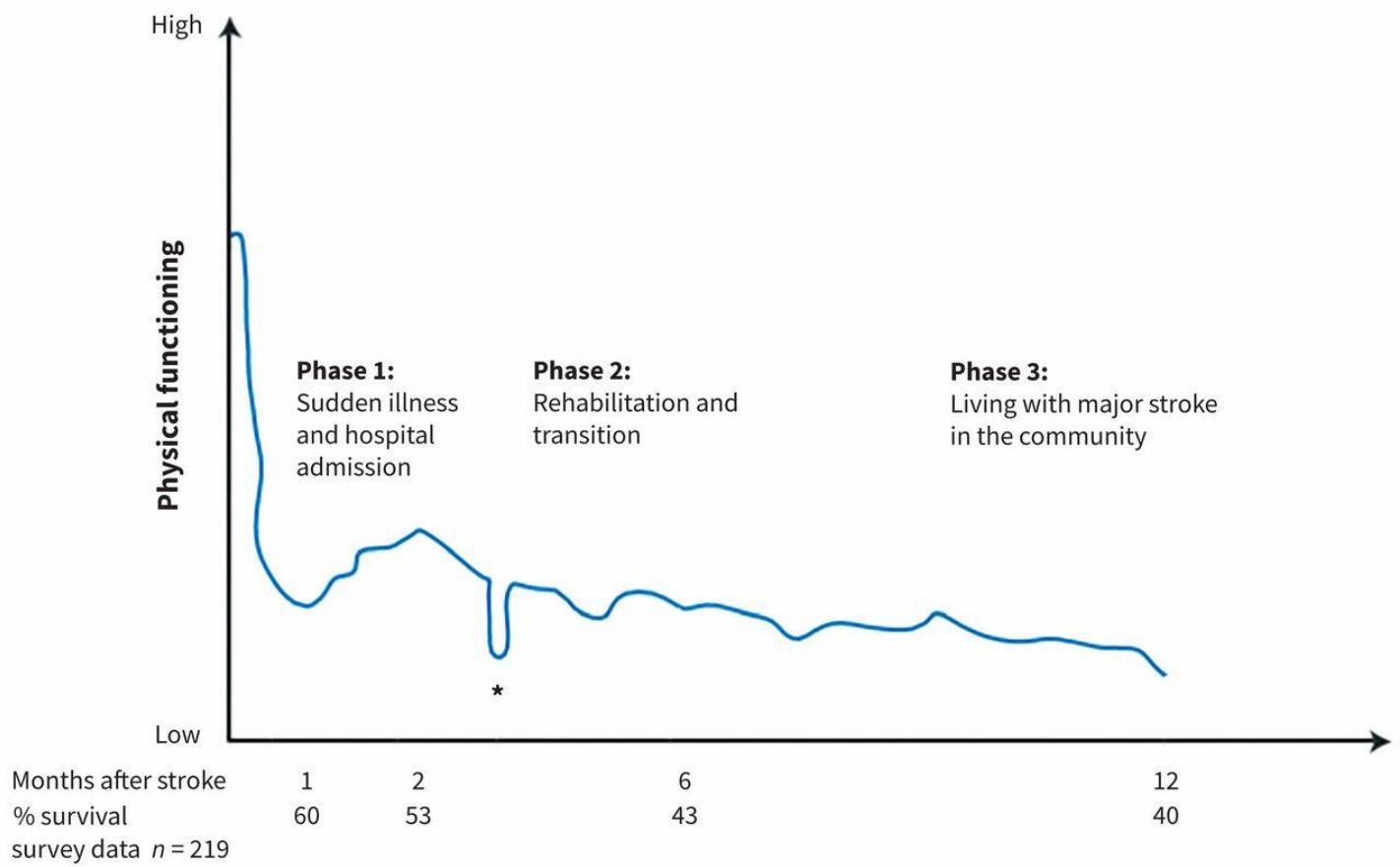
Trajectories of Decline



Source: Predicting decline and survival in severe acute brain injury: the fourth trajectory | The BMJ
Claire J Creutzfeldt et al. BMJ 2015;351:bmj.h3904

Archetypal physical trajectory of decline for people with total anterior circulation stroke.

***At some time in the first 12 months, most people have 1 or more episodes of acute functional decline owing to a comorbidity such as a chest infection.**



Source: Outcomes, experiences and palliative care in major stroke: a multicentre, mixed-method, longitudinal study - PubMed

Marilyn Kendall et al. CMAJ 2018;190:E238-E246

Supportive and Palliative Care Indicators Tool (SPICT)

Source: e-SPICT | Supportive and Palliative Care Tool

Look for any general indicators of poor or deteriorating health.

- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility. (eg. The person stays in bed or in a chair for more than half the day.)
- Depends on others for care due to increasing physical and/or mental health problems.
- The person's carer needs more help and support.
- Progressive weight loss; remains underweight; low muscle mass.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Cancer

Functional ability deteriorating due to progressive cancer.

Too frail for cancer treatment or treatment is for symptom control.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Urinary and faecal incontinence.

Not able to communicate by speaking; little social interaction.

Frequent falls; fractured femur.

Recurrent febrile episodes or infections; aspiration pneumonia.

Heart/ vascular disease

Heart failure or extensive, untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal effort.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe, chronic lung disease; with breathlessness at rest or on minimal effort between exacerbations.

Persistent hypoxia needing long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping or not starting dialysis.

Liver disease

Cirrhosis with one or more complications in the past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is not possible.

Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/or progressive difficulty with swallowing.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Persistent paralysis after stroke with significant loss of function and ongoing disability.

Would you be surprised if your patient dies in the next 12 months?

Figure 2. Percentage of patients who died in hospital following CPR for cardiac arrest, stratified by CFS. Deaths are shown i
black.

Mrs MS

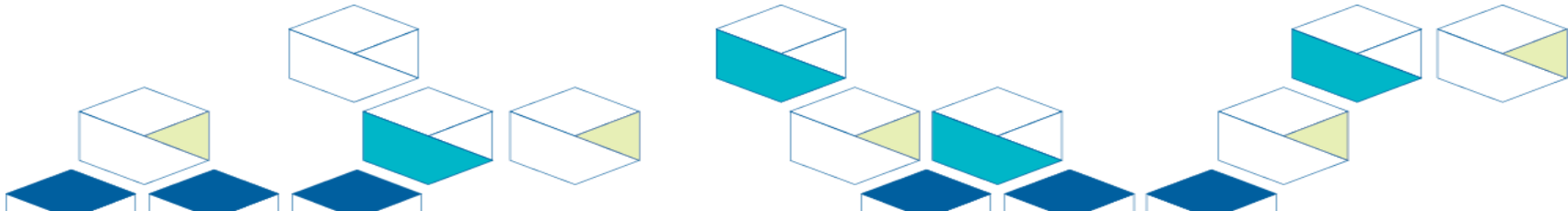
- Completes an AHD and appoints her niece as Enduring Power of Guardianship (EPG).
- At present – teaching seated Yoga to a retirement community, still getting help with her shopping
- Bike has not yet been sold!

What is the difference between advance care planning, a Values and Preferences Form, an Advance Care Plan and an Advance Health Directive

- Values and Preferences Form: Planning for my future care (PDF 485KB)
  - in which an individual can record what they value and what they want for their care in the future including where they want to live, and other things that are important to them. May be considered a Common Law Directive.

- Advance Care Plan for someone with insufficient decision-making capacity (external site)
  - written on an individual's behalf by a recognised decision-maker(s) who has a close and continuing relationship with the individual. Can be used to guide health professionals when making medical treatment decisions on the individual's behalf, if they do not have a valid Advance Health Directive or Values and Preferences Form. It should only be used when a person no longer has decision-making capacity to complete a Values and Preferences Form or an Advance Health Directive. This document is a non-statutory document and is not a document in which a person is able to give legal consent to or refuse treatment. Non-statutory documents are not recognised under specific legislation.

- Advance Health Directive (PDF 578KB)
  - is a legal record of an individual's decisions about treatment(s) they do or do not want to receive if they become unwell or injured in future. It can only be made by a person older than 18 years who is able to make and communicate their own decisions. The Advance Health Directive is a statutory document as it is recognised under legislation. Statutory documents are the strongest and most formal way to record an individual's wishes.



Patient Resources

Source:

[Dying to Talk – What Matters Most guide and cards]

[Advance Care Planning patient Guide]


Government of Western Australia
Department of Health

Advance care planning

Planning for your future health and personal care

What is advance care planning?

Advance care planning can help you to have a say in what type of care you receive in the future. It helps others understand your values, beliefs and preferences for when you are no longer able to make or communicate decisions about your health and personal care. Advance care planning can start at any age. It is best started when you are feeling well and able to make decisions.

Why is advance care planning important?

Advance care planning can give you peace of mind by knowing that others understand your wishes in case a time comes when you are no longer able to tell them what is important to you.

It can also make it easier for your family, friends and health professionals who may care for you in the future.

Families and friends of those who take part in advance care planning say they feel less stressed and are happier with the care their loved one received.

Advance care planning is an ongoing process and involves 4 key elements:

- **Think**
- **Talk**
- **Write**
- **Share**.

You can move between these elements and change your choices to suit changes in your personal situation, health or lifestyle.

Think

Your advance care planning process will be guided by you and your beliefs, values and preferences.

Spend time gathering your thoughts and thinking about what 'living well' means to you. What worries you when you think about your future health? Are there any medical treatments that you would not want?

Talk

Talk to your loved ones about your values and beliefs, and the care you would like when you are unwell.

Discuss your health concerns and options for future care with your health professionals.

healthywa.wa.gov.au


dying to talk®

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

Where to go for further information

Advice and support for staff at residential care facilities

Metropolitan Palliative Care Consultancy Service (MPaCCS)
A mobile specialist palliative care team that works collaboratively with GP's and other health professionals.
Phone: 9217 1777
Email: MPaCCS@bethesda.org.au
Website: bethesda.org.au/facilities-services/mpaccs

Residential Care Line
Phone: 6457 3146

Further Information

- Goals of Patient Care - https://ww2.health.wa.gov.au/Articles/F_I/Goals-of-patient-care
- End of Life - https://ww2.health.wa.gov.au/-/media/Files/Corporate/general-documents/End-of-Life/Goals-of-Care/PDF/GOPC-discussion-tips.pdf
- Workshop and information for community members on Advance care planning and palliative caring - https://palliativecarewa.asn.au/
- WA End-of-Life and Palliative Care Strategy 2018-2028 (health.wa.gov.au)
- Advanced Care Directive Form - Source: Advance Health Directive Form

Further Information

- Palliative Care Curriculum for Undergraduates (Free online modules) https://pcc4u.org.au/learning/modules-landing/
- End of Life Essentials (Free online modules) https://www.endoflifeessentials.com.au/tabid/5195/Default.aspx
- Palliative and Support Care Education (PaSCE) (Communication video resources, online modules and workshops - https://www.cancerwa.asn.au/professionals/pasce/
- Guidelines for palliative approach to aged care in the community https://www.pallcaretraining.com.au/
- Online learning - https://www.palliaged.com.au/tabid/5683/Default.aspx

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