NSW GOVERNMENT Health
Hunter New England
Local Health District

Advance Care Planning

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Advance Care Plans

- Advance Care Planning is an ongoing process that helps people to plan for future medical care.
  - Discuss their values and beliefs
  - Discuss their wishes about preferences for medical care if they cannot make their own decisions.
  - Discuss their wishes with their family and other people who are close to them
  - Discuss with their General Practitioner or other health professionals about any medical conditions they have.

Advance Care Directive in NSW

- As part of the Advance Care Planning process, people may decide to write an Advance Care Directive (ACD)
- Often involves appointing substitute decision maker
- As a treating doctor, the ACD is valid if:
  - the patient had capacity when they wrote it and they made it voluntarily
  - it has clear and specific details about treatments that they would accept or refuse
  - it applies to the situation you are in at the time.

Advance Care Directives in NSW

- They only apply when a person does not have capacity.
- The ACD does not need to be witnessed
- An ACD is a legal document. No one can override an ACD, not even the legally appointed guardian.
- As treating clinicians you can be charged with assault if you **knowingly** treat against the conditions set out in a valid ACD (Similar to a Jehovah Witness Card)
- Everything else is considered to be an advanced care plan
  - ie signed by family, Person Responsible, RACF manager, friend or Enduring Guardian

Capacity

- Capacity is decision specific
- People with cognitive impairment can have capacity
- A person has capacity if they are able to
  - Understand and retain the information and consequences relevant to decision
  - Use information to make decision
  - Explain decision and communicate it

Advanced Care Planning audit at Belmont Chua et al 2020

- 92 patients from RACFs
  - 49% had ACP documentation
  - 69% had cognitive impairment
- Most ACPs lacked sufficient information for ED to make a decision
  - 92% had nominated substitute decision maker
  - 46% had medical treatment
  - 17% had end of life wishes
  - 8% had values

Why should people have an ACD?

RCT of Advance Care Planning in Melbourne

ACP resulted in:

- 86 vs 30% end of life wishes followed ($p<0.001$)
- 86 vs 37% Patient satisfied with quality of death ($p<0.001$) [Family perception]
- 83 vs 48% family satisfied with quality of death ($p=0.02$)

(Detering et al, 2010)

Advanced Care Plans are valued by older people

- Want to discuss end of life issues (Murray et al 2006)
- Reduced end of life hospital admissions (Caplan et al 2006)
- Residents of Residential Aged Care Facilities are complex and frail (Clegg et al 2013)
  - 40% of residents die within 12 months of ED visit. (Hullick et al 2020)
- Improved compliance with care preferences
- Reduced depressive and stress symptoms (Waller et al 2017)

Person Responsible / Substitute Decision Maker

- When a patient does not have capacity to make medical decisions– they require a Person Responsible
- Under the NSW Guardianship Act (1987) the "next of kin" has been replaced by the term Person Responsible
- The Person Responsible needs to be over 18 and agree to be a Substitute Decision Maker.

Enduring Guardian

- An Enduring Guardian is a legal document detailing the appointment of a person of your choice to make important personal, lifestyle and treatment decision on your behalf should you lose capacity.

NSW Guardianship Act Hierarchy

Guardian /Enduring or Public or Private

With the function of consenting to medical, dental and health care treatments

If there is no Guardian

A Spouse or De Facto Spouse

With whom the patient has a close, continuing relationship (de facto spouse includes same sex partners)

If there is no spouse or de facto spouse

An Unpaid Carer

Who is now providing support to the person or provided this support before the person entered care

If there is no Unpaid Carer

A Relative or Friend

Who has a close and continuing relationship with the person

What do clinicians need to know about ACP

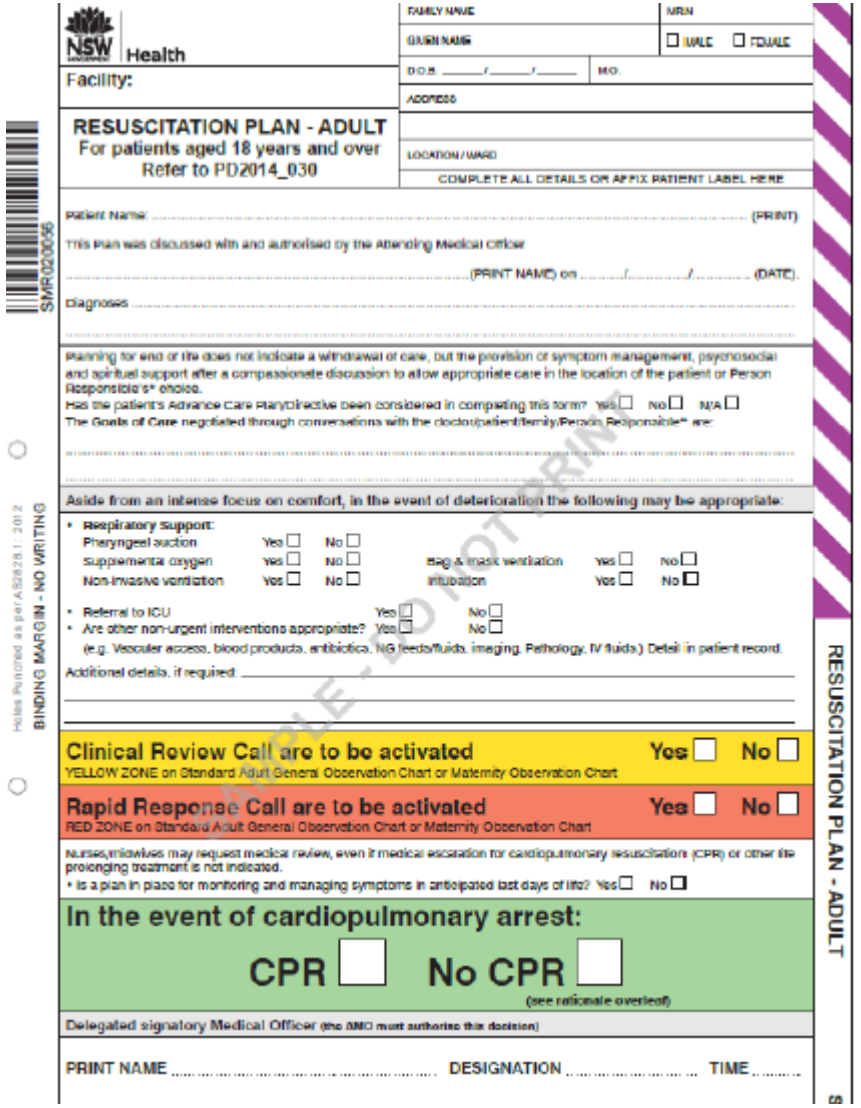
- It is subject to change (patient or family)
- If a plan exists then previous conversations have probably taken place
- It is a trigger for another respectful conversation ALWAYS! Preferably before aggressive treatment begins
  - Other triggers for a respectful conversation may include the presence of a MOLST, an Enduring Guardian document, concerned family and friends, serious illness, hospitalisation
- The conversations should be with the right people ie Person Responsible or Enduring Guardian

What do Clinicians need to know?

- As a Doctor you cannot be forced to provide treatment considered futile treatment by your peers
- Symptom management and comfort measures is also an appropriate treatment plan (it is NOT withdrawing treatment)
- Antibiotics (IV or oral) and other limited treatment options maybe part of symptom management plan or an ACP
- ACPs may include any, all or none of the of the available treatment options
- Consider the “Goals of care”

Adult Resuscitation Plan triggers

- Patient is clinically deteriorating requiring Rapid Response
- If the patient is at high risk
  - More than 2 admissions in the last 12 months, metastatic disease, frail
- Would I be surprised if the patient dies in the next 6-12 months?
- Patient has an Advanced Care Plan or Directive
- If a patient's recovery is uncertain



NSW Health

Facility:

FAMILY NAME | MRN

GIVEN NAME | ☐ MALE ☐ FEMALE

D.O.B. ____/____/____ | M.O.

ADDRESS

LOCATION / WARD

COMPLETE ALL DETAILS OR AFFIX PATIENT LABEL HERE

RESUSCITATION PLAN - ADULT
For patients aged 18 years and over
Refer to PD2014_030

SHR020056

Patient Name: ..... (PRINT)

This Plan was discussed with and authorised by the Attending Medical Officer

..... (PRINT NAME) on ____/____/____ (DATE)

Diagnoses .....

Planning for end of life does not indicate a withdrawal of care, but the provision of symptom management, psychosocial and spiritual support after a compassionate discussion to allow appropriate care in the location of the patient or Person Responsible's* choice.

Has the patient's Advance Care Plan/Directive been considered in completing this form? Yes ☐ No ☐ N/A ☐

The Goals of Care negotiated through conversations with the doctor/patient/family/Person Responsible* are:

.....

Aside from an intense focus on comfort, in the event of deterioration the following may be appropriate:

- **Respiratory Support:**
  - Pharyngeal suction Yes ☐ No ☐
  - supplemental oxygen Yes ☐ No ☐
  - Non-invasive ventilation Yes ☐ No ☐
  - Bag & mask ventilation Yes ☐ No ☐
  - intubation Yes ☐ No ☐
- Referral to ICU Yes ☐ No ☐
- Are other non-urgent interventions appropriate? Yes ☐ No ☐

(e.g. Vascular access, blood products, antibiotics, NG feeds/fluids, imaging, Pathology, IV fluids.) Detail in patient record.

Additional details, if required: .....

Clinical Review Call are to be activated Yes ☐ No ☐
YELLOW ZONE on Standard Adult General Observation Chart or Maternity Observation Chart

Rapid Response Call are to be activated Yes ☐ No ☐
RED ZONE on Standard Adult General Observation Chart or Maternity Observation Chart

Nurses/midwives may request medical review, even if medical escalation for cardiopulmonary resuscitation (CPR) or other life prolonging treatment is not indicated.

- Is a plan in place for monitoring and managing symptoms in anticipated last days of life? Yes ☐ No ☐

In the event of cardiopulmonary arrest:

CPR ☐ No CPR ☐
(see rationale overleaf)

Delegated signatory Medical Officer (the MMO must authorise this decision)

PRINT NAME ..... DESIGNATION ..... TIME .....

RESUSCITATION PLAN - ADULT

BINDING MARGIN - NO WRITING

Holes Punched as per AS3828.1 : 2012

SAMPLE - DO NOT PRINT

NSW GOVERNMENT Health
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Hospitalisation is risky for residents

	Community	RACF
Pressure injuries	4.3%	19%
Delirium	8%	38%
Invasive procedures	49%	72%
Hospital acquired pneumonia		3 times risk
Death (ACE data)		
During hospital admission		7% 33% die in the first 24 hours
Died within 3 months of ED presentation		26% (n= 4974)
Died within 12 months of ED presentation		41% (n=7638)

Dwyer R, Gabbe B, Stoelwinder JU, Lowthian J. A systematic review of outcomes following emergency transfer to hospital for residents of aged care facilities. Age Ageing 2014;43:759-66.
ACE 5 year evaluation. Hullick et al., 2020

Goals of Care for ED transfer

- Why is the resident coming to hospital?
- What *phase of care* is the person requiring?
  - Curative (pneumonia)
  - Restorative (heart failure)
  - Palliative (symptoms management)
  - Terminal (end of life care)
- What is the *Goal of care* for this transfer to ED?
- What do you want the ED staff to address?

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.

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Appendix 2: Outcomes in acute care (NOT COVID specific) associated with frailty

CFS grade	Length of stay	Readmission rate	In-patient mortality	Care intentions	Service referrals	Post-discharge support
1	4	4%	2%	Detect and manage geriatric syndromes e.g. delirium	General internal medicine	Self-care
2	5	7%	2%			
3	7	11%	2%			Prevention (e.g. falls, memory clinic)
4	8	13%	3%			
5	10	15%	4%			
6	12	15%	6%			
7	13	14%	11%	Think about palliative vs. restorative care	Geriatric medicine	Transitional care
8	12	10%	24%			
9	10	13%	31%			

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COVID-19 Assessment and Management in Residential Aged Care

This pathway is for general practitioners assessing and managing patients in Residential Aged Care Facilities (RACFs). See also:

- COVID-19 Information
- COVID-19 Assessment and Management

Clinical editor's note

Last updated: 26 April

Background

About COVID-19 in Residential Aged Care Facilities

Assessment

1. Consider:
   - preparatory measures that the RACF has in place to facilitate assessment and management of patients in the facility.
   - measures to minimise infection risk to the RACF due to general practitioner visits.
2. Ensure RACF:
   - has recorded a baseline O_2 saturation.
   - is regularly monitoring observations for any residents deviating from usual daily behaviours e.g., increased confusion, falls, altered gait.
   - is isolating all new residents and residents returning from hospital (including short emergency department visits) for 14 days, and monitoring their observations twice daily.
3. Ensure all nebulised medication has been replaced by metered dose inhalers with spacers, due to risk of aerosolisation with nebulisers.
4. Discuss whether to continue or cease any non-invasive ventilation (CPAP and BiPAP) considering the risks and benefits for the patient and implications for the facility.
5. Assess all residents' current health status, to avoid unnecessary general practitioner visits during an outbreak.
6. Encourage COVID-19 specific conversations about end of life with patients and families, and ensure all patients have an updated Advance Care Plan and Advance Care Directive.
7. If contacted by the RACF about a patient with suspected COVID-19, ensure that:
   - the patient, their room-mate, and any close contacts are isolated in single rooms with the doors closed.
   - anyone entering their rooms or assessing the patient is using appropriate infection control measures, including PPE.
8. Consider using telehealth in collaboration with a nurse where it is safe and clinically appropriate to assess the patient.
9. Take a history including:
   - signs and symptoms
   - risk factors for complications of COVID-19
   - any worsening of any chronic health problems e.g., congestive heart failure, asthma and diabetes.

Community HealthPathways

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Resources

- CFS website
  - https://www.acutefrailtynetwork.org.uk/Clinical-Frailty-Scale
- End of life directions for Aged Care
  - https://www.eldac.com.au
- CAPACITY Australia website
  - https://capacityaustralia.org.au
- Advanced Care Planning Australia
  - https://www.advancecareplanning.org.au
- End of life law for clinicians https://palliativecareeducation.com.au