

## **Questions & Answers for Webinar Advanced Care Planning in times of rapid change (Nov. '20)**

- Is a Dr required to sign an ACD?
  - No, no witnesses are required in NSW
- It is suggested in a ACD that a client appoint a spokesperson in case they are unable to speak for themselves – does this person need to be an Enduring Guardian?
  - No, but it is a good idea
- Who can the person choose/nominate as a substitute decision maker?
  - As long as they have capacity, they can choose anyone. If there is no ACP and the person does not have capacity, it follows the NSW Guardianship Act Hierarchy
- Can an ACD be changed or revoked?
  - Yes
- How does the hospital know I have an ACD – what happens in Emergency?
  - They won't know. In some States clinicians are required to make reasonable efforts to find it. This is not the case in NSW
  - They can be loaded onto My Health Record. It's good for your GP, your family, your substitute decision maker to also have copies
- Is a ACD/ACP confidential – who can view it?
  - Its not confidential but people will only see it if you show them
  - Copies can be in medical and aged care records. These are confidential.
- COVID restrictions create difficulties in ACD being signed by the appropriate people – is it ok to email/fax ACD to have it signed by a witness?
  - No, ACD does not need to be witnessed, though it's a good idea. It must be signed by the person
  - If one of the RACF staff are present, they can be the witness and document that the substitute decision maker supports the document. Faxed/emailed to the substitute decision maker and returned signed to the Facility is reasonable
- I understand that a Common Law ACD can be created which will “support” service providers – is it a legally binding document?
  - Yes, it is legally binding if the person has capacity to write it and have signed it.
  - An ACP is a guide but would be supported by the courts
  - A clinician is not required to provide futile care
- Does the client still have the right to refuse medical treatment contrary to their ACD/ACP?
  - Yes, an ACD only applies if the person does not have capacity. People with cognitive impairment can have capacity. They have the right to refuse medical treatment
  - An ACP is only a guide so care can be provided in contradiction to them but it would be important to have a good and clear reason to do this.
- Aged Care provider have obligations under the Aged Care Quality Standard 2 (b) that assessment & planning identifies & addresses consumers current needs & goals – is this the responsibility of the RACF or GP?
  - Its everyone's responsibility. A GP does not have to be involved though this is a good idea, particularly around describing medical conditions, possible complications, short and long term risk and prognosis
- Why are we so bad at planning for death?
  - Many cultural issues though our experience is that most older people know what they want when you ask them
- How do we start the conversation?
  - There are lots of good resources on this. <https://www.advancecareplanning.org.au/>
- Can ACD planning be done through Telehealth? If so how is this done?
  - Yes, a document needs to be written and signed by the resident

- An ACP can be signed by the clinician supporting the planning. It can also be emailed to the Substitute Decision Maker for witnessing and also to have their own copy.

### **Attendee Questions During the Livestream:**

1. How do you determine whether or not a COVID patient should be treated in hospital?

There is a link for transfer to hospital in the [COVID Health pathway](#) that is worth reviewing. It's a complex question and I think the answer is also complex despite the straightforward answers that some are advocating. If a person is COVID positive, they are unlikely to be able to see their family whether they are in hospital or the RACF including when they are dying. This is extremely stressful for everyone involved including the clinicians.

#### A. Patient perspective:

- a. If patients need treatment that can't be given in the RACF eg oxygen, IV fluids, IV antibiotics, increased nursing care. This would be based on assessment, particularly vital signs and dehydration
- b. If the patient has distressing symptoms that can't be managed in the RACF eg difficult palliative symptoms like pain, shortness of breath
- c. One of the things to think about is the COVID negative patient in an RACF outbreak and keeping them safe from COVID. Given many patients will be asymptomatic, pre-symptomatic, have significant cognitive impairment, judging who is COVID negative is difficult.
- d. Risk of hospital includes increasing adverse events: delirium, falls, pressure injury, deconditioning
- e. Risk/disturbance of a patient with Behavioural and Psychological Symptoms of Dementia when they are in a new environment, can't see their families, can't see the staff that they know.
- f. Provisions have also been made for families to be able to take residents home without penalty and losing their place though I am not sure of the logistics around this.

#### B. RACF perspective:

- a. Not enough/suitable staff to deliver safe care
- b. Not able to ensure infection control. This is one of the big barriers to enable care in a facility. If there is no clear way of isolating the patient, then it is better to transfer the patient to limit spread within the facility.

#### C. Public Health perspective

- a. I think it depends on the prevalence of the disease in the community, hospital and RACF. The risk and benefits of moving large number of residents needs to be consider in all these scenarios where risk to the individual and the community will be different.
- b. There are much more aged care beds across the PHN footprint than hospital beds

2. How would have ACP helped in Newmarch?

- A. Probably not in a practical sense, as Nepean Hospital would have enacted Hospital In The Home service anyway. It may have helped with communication if a discussion about pandemic care had occurred prior to the incident.
- B. When all the clinical staff, including the GPs and nurses and care staff, are all new and don't know the resident, they rely on the ACPs to make end of life decisions. ACPs need to be

updated to be specific about COVID. What would a resident and their family want if there is a COVID Outbreak in the RACF?

3. Why do you think only 49% of ACPs came to hospital when RACFs believe that most people have an ACP in their facility, was it that they just were not sent?

A. I would suspect that the ACP is not sent. I do work with Supportive and Palliative Care stream at Flinders Uni and I do know that there is a huge problem with the after-hours care of residents. Often, facilities have agency staff, and often, they can't contact the regular GP and rely on a locum service. In these cases, a decision to send a resident to ED is made without a consideration of any care plans, and following the facility procedures for the transfer of a resident.

I think the answer is multi-factorial. Some don't have ACPs, some are not sent to hospital, some are lost in transit. Relying on a paper-based system for such important information is not the best solution. ACPs can be registered on My Health Record by patients. We can see them in hospital when the patient arrives in the ED. The PHN support person for My Health Record is your Primary Care Improvement Officer.

4. Sometimes a person will have two people or more as EGs, sometimes people don't agree - how do you determine what happens in these situations?

A. This is difficult, but it relies on communication and developing a rapport with the family. Your message needs to be consistent. Always bear in mind who you are treating, and sometimes, you do need to ask the relative why they have a particular viewpoint.

It is relatively common for people to have two Enduring Guardians. Unfortunately, this can occur in families where there is already conflict. Its important to involve them both or at least check with them both that they are happy for the other person to speak on their behalf. Most people are reasonable and it is not a problem.

In ED, we seek support from other colleagues, specialists to negotiate an outcome. The Director of Medical Services is the next level up for concerns. Ultimately there is a legal framework that can be pursued including urgent court hearings if it is required. I would encourage you all to look at the End of Life Law for [Clinicians training modules](#)

5. What is MOLST?

A. Medical Orders for Life-Sustaining Treatment. It is a commonly used ACP in Newcastle RACFs. It is quite brief and can be quite difficult to interpret with a resident that you don't know.

6. How do you frame comfort care v's active treatment with families?

A. Don't make it an "either/or" situation. The aim is to provide treatment based on your best information about the illness and patient, and your understanding of the likelihood of response and the patient's wishes. Sometimes, you might suggest a treatment, eg, IV antibiotics, but review at 24-48 hours to gauge response. Ongoing communication is the key.

7. Do you think we should call Aged Care Facilities hospice instead?

A. They are often used as de-facto hospices, so it is not a bad idea. 41% of residents die within 12 months of visiting an ED in our region. Given their complex healthcare needs, frailty and vulnerability, this is not unexpected for us as clinicians, sometimes families have not heard this message though.

8. What can facilities / managing companies do to ensure this does not happen again?
- A. The main focus is to maintain screening of visitors to prevent an outbreak occurring. Prevention is the key. Also, the facility needs to have an Outbreak Management Team, which must include a local GP, which meets regularly to plan the response if an outbreak does occur. The Primary Health Network has worked closely with the Local Health Districts to plan for outbreaks. The [healthpathways](#) have lots of information that is helpful.
- Most years we have some kind of outbreak though this is more often influenza or noro virus. The principles remain the same.
9. Did lack of regular staff in Newmarch lead to confusion about end of life wishes for residents?
- A. It was just confusion all round. The vast majority of residents had an ACP for symptom relief in the facility. The problem was having staff (nursing/medical) review the patient to ascertain what their symptoms were. Unfamiliar staff take longer to know what the prodromal state of the resident is. The non-COVID affected patients were neglected, to some extent.
10. If we ask residents and families what they would like if they were to get COVID-19 what information should we be giving them what are the alternatives?
- A. You need to explain that, in a pandemic, choices may be limited, e.g., state government health orders, facility may go into lockdown so limiting contact with family, and so forth. It is more explaining what has happened when an outbreak has occurred, and the decisions may be more for convenience of family and easier way to handle infection control. In terms of management of various symptoms, you can explain that standards treatments will be follow (eg, relief from breathlessness) but that it comes down to the body's ability to mount a response to the infection. Sometimes this can be managed in the facility, sometimes residents need to go to hospital.
11. Do you think ACP or ACD should be a standard form across all residential age care and MPS?
- A. I don't know the reason why, but in NSW, there is no standard form for ACP. I read somewhere that there were 19 different versions available on-line. At the end of the day, though, it is still having ongoing discussions and ensuring access of the documentation is available for when it is needed.