

SESLHD GUIDELINE COVER SHEET



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SUMMARY	The document aims to guide staff on the development and review of Advance Care Planning documents used within the South Eastern Sydney Local Health District (SESLHD) facilities.

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Advance Care Planning

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Section 1 – Introduction

The SESLHD Comprehensive Care at End of Life Plan reconciles local priorities in accordance with the National Safety and Quality Health Service Standards. Considerable work has been completed within SESLHD in terms of identifying patients who may be approaching end of life, and providing mechanisms to support clinicians to assist patients to provide input into their care planning and developing goals of care.

One key component of delivering comprehensive care is to invite patients to consider their care needs and options in advance of experiencing serious or critical illness. SESLHD has developed this guideline to ensure our patient's wishes regarding decision making in critical illness and end of life care are known and respected, as well as providing guidance for staff on having advance care planning discussions.

The process of advance care planning is an ongoing one and can be integrated into routine clinical care. It may include one or more of the following:

- A conversation between a person and/or person responsible and/or their health professionals
- Documentation of an Advance Care Plan (ACP) as a result of one of these conversations
- Documentation of a formal Advance Care Directive (ACD), which has its own specific features and legal status
- Appointment of a substitute decision maker including an Enduring Guardian.

Section 2 – Executive Summary

Advance care planning is considered a core component of enabling patient involvement in health care decision making, and delivering quality patient care, particularly at end of life. This process enables the person's values and preferences to be clarified for those involved in their care before they are seriously or critically ill. The goal is to enable these preferences to be respected and use them to guide decision making when patients do not have capacity to make or are unable to communicate decisions for themselves.

This document has been developed to assist clinicians to establish advance care planning processes and is not intended to alter processes already underway. Advance care planning processes and pathways can be tailored to suit individual workflows within inpatient and outpatient areas.

All patients being cared for within SESLHD facilities and outreach teams who are approaching end of life should be identified as soon as possible to maximise opportunities to have advance care planning discussions so that patient's wishes for end-of-life care are known and respected.

In order to accept an advance care planning document, it must be reviewed by SESLHD staff, including the Admitting Medical Officer for validity and applicability and assessed in consultation with the patient or person responsible.

The advance care planning documents upload process is outlined separately in: [SESLHDPR/643 - Upload of Advance Care Planning Documents into the Patient Electronic Medical Record \(eMR\)](#).

Section 3 – Definitions

3.1 Advance care planning

Advance care planning is the process of reflection, discussion and communication that enables a person to plan for their future medical treatment and other care for a time when they cannot make their own healthcare decisions. This communication process enables the person's values and preferences to be clarified for all those involved in their care, before they are seriously or critically ill. The goal is to ensure the patient's preferences for care and treatment guide clinical decision making for a time when they are not competent to make or communicate decisions for themselves. At other times, decisions should be discussed with the patient in line with the principles of shared decision making and informed consent.

Formal advance care planning processes usually operate within a health, institutional or aged care setting after a life-limiting condition has been diagnosed and may involve the assistance of trained professionals. However, people can also choose to discuss their advance care plans in an informal family setting (A National Framework for Advance Care Planning Documents [2021]).

3.2 Advance Care Directives (ACDs)

An ACD is a type of advance care planning document recognised by common law or authorised by legislation that can only be completed by a person with decision making capacity. An ACD can record a person's preferences for future health care and can enable the appointment of a substitute decision-maker to make decisions about health care and personal life management. An ACD may be made in a wide variety of circumstances. These may include the person who is healthy but wants to plan their future medical care, the chronically ill person who anticipates deterioration in their condition, or someone who is terminally ill and faces more immediate treatment choices.

When an ACD is determined to be valid (see section 5.2) the content must be observed where there is specific consent for or refusal to appropriately offered treatments. Health professionals and family members have no authority to override a valid ACD.

3.3 Advance Care Plans (ACPs)

ACPs record the outcomes of an advance care planning discussions. The document may be completed by the patient or on their behalf by caregivers and healthcare professionals but should be prepared from the person's perspective.

There are multiple ways of recording an ACP, including oral and written versions, and different forms are available within Australia. If made on behalf of a person who does not have decision-making capacity, by their person responsible, relative or friend who has a close personal relationship, they should record any known preferences of the person. A preferred decision maker named in an ACP is not a statutory appointment.

It is important to note that ACPs are guiding only. All clinical decisions involve a reassessment of the goals of care, patient's values and preferences, and medically appropriate interventions specific to the circumstances at the time decisions need to be made.

3.4 Person Responsible

If a patient is not capable of consenting to their own treatment, the practitioner may need to seek consent from the patient's 'person responsible' (not the 'next of kin' as commonly referred). Under the Guardianship Act NSW (1987), there is a hierarchy of people who can

provide substitute consent. The 'person responsible' is one of the following people in order of priority:

An appointed guardian (including an enduring guardian) with a medical and dental function or, if there is no guardian:

1. The most recent spouse or de facto spouse where there is a close and continuing relationship or, if there is no spouse or de facto spouse
2. The unpaid carer or the carer at the time the person entered residential care (note: recipients of a government carer benefit are not considered to be paid) or, if there is no carer
3. A relative or friend who has a close personal relationship with the person

A person responsible does not have the same legal status as the person themselves.

Importantly, a person responsible cannot consent to:

- Special medical treatment, such as sterilisation operations, terminations of pregnancy and experimental treatments
- Treatment if the patient objects or has previously objected.

For further information see [Person Responsible Factsheet](#).

3.5 Substitute decision-maker

In New South Wales, a 'substitute decision maker' is a collective term for those appointed or identified by law to make decisions on behalf a person whose decision-making capacity is impaired.

3.6 Guardianship Appointments

An appointed guardian is legally authorised to make health and lifestyle decisions for a person who cannot do this for themselves. Appointed guardians are given functions or domains of decision-making such as accommodation, lifestyle and health services as well as medical and dental consent function. Documents should be reviewed to clarify functions assigned and directions within guardianship forms.

Appointed guardians include:

- An Enduring Guardian/s – in NSW, a legal appointment of a person to make healthcare and lifestyle decisions prior to the appointee's loss of mental capacity. The appointment is signed by the person (appointee) as well as their enduring guardian/s and these signatures are witnessed by a legal professional on a prescribed form.
- A private guardian – Following a NSW Civil and Administrative Tribunal (NCAT) Guardianship Division hearing, a person known to the patient may be appointed to provide substitute consent and/ or make healthcare and other decisions.
- The Public Guardian - Following an NCAT (Guardianship Division) hearing, a person employed by the Public Guardian may be appointed with specific functions as required such as, provide substitute consent and/ or make healthcare and other decisions.

Only Appointed Guardians (including Enduring Guardians) with a health service function are authorised to make treatment decisions regarding withdrawing and withholding of life sustaining treatment.

Section 4 – Responsibilities

Medical Head of Department

- Developing departmental clinical triggers or use of available systematic assessment tools to identify and offer patients and the person responsible an advance care planning discussion.

Medical Officers

- Review and validation of existing advance care planning documents and where applicable, arrange upload of documents into the patient's eMR
- Ensuring the existence of advance care planning documents are communicated within the multidisciplinary team in team meetings and handovers
- Monitoring the patient's condition and the directions within the advance care planning documents so that care can be provided in accordance with the patient's goals and preferences as far as this is possible and appropriate
- Review of advance care planning documents at each admission, and in discussion with the patient/person responsible where possible, document as required the medically appropriate care on the NSW Health Resuscitation Plan-Adult.

Nurse Managers and Nurse Unit Managers

- Assist with development of advance care planning departmental processes, referral pathways and the availability of resources within the unit/department
- Support staff training, awareness and understanding of advance care planning processes.

Registered Nurses and Allied Health Clinicians

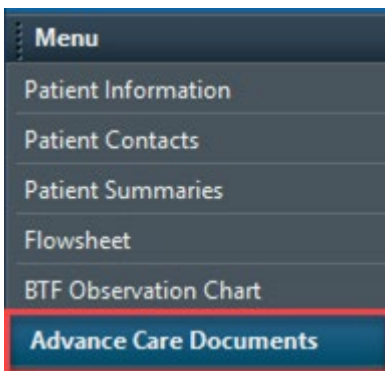
- On admission locating existing advance care planning documents and after review and validation by the Admitting Medical Officer, arrange upload of the documents into the patient's eMR as per the [SESLHDPR/643 - Upload of Advance Care Planning Documents into the Patient Electronic Medical Record \(eMR\)](#)
- Supporting patients and the person responsible to have advance care planning discussions
- Participating in available training opportunities to support understanding of advance care planning
- Ensuring the existence of advance care planning documentation is communicated in all team meetings and handovers.
- Be aware of departmental processes and pathways to enable advance care planning discussions.

Section 5 – On Admission

5.1 Locating pre-existing advance care planning documents

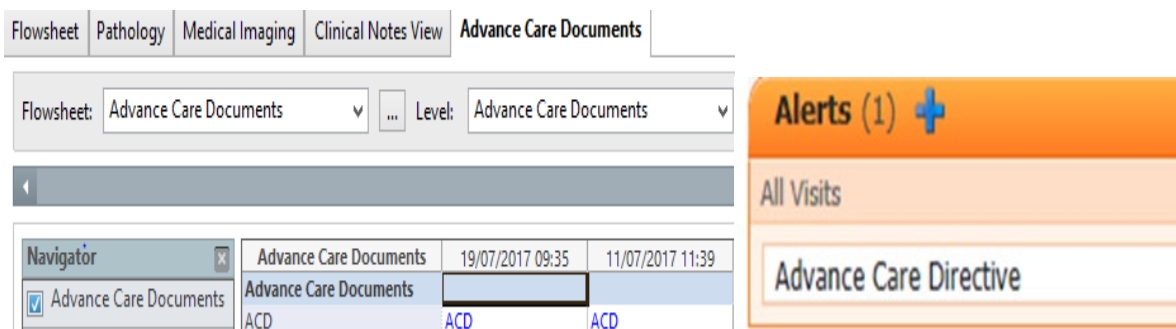
As part of the patient admission process it is the responsibility of all clinical staff to identify the existence of any previously completed advance care planning documents for patients. Currently, advance care planning documents are able to be located and stored in various ways. These include:

- The patient and/or person responsible providing a hard copy
- Included with the paperwork when a patient is transferred from their Residential Aged Care Facility (RACF) or other facility
- Already located in eMR and accessed via the Advance Care Documents tab
- Located in 'My Health Record' accessed via eMR- in FirstNet (ED) or PowerChart- Patient Summary view-HealthNet -Advance Care Directives
- Located in the paper medical record.



Where there are multiple uploads of documents within the Advance Care Document tab, the most recent document type should be referred to.

There will be an Alert in eMR notifying clinicians if an advance care planning document has been uploaded as below:



Flowsheet	Pathology	Medical Imaging	Clinical Notes View	Advance Care Documents												
Flowsheet: Advance Care Documents				Level: Advance Care Documents												
<table border="1"> <thead> <tr> <th>Navigator</th> <th>Advance Care Documents</th> <th>19/07/2017 09:35</th> <th>11/07/2017 11:39</th> </tr> </thead> <tbody> <tr> <td><input checked="" type="checkbox"/> Advance Care Documents</td> <td>Advance Care Documents</td> <td></td> <td></td> </tr> <tr> <td></td> <td>ACD</td> <td>ACD</td> <td>ACD</td> </tr> </tbody> </table>					Navigator	Advance Care Documents	19/07/2017 09:35	11/07/2017 11:39	<input checked="" type="checkbox"/> Advance Care Documents	Advance Care Documents				ACD	ACD	ACD
Navigator	Advance Care Documents	19/07/2017 09:35	11/07/2017 11:39													
<input checked="" type="checkbox"/> Advance Care Documents	Advance Care Documents															
	ACD	ACD	ACD													

If a competent patient has any completed advance care planning documents, staff should ask the patient;

- If the documents are still current and accord with the patient's wishes
- Where appropriate, staff should offer the patient the opportunity to review or make any changes to the documents if required. Revocation of advance care planning documents is detailed in [SESLHDPR/643 – Upload of Advance Care Planning Documents into the Patient Electronic Medical Record \(eMR\)](#).

5.2 Validating an ACD

ACDs are a type of advance care planning document that has a specific legal status. If a patient presents to a hospital or health service with an ACD it must be assessed for validity by the Admitting Medical Officer prior to acceptance and upload.

An ACD is valid and legally binding if:

1. It was completed voluntarily by a capable adult (a person with decision making capacity)
2. It is clear and unambiguous about the treatments that the person would accept or refuse
3. It is current, and extends to the specific circumstances/situation at hand

ACDs made in other states and territories are enforceable in NSW.

5.3 Reviewing the directions in documents

In order to accept an advance care planning document, it must be reviewed by SESLHD staff, including the Admitting Medical Officer and assessed in consultation with the patient or person responsible.

The documents must be checked for directions, and consideration must be given as to whether these apply to the current clinical situation. There may be occasions when the medical officer is required to interpret or gain further clarity around the wishes expressed in the document, or where the patient's presenting illness or condition is such that the contents of the document are not directly applicable.

Any treatment limitations outlined in the advance care planning document should be considered within the context of the patient's clinical condition, discussed with the medical officer, the patient and person responsible, and if appropriate and relevant, be specifically documented on the NSW Health Resuscitation Plan-Adult, for the current admission.

As the patient's condition could change at any time, decisions around care and the directions within these documents should be monitored and communicated within all handovers so that care can be provided in accordance with the patient's goals and preferences where possible.

5.4 What to do if there is conflict or uncertainty around care provision

It is not unusual for conflict to arise between the wishes and preferences of family members who are with the patient at the time of serious or critical illness, and the person responsible and/or the patient's wishes and preferences as reflected in the advance care planning documents.

It is critically important to remember that it is the patient's wishes and preferences that are guiding, both ethically and legally. These are heard either from themselves directly through the advance care planning process, or through the person responsible, and are what should be primarily considered in light of what is medically appropriate. The wishes and preferences of the person responsible and family members are also important, but not ultimately deterministic in how treatment decisions are made for the patient.

The gold standard is 'shared decision making' about goals of care, and subsequent agreement about appropriate treatments orientated around achieving these goals. Ideally, advance care planning discussions result in consensus about the best way to care for the person themselves.

Where conflict arises, communication between a senior medical officer and the person responsible is key. Good communication usually results in improved shared understanding of the situation, and resolution of any perceived or actual conflict.

If there is an ongoing disconnect between the preferences of patient or person responsible, and the clinical opinion regarding medically appropriate treatments, discussions may still be appropriately documented and uploaded as ACPs as they may provide guidance for clinical decision making in emergent situations.

If there is uncertainty or concern about decision making raised by the person responsible, senior medical assistance (Consultant or Director of Clinical Services) must be sought and appropriate treatment instituted while the situation is clarified. This may include a second senior medical opinion (of the same specialty) or relevant specialty consult i.e. Palliative Care, Geriatrician or Clinical Ethics Service.

For further information on dealing with uncertainty or conflict see:

- [SESLHDGL/091 - Dealing with family conflict in end-of-life decision making - Checklist for senior medical staff](#)
- [NSW Health Guideline GL2021_004 - End of Life Care and Decision-Making](#)
- [NSW Health Consent to Medical and Healthcare Treatment Manual - Section 6 Refusal of Treatment 2020](#)

Section 6 – Supporting Patients to have Advance Care Planning Discussions

6.1 Triggers when to offer patients an advance care planning discussion

Ideally, advance care planning discussions should be initiated when the patient's condition is stable, before they are acutely unwell or reaching end of life.

The discussion is particularly relevant for patients who;

- Healthcare staff believe the answer is "no" to the surprise question – "would I be surprised if this patient died in the next 12 months?"
- Have multiple or complex medical problems
- Are regularly admitted to hospital
- Are diagnosed with a chronic disease affecting major organs such as kidneys, lungs or heart
- Are diagnosed with a serious or life-limiting illness such as cancer
- Have had a Resuscitation Plan with a "Not for Cardiopulmonary Resuscitation (CPR)" order or other limitation of treatment order made in hospital
- Have previously had a critical event requiring resuscitation
- Are elderly or frail of health, and receiving supportive care services
- Are diagnosed with cognitive impairment or dementia
- Are relatively healthy but keen to plan for future healthcare
- Have requested a discussion around advance care planning
- Are transitioning from home or hospital to an RACF.
- Has been identified by departmental criteria or systematic tools E.g. Supportive and Palliative Care Indicators Tool (SPICT) - see Appendix 2.

6.2. Co-ordinated by

An advance care planning discussion can be coordinated by a senior medical officer or be referred to another experienced staff member (Allied Health, Medical or Nursing) to initiate or progress the discussion. Conversely, staff conducting advance care planning discussions must ensure the admitting medical officer is made aware that such a discussion has taken place, where this is not a pre-planned occurrence, and is broadly in agreement with the outcomes of that discussion. If there is disagreement, a further follow up discussion with the patient and other key clinicians should be arranged.

6.3 Location of discussion

In preparing a patient and person responsible for an advance care planning discussion, it is recommended that adequate time is arranged in a quiet and private location (ideally outside of the acute inpatient hospital setting). Advance care planning discussions can be held in a variety of settings including:

- the community with their GP
- an inpatient or outpatient clinic environment
- medical specialist rooms
- their home or Residential Aged Care Facility, sometimes with the help of a consultative service (i.e. Geriatric or Chronic Care Outreach Service, Inpatient or community Social Worker, Advance care planning Clinical Nurse Consultant, Geriatric Flying Squad or Community Palliative Care Team).

6.4 The discussion

6.4.1 Educate and inform

Prior to having an advance care planning discussion the patient and person responsible must be educated and fully informed on the advance care planning process. This may include offering advance care planning resources for consideration prior to the discussion- see section 10.

6.4.2 Including and supporting the patient

Discussions should involve the patient and person responsible. The goal is to enable the patient to participate if possible, regardless of their decision making capacity.

In all instances when communicating with patients and person responsible where English is not the language spoken, the interpreter service must be used and support services such as social work and/or chaplaincy should be made available as required.

6.4.3 Allow time

Sufficient time should be allocated for these discussions to allow the patient or person responsible to discuss what is important to them and to ask questions and express emotions. It may take several meetings and referral to appropriate staff (if required) to ensure that there is an understanding of the illness, prognosis and expected response to treatment.

6.4.4 Use the shared-decision making model

These discussions should use a shared-decision making model that acknowledges the patient's wishes and hopes and takes these together with the medical opinion about what is possible and appropriate in terms of harms and benefits. The aim of the discussion(s) is to reach consensus on a plan that will fit best with available options and is aligned with what is most important for the patient.

6.4.5 How to begin

Clinicians will each have their own approach to these discussions and it will need to adapt to each patient and situation.

As a general rule, it is usually helpful to start with confirming who the 'person responsible' is and their understanding of the situation, what they want to know and what they expect will happen. Clinicians may then be able to provide more information or correct misunderstandings if required.

6.4.6 Explore patient's goals

Clinicians can ask questions to find out what is important to their patients in the future, their values and preferences. This may include exploring patient's hopes, concerns, quality of life goals, spiritual, religious, cultural or interpersonal values, preferred place of care, preferred place or death and/ who they would like to help make their medical decisions if they are unable to.

6.4.7 Plan ahead

Based on the patient's values and the clinician's expectations about what is medically possible, the discussion may focus on planning ahead. This may include discussions about some or all of the following, based on what is appropriate to the situation such as:

- identifying the person/s responsible and considering the benefits of formally appointing an enduring guardian
- quality of life goals and what would be acceptable or unacceptable to them
- preferred place for future care if staying at home were too difficult
- preferred place for end of life care
- directions about medical care including CPR and other medical treatments
- specific requests after death e.g. personal or religious needs, organ or tissue donation
- their preferences for documentation of the plan/directive
- who they would like to have copies of the plan/directive.

6.4.8 Allowing for ongoing conversations

Patient's should be allowed to ask any questions about the process and an offer made to continue them during future visits and can be revised when the situation changes.

6.4.9 Documentation

It is important for documentation to clearly reflect the patient's values and preferences, as well as the consensus about what is considered 'medically appropriate' in their particular circumstance. See section 7 Process of Documentation.

For further information on supporting patients to have advance care planning discussions see [Advance Care Planning Australia for health and care workers](#) or Appendix 3 - Medical Communication Guide for Goals of Care and Future Care Planning.

Section 7 – Process of Documentation

SESLHD does not mandate a specific form or formats that must be used for advance care planning. It is important that patients are able to express their values and preferences about their future care in a form or format of their choice. This includes advance care planning documentation accompanying patients who are transferred from residential aged care facilities.

7.1 Completing an ACD

Within NSW there are many versions of ACD forms available to patients and all are acceptable presuming they are determined valid. Within the SESLHD, the ACDs available are:

- [Making an Advance Care Directive form and information booklet-NSW Health](#) a booklet with 10 pages of information and an attached form. It can be printed directly off the web or ordered through NSW Health website-see ordering details in section 10.
- [SESLHD Advance Care Directive form](#) and Information booklet which contains the same information as the booklet above but is located on the SESLHD forms site-see ordering details in section 10.

Both the NSW Health and SESLHD ACD forms should:

- Be assessed for validity prior to acceptance as per section 5.2.
- Be written in English
- Include the full name, date of birth and address
- Be signed and dated by the patient. While this is not legally required, inclusion provides reassurance around the patient's agreement with the document contents and the document currency.
- Be witnessed if possible. While this is not legally required it is encouraged to allow follow-up for clarification purposes if necessary.
- Be signed by a health professional. Although not a legal requirement, the form should be co-signed by a health professional who confirms that the person making the ACD had capacity and was aware of the implications of the information in the document.

7.2 Completing an ACP

If the patient is unable to participate in the advance care planning process due to irreversible illness or injury, an ACP can still be made in discussion with the clinical team and the person responsible, involving the patient wherever possible. The person responsible may document the known wishes of the patient on a [SESLHD Statement of Values and Wishes form*](#) to assist clinicians in treatment decisions. This document is based on the known values and preferences of the patient as understood by the person responsible.

*The Statement of Values and Wishes form was originally developed by the SWSLHD and the Director of the Clinical Governance Unit has given permission for its use within SESLHD.

The [SESLHD Medical Record of Advance Care Planning](#) is also available which is completed by a Medical Officer which is used to GUIDE decision making where the patient does not have capacity. It documents a future care planning discussion with the patient and/or their substitute decision maker, addressing agreed upon or not agreed upon medically appropriate care, and includes the patients expressed goals and preferences, preferred place of death and other wishes.

It is available on the SESLHD forms website.

7.4 NSW Health Resuscitation Plan-Adult

This Guideline does not seek to encompass policy and practice related to Resuscitation Plans, although the two patient care areas are closely linked.

It is important to differentiate advance care planning documents aimed at aligning care decisions with the patient’s values and preferences, from a Resuscitation Plan which is a medical order completed by a medical officer when the person is a patient in hospital. Any discussion and decision about resuscitation should always include consideration of whether there has been any form of advance care planning discussions undertaken with the patient or person responsible. Any refusal of CPR in a valid ACD must be respected. The content of any advance care planning documents should inform resuscitation decisions if clinically applicable on admission, and this should be clearly documented in the patient’s electronic medical record. While there may be an ongoing record of advance care planning discussions that have occurred over time in the electronic medical record, there needs to be a new Resuscitation Plan completed for the patient at each hospital admission.

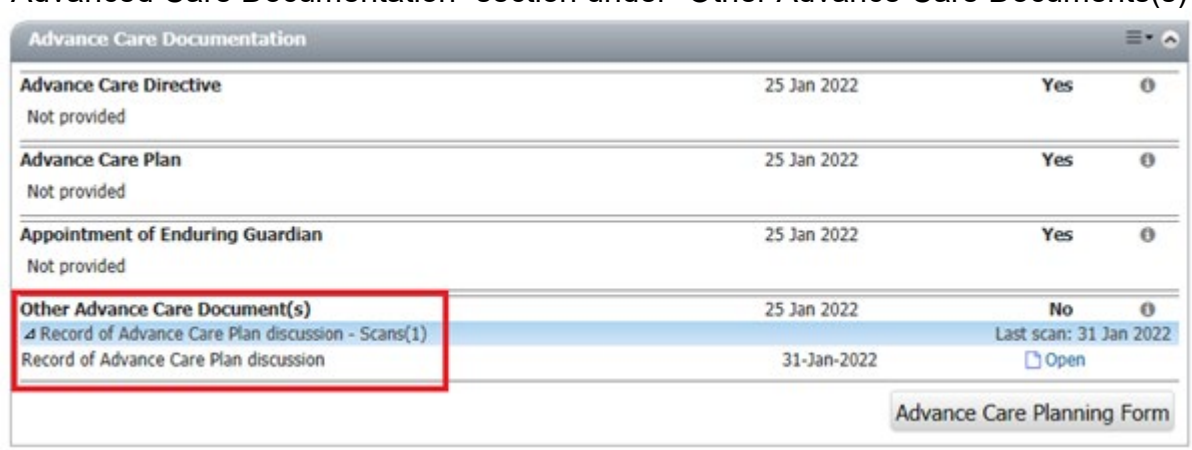
7.5 Documentation of discussions

All advance care planning discussions undertaken should be documented contemporaneously in the patient’s electronic medical record to ensure all members of the primary and associated treating teams are aware of the progress of the discussions.

7.6 Record of Advance Care Planning Discussion electronic field

A new ‘Record of Advance Care Planning Discussion’ documentation area has been built within Powerchart (eMR) to record brief Advance Care Planning discussions. This area is located in the Adhoc tab and opens to a free text area for medical, nursing or allied health to record discussions prior to completion of the formal SESLHD/ NSW Health ACD or SESLHD ACP. This area allows a continuum of discussions to be viewed in the Advance Care Documents tab and assist clinicians to find important advance care planning information that has occurred previously in a timely manner.

All existing ACDs and any Resuscitation Plan orders can be viewed on a single page. If a Record of ACP Discussion is completed via the Adhoc tab, it can be viewed in the “Advanced Care Documentation” section under “Other Advance Care Documents(s)”.

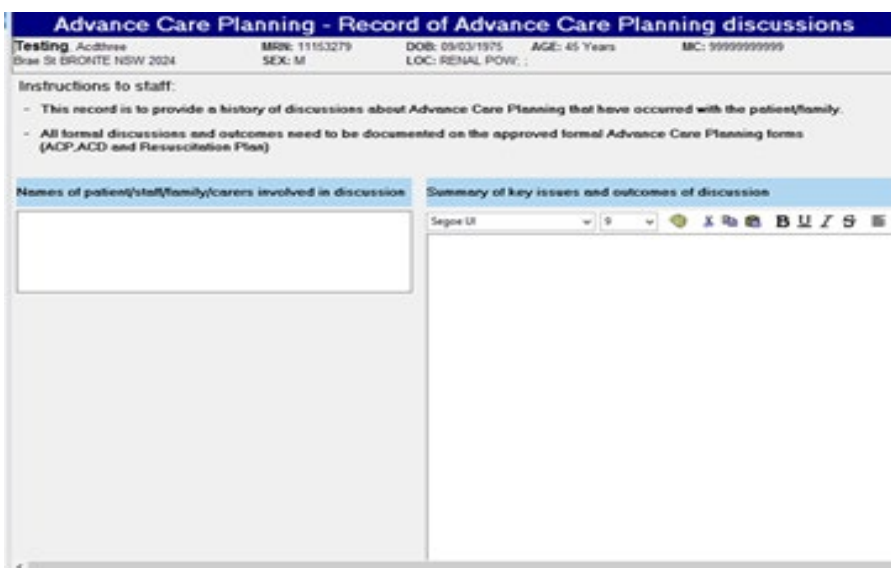
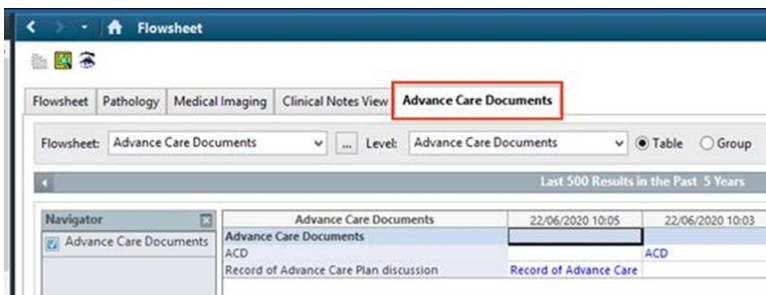
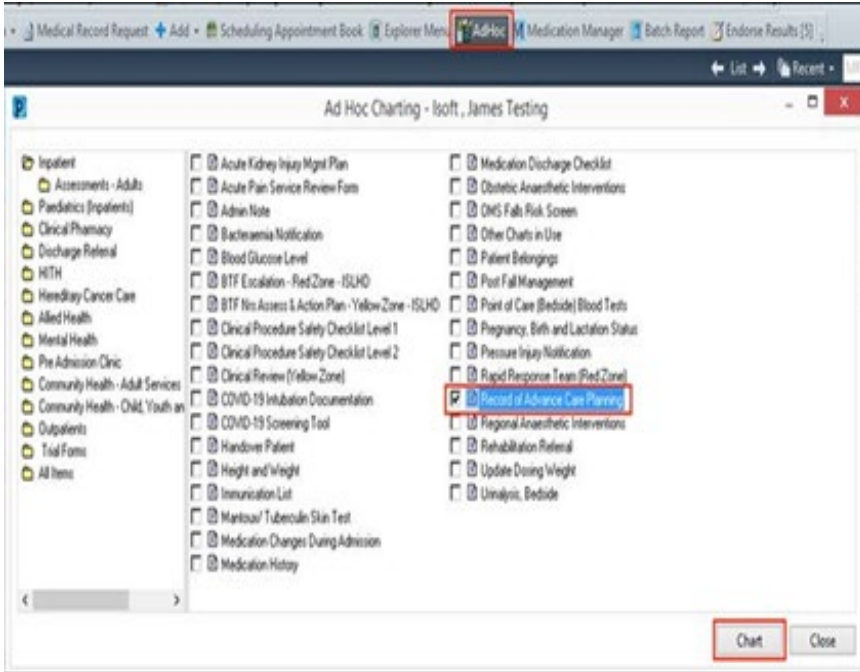


Advance Care Documentation			
Advance Care Directive	25 Jan 2022	Yes	ⓘ
Not provided			
Advance Care Plan	25 Jan 2022	Yes	ⓘ
Not provided			
Appointment of Enduring Guardian	25 Jan 2022	Yes	ⓘ
Not provided			
Other Advance Care Document(s)	25 Jan 2022	No	ⓘ
📄 Record of Advance Care Plan discussion - Scans(1)		Last scan: 31 Jan 2022	
Record of Advance Care Plan discussion		31-Jan-2022	Open

All subsequent formal documentation of these discussions should be uploaded to the electronic medical record according to the [SESLHDPR/643 - Upload of Advance Care Planning Documents into the Patients eMR.](#)

7.7 Integration of Care with Primary Health Providers and RACFs

One of the key challenges with implementing advance care planning is that there can be poor continuity of care between GPs, RACFs and hospitals. SESLHD aims to work collaboratively with the Primary Health Network and local RACF networks to develop a more coordinated approach in advance care planning processes. This may include the use of common forms, as well as shared education programs and information resources.



Section 8 – Patient Discharge

The patient retains the original advance care planning document and a copy should be included in the discharge summary so the GP and outreach teams are aware of its existence and content. Every effort is to be made to ensure communication of newly developed or ongoing discussions regarding advance care planning are known to the primary care providers.

If the patient meets any of the criteria outlined in Section 6.1, and on discharge hasn't been offered an advance care planning discussion in hospital, an explanation, and offer of resources, should be provided to the patient and person responsible - see resources section 10.

If the patient is returning to or transitioning to a RACF without an ACP, this information should be included in the discharge summary so that this can be attended to on admission to the facility.

If patients are returning home with outreach support services, or are known to chronic and supportive care programs, these teams should also be involved and progress advance care planning discussions where appropriate.

Section 9 – Quality Processes

Participation in any advance care planning quality activities (file audits, audits of upload procedure, incident monitoring and gap analysis) is recommended at each site to evaluate and improve the delivery of quality end of life care for patients, person responsible, family and carers.

Section 10 – Advance Care Planning Resources and Ordering Details

Advance care planning document	Ordering details
Advance Care Planning – ‘Making your wishes known’ fold out flyer	Advance Care Planning 'Making your Wishes Known' foldout flyer can be printed from the NSW Health website or order through Stream solutions; Product code - NH700599
Advance Care Planning Directive Information booklet and form-NSW Health (Ten page information and six page tear out form in a glossy blue booklet. Not yet available in other languages)	Options for ordering 1) Printed from NSW Health website 2) Order through Stream solutions; Product code - NH700682 (in English- not yet available in other languages)
SESLHD Advance Care Directive information booklet and form contains the same information as the NSW Health booklet above though in SESLHD form format.	SESLHD Advance Care Directive form and Information Booklet Order from Stream Solutions Advance Care Directive Information Booklet Product Code NHSIS0969 Advance Care Directive Product Code NHSIS0968
SESLHD Statement of Values and Wishes form	Values and Statement Wishes form Order from Stream Solutions Product code - NHSIS0971
Enduring Guardianship Information booklet and form	Enduring Guardianship in NSW - Your Way to Plan Ahead information booklet NSW Trustee and Guardian-Enduring Guardian booklet Enduring Guardianship Appointment Form.

Section 11 – Education and Training

This guideline will be supported through in-services and workshops by the SESLHD advance care planning leads. Workshops are open to all health professionals to attend and are aimed at increasing confidence in discussing advance care planning as part of routine care. Facility leads are available to assist in developing departmental processes and to mentor clinicians to have advance care planning discussions.

<u>Advance Care Planning Health Education and Training Courses (HETI)</u>	
Introduction to Advance Care Planning Course Code: 39997722 Duration: 30 minutes	The aim of this module is to raise clinician awareness of advance care planning including key terms and process of advance care planning
SHAPE End of Life Conversations Course Code: 88619342 Duration: 30 minutes	This module provides a step by step communication framework for clinicians to conduct effective end of life conversations with patients, families and carers. The module is most appropriate to clinicians in hospitals, who do not regularly have end of life conversation as part of their role. The content is targeted at doctors, nurses and social workers.

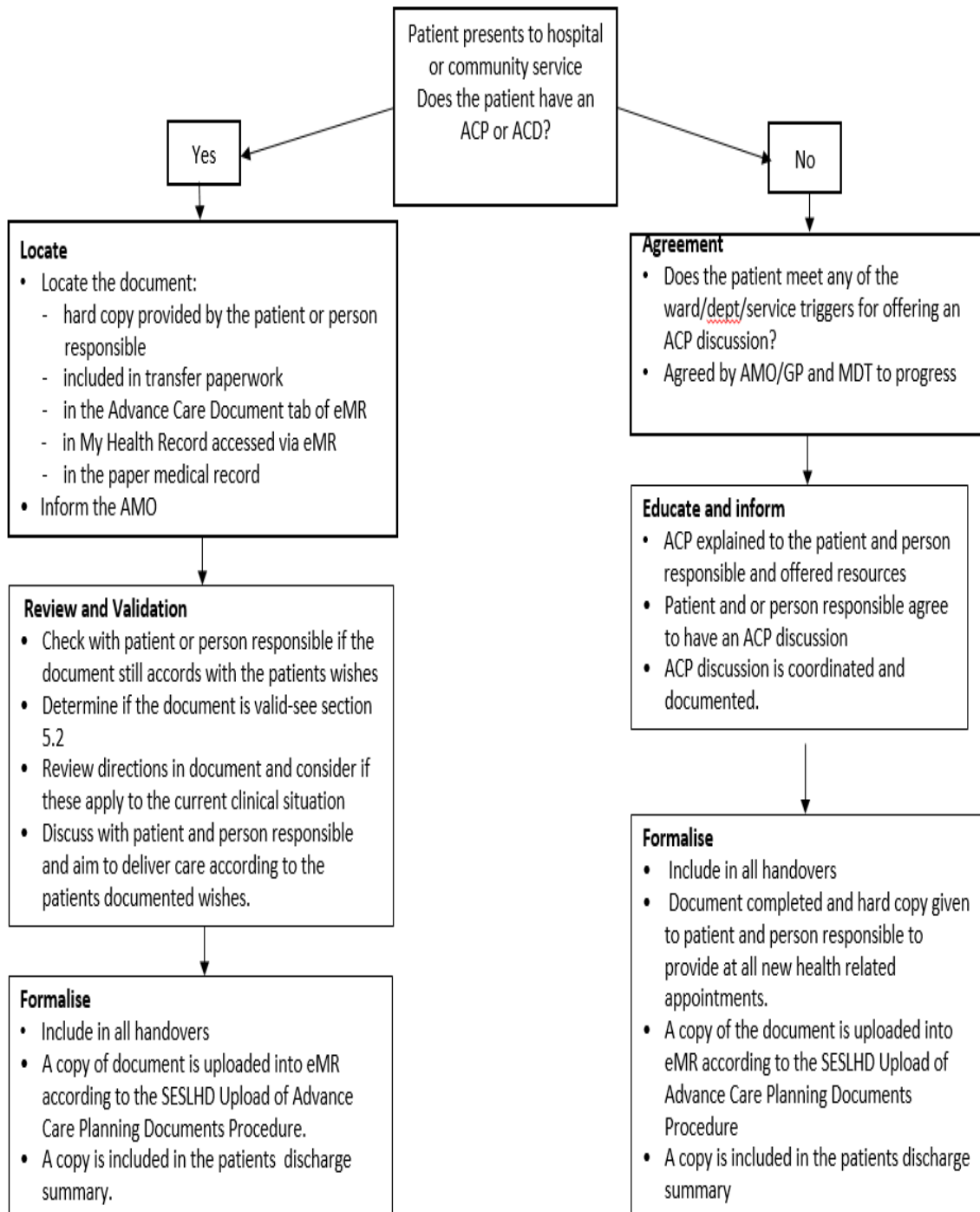
References and Resources

- [NSW Health Policy Directive PD2014_030 - Using Resuscitation Plans in End of Life Decisions](#)
- [NSW Health Guideline GL2021_004 - End of Life Care and Decision-making](#)
- [Consent to gender affirming medical treatment - update to Consent to Medical and Healthcare Manual](#)
- [NSW Health End of Life and Palliative Care Framework 2019-2024](#)
- [NSW Ministry of Health \(2015\) Dignity, Respect and Choice: Advance Care Planning for End of Life for People with Mental Illness](#)
- [Australian Commission on Safety and Quality in Healthcare \(2021\) Delivering and Supporting Comprehensive End of Life Care: a user guide](#)
- [Advance Care Planning Australia](#)
- [The National Safety and Quality Health Service Standards - Version 2](#)
- [National Framework for Advance Care Planning Documents \(2021\)](#)
- [NSW Government - NSW Trustee and Guardian](#)
- [SESLHDPR/643 - Upload of Advance Care Planning Documents into the Patient Electronic Medical Record \(eMR\)](#)
- [VITALtalk](#)
- [SESLHD Advance Care Planning Statement of Values and Wishes SES001003](#)
- [SESLHD Advance Care Directive SES001001](#)
- [SESLHD Medical Record of Advance Care Planning Discussion](#)

Version and Approval History

Date	Version no:	Author and approval notes
April 2020	Draft	Draft for Comment period
July 2020	Draft	Endorsed by Executive Sponsor
August 2020	Draft	Processed by Executive Services prior to submission to Clinical and Quality Council
September 2020	Draft	Approved by Clinical and Quality Council Published by Executive Services
August 2021	1	Minor Review: Removed details related to Ambulance Plans, updated resources ordering information and references. Approved by Executive Sponsor.
March 2022	2	Minor review: Addition of screen shots to identify location of Advance Care documents in eMR. Approved by Executive Sponsor.
12 September 2024	2.1	Minor review: References updated and addition of SESLHD clinical forms in resources section. Minimal .changes made to Section 3.2 and Section 6.4.5

Appendix 1: Advance Care Planning Process Flowchart



Appendix 2: Supportive Palliative Indicators Tool



Supportive and Palliative Care Indicators Tool (SPICT™)

The SPICT™ is used to help identify people whose health is deteriorating. Assess them for unmet supportive and palliative care needs. Plan care.

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.
- The person has had significant weight loss over the last few months, or remains underweight.
- 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.

Look for clinical indicators of one or multiple life-limiting conditions.

Cancer	Heart/ vascular disease	Kidney disease
Functional ability deteriorating due to progressive cancer.	Heart failure or extensive, untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal effort.	Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.
Too frail for cancer treatment or treatment is for symptom control.	Severe, inoperable peripheral vascular disease.	Kidney failure complicating other life limiting conditions or treatments.
Dementia/ frailty	Respiratory disease	Stopping or not starting dialysis.
Unable to dress, walk or eat without help.	Severe, chronic lung disease; with breathlessness at rest or on minimal effort between exacerbations.	Liver disease
Eating and drinking less; difficulty with swallowing.	Persistent hypoxia needing long term oxygen therapy.	Cirrhosis with one or more complications in the past year:
Urinary and faecal incontinence.	Has needed ventilation for respiratory failure or ventilation is contraindicated.	• diuretic resistant ascites
Not able to communicate by speaking; little social interaction.	Other conditions	• hepatic encephalopathy
Frequent falls; fractured femur.	Deteriorating and at risk of dying with other conditions or complications that are not reversible; any treatment available will have a poor outcome.	• hepatorenal syndrome
Recurrent febrile episodes or infections; aspiration pneumonia.	Review current care and care planning.	• bacterial peritonitis
Neurological disease	<ul style="list-style-type: none"> ▪ Review current treatment and medication to ensure the person receives optimal care; minimise polypharmacy. ▪ Consider referral for specialist assessment if symptoms or problems are complex and difficult to manage. ▪ Agree a current and future care plan with the person and their family. Support family carers. ▪ Plan ahead early if loss of decision-making capacity is likely. ▪ Record, communicate and coordinate the care plan. 	• recurrent variceal bleeds
Progressive deterioration in physical and/or cognitive function despite optimal therapy.		Liver transplant is not possible.
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.		

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

SPICT™, April 2017

Appendix 3 - Medical Communication Guide for Goals of Care and Future Care Planning

Tips for doctors having complex discussions in the clinic, on the wards and in the context of COVID-19

Ideally, goals of care discussions use a **shared decision making model**. This means that a patient's wishes and hopes are understood and acknowledged, and taken together with the medical opinion about what is possible and appropriate in terms of harms and benefits. The aim is to reach consensus on a plan for what will **fit best with the available options** and is aligned with what is **most important for this person**. Having these discussions in the Emergency Department or on the Wards often feels pressured, and can be very challenging when patients are critically unwell. *It's ok to feel apprehensive or uncomfortable before these conversations*, especially in these extraordinary circumstances.

PREPARE. Before you begin:

- Does this patient have capacity to have these conversations?
 - o If they do not have capacity, establish their person responsible first and involve them in the discussion.
- Do they already have an Advance Care Directive or Advance Care Plan that you can start with and build on?
- Take a moment to think about the things you are going to say.
- Try to find out about your patient's chronic health problems (severity, frequency of hospital admissions) AND their level of function/frailty (assistance with ADLs, mobility, ECOG status etc). This will help you to frame your discussions

GENERAL TIPS

- Goals of care discussions are not just about resuscitation and dying – they are as much about **how the patient wants to live**.
- ALWAYS check the patient and / or family's understanding of the situation BEFORE you give any medical information
 - o What does the patient/family **know, expect or want to know** about their current health situation?
 - o Don't be afraid to ask several questions if you need to
- Acknowledge **emotion** during conversations. It's normal for patients/families to feel strong emotions in these discussions
 - o Have a look at the guides below or use the NURSE acronym on page 2 to aid you
- Remember that you might be **breaking unexpected bad news**
 - o Give information slowly in **chunks** with **pauses** for people to respond especially if over the phone or if wearing a facemask
- **Remember we're not obliged to offer futile interventions**, so avoid offering a choice about an intervention where there little chance of success.
 - o If a patient would not benefit from CPR, do not say "Would you want CPR if your heart stops?"
 - o If a patient would not benefit from invasive ventilation do not say "Would you want a breathing tube and ventilation if your lungs fail?"
 - o Instead, use the guides below to **provide recommendations that align the patient's goals with what is medically possible**
- **If you say the wrong thing, it's ok** – "*I'm sorry, that didn't come out right, can I start again?*"

Resource prepared 17/07/2020 by Dr Lisa Potter (Palliative Care Specialist, The Sutherland Hospital),

AFTERWARDS

- Check-in with yourself – how are you feeling? Do you need to take moment for yourself? What went well/ what did you learn for next time?
- Consider debriefing with a colleague – what phrases do they use that you could incorporate for next time?
- Work with a Social Worker who can support the family/patient
- Struggling to reach consensus? Consider referral to another team for a second opinion e.g. ICU, Palliative Care or Aged Care
- Document these conversations in detail, even if you didn't get to talk about CPR

SUGGESTED SCRIPTS for FUTURE CARE PLANNING DISCUSSIONS

The three guides below all follow the **REMAP** acronym as a roadmap for goals of care discussions in different settings (adapted from VitalTalk¹)
Adjust the scripts below to suit you and your patient

Reframe changes to patient's condition
Expect emotion
Map the future
Align with patient's goals
Plan treatment

TIPS FOR RESPONDING TO EMOTIONS

Use the **NURSE** acronym. Adapted from VitalTalk²

Name the emotion *"You sound really **frustrated**" "You seem anxious"*
Understanding *"You've had a really hard time over the last few weeks" "It sounds like everything has changed very quickly"*
Respecting *"You've done a great job looking after your mum at home for so long"*
Supporting *"We'll do everything we can to support you through this"*
Exploring *"Tell me more about that" "what worries you most?"*

Resource prepared 17/07/2020 by Dr Lisa Potter (Palliative Care Specialist, The Sutherland Hospital),
 Dr Linda Sheahan (Palliative Care Specialist and Clinical Ethicist St George Hospital)
 Dr Amy Waters (Palliative Care Specialist Calvary & St George Hospitals)

² VitalTalk 

SETTING 1: Future care planning and goals of care discussions in clinics (e.g. progressive chronic illnesses or frailty).

Triggers for these discussions might be a recent admission to hospital, a deterioration in health/test results, increasing frailty, patient interest in advance care planning discussions or specific prognostic criteria outlined by your department.

<p>Reframe changes to patient's condition</p>	<ol style="list-style-type: none"> 1) Assess understanding 2) Confirm or correct understanding - reflect what the patient says 3) Reframe the changes 	<p><i>"What is your understanding of your health situation and what is likely to happen?"</i> <i>"What have you been told about where things are up to with your cancer/kidney disease/lung disease?"</i> <i>"What did your cardiologist say about your heart last time you saw her?"</i> <i>"What kind of assistance do you need at home? Is that different to a month ago/6 months ago?"</i> <i>"Do you know what the last tests showed? Would you like me to take you through them?"</i> <i>"I agree, your lungs really are a lot worse than they were 6 months ago"</i> <i>"You're right, the cancer isn't responding to the treatment"</i> <i>"I agree, <u>it sounds like things are changing / we are in a different place now</u>"</i> <i>"Based on ... we need to think differently about your care going forward"</i></p>
<p>Expect emotion</p>	<p>Address the emotions before you continue</p>	<p><i>"I can see this is really upsetting for you"</i> <i>"I wish things were different"</i> <i>"This is a really hard thing to talk about"</i></p>
<p>Map the future</p>	<p>Explore possibilities Plan ahead together</p>	<p><i>"Have you thought about what would happen if you become more unwell?"</i> <i>"With your current treatment we've been hoping for... It's possible that things won't improve"</i> <i>"This is so difficult/uncertain. Let's work out a plan together"</i></p>
<p>Align with patient's goals</p>	<ol style="list-style-type: none"> 1) Find out what matters to the patient and reflect this back to the patient 2) Establish their person responsible 	<p><i>"Tell me what matters to you/what you're hoping for."</i> <i>"Given this situation, what's most important to you?"</i> <i>"What worries you the most?"</i> <i>"I'm hearing from you that it's important to [maintain your independence/ spend time with your family/be free from pain/spend time out of hospital/not be a burden/ not be a vegetable]"</i> <i>If the patient asks for something impossible "I wish I could turn this around"</i> <i>"It's important that we make decisions about your care together whenever we can. If you become too sick to make decisions for yourself, who would you wish to make decisions on your behalf?"</i></p>
<p>Plan treatment</p>	<p>Plan ahead and make recommendations based on their priorities and what is possible Keep the conversation open</p>	<p><i>"It sounds like the most important things to you are [reflect their goals]"</i> <i>"Let's make a plan so you can do more of that"</i> <i>"I would recommend we [start with what you CAN do] and I would not recommend using machines to support your lungs or resuscitation if your heart stops as they're unlikely to be beneficial for you"</i> <i>"Thank you for talking about this with us. These conversations are difficult but so important"</i> <i>"We can continue to talk about our plan when we meet next time and you can ask me any questions"</i></p>

SETTING 2: Goals of care discussion for the acutely unwell hospital inpatient where ICU admission may not be / is not appropriate – “Late Goals”

<p>Reframe changes to patient’s condition</p>	<p>1) Assess understanding</p> <p>2) Confirm or correct understanding - reflect what the patient says</p> <p>3) Reframe the changes</p>	<p><i>“What is your understanding of your health situation and what is likely to happen?”</i> <i>“What have you been told about where things are up to with your chest infection/kidney failure/cancer?”</i> <i>“What did your cardiologist say about your heart last time you saw her?”</i> <i>“Do you know what the last tests showed? Would you like me to take you through them?”</i> <i>“I agree, things are changing quickly/ your Dad is needing a lot more oxygen than when he came in / his kidneys are getting worse each day despite the fluids and medications/ the cancer isn’t responding to the treatment”</i> <i>“This infection really <u>changes things</u>. We are in a different place now”, “I agree, I’m worried too”</i></p>
<p>Expect emotion</p>	<p>Address the emotions before you continue</p>	<p><i>“I can see this is really upsetting for you”</i> <i>“I wish things were different”</i> <i>“This is a really hard thing to talk about”</i></p>
<p>Map the future</p>	<p>Explore possibilities</p> <p>Plan ahead together</p>	<p><i>“Have you thought about what would happen if you become more unwell?”</i> <i>“Has your mum ever talked about what sort of treatment she would want in this situation?”</i> <i>“This is so difficult/uncertain. Let’s work out a plan together”</i></p>
<p>Align with patient’s goals</p>	<p>1) Find out what matters to the patient and reflect this back to the patient</p> <p>2) Establish their person responsible</p>	<p><i>“Tell me what matters to you/what you’re hoping for”. “Given this situation, what’s most important to you?”</i> <i>“I’m hearing from you that it’s important [recover from this illness/ to spend time with your family/be free from pain/spend time out of hospital]”</i> <i>If patient asks for something impossible “I wish I could turn this around”</i> <i>“If you become too sick to make decisions for yourself, who would you wish to make decisions on your behalf?”</i></p>
<p>Plan treatment</p>	<p>Plan ahead and make recommendations based on their priorities and what is possible</p> <p>Keep the conversation open</p>	<p><i>“It sounds like the most important things to you are [use their goals]”</i> <i>“Based on what we’ve just discussed, I would recommend we [start with what you CAN do eg, support you with fluids, oxygen and antibiotics / stop these treatments that aren’t working and focus on your comfort and dignity]. I would not recommend using machines to support your lungs or resuscitation if your heart stops as they’re unlikely to be beneficial for you”</i> <i>“If it looks like you are dying we will focus on keeping you comfortable”</i> <i>“We will continue to look after you and update your family every step of the way”.</i></p>

SETTING 3: Initial goals of care discussions in a COVID-19 positive patient where ICU may not be/ is not appropriate

<p>Reframe changes to condition</p>	<ol style="list-style-type: none"> 1) Assess understanding of their background health and COVID-19 2) Confirm or correct understanding - reflect what the patient says 3) Reframe the changes 	<p><i>“Tell me about how your overall health has been recently before this infection?”</i> <i>“What have you been told about where things are up to with your emphysema/cancer/kidney disease?”</i> <i>“What did your cardiologist say about your heart last time you saw her?”</i> <i>“Have you been needing more help at home? Has this changed recently?”</i> <i>“What do you know about the COVID swab we took yesterday?”</i> <i>“What do you know about COVID?”</i> <i>“You’re right, this COVID result really <u>changes things</u>”, “You’re right, people in your situation often get unwell really quickly with COVID”, “I agree, this is a serious infection and we need to plan ahead together”</i></p>
<p>Expect emotion</p>	<p>Address the emotions before you continue</p>	<p><i>“I can see this is really upsetting for you”</i> <i>“I wish things were different”</i> <i>“This is a really hard thing to talk about”</i> <i>“You are in a very scary situation”, “You seem really anxious about...”</i></p>
<p>Map the future</p>	<p>Explore possibilities Plan ahead together</p>	<p><i>“Have you thought about what would happen if you become more unwell?”</i> <i>“Has your mum ever talked about what sort of treatment she would want in this situation?”</i> <i>“This is so difficult/uncertain. Let’s work out a plan together”</i></p>
<p>Align with patient’s goals</p>	<ol style="list-style-type: none"> 1) Find out what matters to the patient and reflect this back to the patient 2) Establish their person responsible 	<p><i>“Tell me what matters to you/what you’re hoping for”</i> <i>“Given this situation, what’s most important to you?”</i> <i>“I’m hearing from you that it’s important [to recover from this infection/ not prolong suffering / spend time with your family/be free from pain/ get back home]”</i> <i>If patient asks for something impossible “I wish I could turn this around/I wish things were different”</i> <i>“If you become too sick to make decisions for yourself, who would you wish to make decisions on your behalf?”</i></p>
<p>Plan treatment</p>	<p>Plan ahead and make recommendations based on their priorities and what is possible Keep the conversation open</p>	<p><i>“It sounds like the most important things to you is that you don’t want to suffer/ your life prolonged unnecessarily if this infection gets worse. I think that’s really sensible, and I’d recommend that we do everything we can to support you through your COVID infection but if you’re getting worse despite all the treatment, we’ll keep you comfortable here on the ward and we won’t put you on a breathing machine ”</i> <i>“If it looks like you are dying we will focus on keeping you comfortable”</i> <i>“We will keep you and your family updated every step of the way”</i></p>