The Advance Project™ Toolkit

Better primary health care through team-based initiation of advance care planning and palliative care

The Advance> Project™

RACGP Accepted clinical resource

APNA CPD ENDORSED 2019

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Better primary health care through team-based initiation of advance care planning and palliative care

For more information about The Advance Project and Toolkit, see our website at *www.theadvanceproject.com.au*

This resource has been endorsed by Australian Primary Health Care Nurses Association (APNA) according to approved quality standards criteria.

The Advance Project Toolkit has been officially recognised as an Accepted Clinical Resource by The Royal Australian College of General Practitioners.

Contact us at:
AdvanceProject@hammond.com.au

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IN COLLABORATION WITH

CareSearch palliative care knowledge network
The University of Sydney
The University of Queensland Australia
University of Wollongong Australia
Austin Health
UTS
La Trobe University

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Section 1

Introduction

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- The role of general practice in advance care planning and palliative and supportive care.

Section 1 - Introduction

What is the Advance Project?

The Advance Project includes a practical, evidence-based toolkit of screening and assessment tools and a training package, which are specifically designed to support Australian general practices to implement a team-based approach to initiating advance care planning and palliative care into everyday clinical practice. It will help your practice to:

- Sensitively introduce the topic of advance care planning to either elderly or chronically ill patients
- Identify patients who might be at risk of deteriorating and dying and hence benefit from an assessment of their supportive care needs
- Build on relationships with patients who might be at risk of deteriorating and dying by conducting a supportive care needs assessment, including screening for these patients' symptoms, concerns, questions, and priorities
- Support and screen the needs of carers of patients who might be at risk of deteriorating and dying
- Assess whether the patient's needs can be met by the practice and existing support structure or whether they may require additional support, including an early referral to specialist palliative care services.

The Advance Project Toolkit is designed to complement the Advance Project online training modules as a 'how-to' guide to help you implement the Advance Project resources into your clinical practice. It is ideally used as a reference document, after completion of the online training modules. Free online training modules are available for general practitioners (GPs), general practice nurses, and practice managers.

What is in this Advance Project Toolkit?

The Advance Project Toolkit consists of tools, patient/carer assessment booklets and resources, and a guide to enable GPs and nurses to undertake screening and assessment of patients to:

- Sensitively promote awareness of advance care planning with elderly and/or chronically ill adults
- Identify those patients who may be at risk of deteriorating and dying
- Assess these patients' symptoms, important questions, and concerns and identify their carers' concerns
- Identify patients who might most benefit from referral to a specialist palliative care service.

The Advance Project Toolkit was informed by a literature review of the best available evidence about tools to support palliative care and advance care planning in general practice, as well as through input from our expert advisory group and feedback from general practice nurses, GPs, and consumer representatives.

What is the aim of the Advance Project?

The Advance Project aims to enable earlier consideration and uptake of advance care planning, more efficient use of GP and nurse time in providing palliative and supportive care, and more appropriate and timely referrals to specialist palliative care services if required. The Advance Project aims to increase confidence and comfort levels for GPs and general practice nurses in initiating conversations about advance care planning and assessing patients' and carers' palliative and supportive care needs. The project also aims to equip general practice managers to support GPs and general practice nurses to overcome any barriers to successful implementation of the Advance Project tools and resources into routine practice.

How is the training funded and delivered?

The program is available FREE of charge for general practice nurses, GPs, and practice managers working in Australian general practices. The Advance Project is funded by the Australian Government Department of Health and delivered by a national consortium. We offer FREE online training and resources and FREE individualised tele-mentoring and support from a specialist palliative care nurse mentor. Grants and train-the-trainer support will also be available for selected champion networks to deliver face-to-face training and support implementation locally. The training will count towards continuing professional development requirements and you will receive a certificate of completion for the online training and face-to-face workshops.

What are advance care planning, palliative care and supportive care? And what is the role of general practice in these areas?

Advance care planning

Advance care planning is a “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 are not competent to make, or communicate, decisions for themselves” (Royal Australian College of General Practitioners). A key step in advance care planning is to establish how the patient would like decisions to be made about their care if they were too unwell to speak for themselves.

Role of general practice in advance care planning

The general practice team is ideally suited to initiate and promote advance care planning due to the ongoing and trusted relationships that develop with patients. The general practice also provides opportunities to have advance care planning discussions in a non-threatening environment and enables these discussions to start early, while a patient is still relatively well, so they don’t miss out on the opportunity to plan for their future care. Both GPs and general practice nurses have an important role in advance care planning. It is important that GPs and nurses have the appropriate training and education to support whatever role they undertake in delivering advance care planning in their practice.

Palliative care

Palliative care can be defined as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (World Health Organisation).

Supportive care

Supportive care is care that eases the symptoms of a disease or the side effects of treatment for a disease. Supportive care does not cure the disease. It is aimed at improving quality of life and it addresses the psychological, social, and spiritual needs of patients and their carers (Fitch, 1994).

People with chronic progressive illness experience a variety of supportive care needs that will change during the trajectory of their illness. Carers of these patients may be profoundly affected by the life-threatening condition and may also experience ongoing supportive care needs that change over time.

Supportive care vs palliative care – which terminology to use

- The terms ‘supportive care’ and ‘palliative care’ are very similar
- In a general practice setting, ‘supportive care’ may be a gentler way to introduce the concept to a patient or carer when first assessing their palliative and supportive care needs
- When a patient first hears the word ‘palliative’, they may assume they have only days to live
- By the time people need referral to specialist palliative care, palliative care needs to be explained. Tips and videos about this can be found on page 77.

Role of general practice in palliative and supportive care

GPs and general practices have a critical role in caring for patients who are at risk of deteriorating health and dying. General practices are ideally placed to identify these patients early so that their palliative and supportive care needs can be assessed. Timely palliative and supportive care is important for patients who might be at risk of deteriorating health.

Both GPs and nurses play a key role in patient management within general practices. The central role played by GPs is obvious. Nurses in general practice are already involved in managing patients who are at risk of deteriorating health and dying. Given their ongoing relationship with patients and carers and the level of trust developed, general practice nurses can help such patients identify their most important symptoms, concerns, and priorities that they would like addressed by their GP.

Assessment tools can be used to identify any unmet supportive care needs of a patient with a chronic progressive condition and the needs of their carer. These tools are a systematic way of gathering information to identify the specific needs, concerns, and problems of patients and carers.

References

Royal Australian College of General Practitioners. Advance Care Planning. Available at: http://www.racgp.org.au/your-practice/business/tools/support/acp/

World Health Organisation. 2016. Definition of Palliative Care. Available at: http://www.who.int/cancer/palliative/definition/en/

Fitch MI. 1994. Providing supportive care for individuals living with cancer (Task Force Report). Ontario Cancer Treatment and Research Foundation: Toronto.

Section 2

The Advance Project Guide

This section contains the following information:

- Description of the Advance Project Guide
- The Advance Project Guide diagram.

Section 2 - The Advance Project Guide

The Advance Project Guide (see the diagram on page 12) provides guidance on how general practices can systematically initiate advance care planning and palliative care with suitable patients in their practice. A video explaining the guide is available from the Advance Project website **www.theadvanceproject.com.au**

The Advance Project Guide describes 3 phases for initiating advance care planning and palliative care in general practice:

1. Identify suitable patients
2. Screen for their needs
3. Evaluate patient needs.

Phase 1: How do I identify patients?

Initially, the following patients would be identified in the general practice:

- Those aged 75 years or over, for example patients attending the 75 years and over annual health assessment
- Patients aged 18 years or over with one or more chronic progressive illnesses. This includes both malignant and non-malignant conditions.

Identifying patients appropriate for advance care planning

All patients who meet the above criteria, given they are elderly or have a chronic progressive illness, would be appropriate for an early introduction to advance care planning. This could be introduced during the annual health assessment, a care plan review, or a routine consultation by a nurse or the GP using the Advance Care Planning Screening Interview or quick guide.

Identifying patients appropriate for palliative and supportive care needs assessment

Not all patients meeting the above criteria may be appropriate for palliative and supportive care needs assessment. The 'surprise' question and the SPICT™ (Supportive and Palliative Care Indicators Tool) can be used to identify a subset of these patients who may also benefit from a full assessment of their palliative and supportive care needs. These tools can be applied either opportunistically or systematically.

- Opportunistically, the GP or nurse can use time set aside for preventative care during routine consultations, health assessments, or care plan reviews to apply the surprise question and/or the SPICT™ to that patient.
- Systematically, the GP and the nurse can apply the surprise question and the SPICT to a group of patients, perhaps on a list generated through a search of the patient database for all active patients aged 75 years or over, and patients aged 18 years or over with chronic progressive diseases (e.g., you may wish to prioritise patients with congestive cardiac failure and chronic kidney disease now and get to the others later). An electronic pop-up can then be applied to the medical records of these patients to remind the GP or the nurse that they have been identified as being suitable for a full assessment of their supportive care needs.

Consider the answer to the 'surprise' question first:

> *"Would you be surprised if this patient died within the next 6 to 12 months?"*

You could ask yourself this question or discuss it with other health care professionals.

Patients for whom the answer to the surprise question is "No" would benefit from a full assessment of their supportive care needs, in addition to an introduction to advance care planning.

If the answer to the 'surprise' question is "Yes", the full supportive care needs assessment is not necessary at this stage, but the patient may still benefit from introduction to advance care planning.

If you are unsure about the answer to the 'surprise' question, the SPICT^{TM} can be a useful aid to decision-making. The SPICT^{TM} tool can help you to determine whether the patient might be at risk of deteriorating and dying and therefore benefit from an assessment of their supportive care needs. If you are a nurse, you might like to discuss the patient with the GP and decide together whether the patient meets enough SPICT^{TM} indicators for being at risk of deteriorating and dying for you both to think that a full supportive care needs assessment would be helpful. In any case, an introduction to advance care planning would still be appropriate.

Phase 2: How do I screen patients?

The second phase of the implementation guide is to 'Screen for needs'.

Screening for advance care planning needs

Advance care planning is likely to be relevant for patients aged 75 years or over, or aged 18 years or over with one or more chronic progressive illnesses, irrespective of whether they meet the SPICT^{TM} or 'surprise' question criteria. The Advance Care Planning Screening Interview or the quick guide can be used to introduce advance care planning into a routine consultation, care plan review, or health assessment of these patients. If the advance care planning screening conversation suggests the patient is ready and interested to further discuss advance care planning, the patient could be provided with the 'Preparing for an advance care planning conversation' booklet and a follow-up consultation arranged to have a more in-depth advance care planning discussion with the GP or nurse.

Screening for palliative and supportive care needs

Patients for whom the answer to the surprise question is "No", and/or who meet the SPICT^{TM} criteria for being at risk of deteriorating and dying, will also benefit from a full supportive care needs assessment. This assessment will help to see if the patient has any unmet needs and also help them to consider their most important concerns and priorities.

Patients who have reasonable health literacy and are well enough can be given the Advance Project Patient Assessment booklet (titled 'Supporting you to live well with a chronic illness') to complete on their own at home or possibly while waiting for an appointment.

The booklet uses non-threatening language to gently explore the person's symptoms and care needs. It does not use the word 'palliative', nor does it imply that the patient has limited life-expectancy. Hence, some practices may feel comfortable training their administrative staff to hand out the booklets to patients to complete (an example script that they can use can be found in the training package). Other practices may still prefer that the nurse or the GP discuss the need for the assessment before handing out the booklet to patients. Patients who need assistance may need an appointment with the nurse to help them complete the assessment.

The Advance Project Patient Assessment booklet includes two assessment tools:

- IPOS (Integrated Patient Outcome Scale)
- NAT-CC Patient (Needs Assessment Tool – Chronic Conditions).

Once the patient has completed the assessment booklet, the GP should review and discuss the patient's responses to the questions. This could be done as part of the doctor's component of the routine health assessment or care plan review, or as a separate consultation. In case of the latter, it is a good idea to book the patient in for a longer appointment.

If the patient is accompanied by their carer, the nurse or GP can suggest that the carer completes the Advance Project Carer Assessment booklet (titled 'Looking after you while you care for someone with a chronic illness', which contains the NAT-CC Carer tool). The carer can then make an appointment to see their own GP or nurse to review and discuss their responses.

Phase 3: How do I evaluate patient needs?

The final phase of implementation is to ‘Evaluate patient needs’. Patients who are ready to have further discussions about advance care planning, based on the results of the screening conversation, should be reviewed by the GP or nurse again to discuss this. If the patient has had a chance to review the ‘Preparing for an advance care planning conversation’ booklet prior to the follow-up consultation, this may help facilitate the discussion. More than one follow-up consultation may be needed with the GP and/or nurse to discuss advance care planning.

Patients or carers of patients who have completed the Advance Project Assessment booklets (patient and carer versions, respectively) will need to be reviewed by the GP to discuss their responses and determine an appropriate action plan. This could be done as part of the doctor’s component of the routine health assessment or care plan review, or as a separate consultation. In case of the latter, it is a good idea to book the patient in for a longer appointment.

During this review, the Advance Project Referral Triage Tool can be used to assess whether the patient’s and/or carer’s current supportive care needs can be met by the practice and support systems in place. If not, consideration should be given to whether the patient may need referral for additional support, including early referral to specialist palliative care services. Finally, it is important to consider when the patient and/or carer next needs follow-up by the general practice.

Where possible, hard copies of the completed Advance Project Assessment tools should be scanned and incorporated into the individual’s medical record. There are also RTF and fillable PDF versions of the Advance Care Planning Screening Interview, which can be incorporated into the practice software as a record of the initial advance care planning discussion.

Summary

The Advance Project Guide provides guidance for how to implement screening and assessment tools for initiating advance care planning and palliative care in general practice.

In the first phase, the nurse and the GP identify two sub-groups of patients:

- Those who would benefit from an introduction to advance care planning only (the majority)
- The much smaller group who would benefit from a full palliative and supportive care needs assessment, including an introduction to advance care planning.

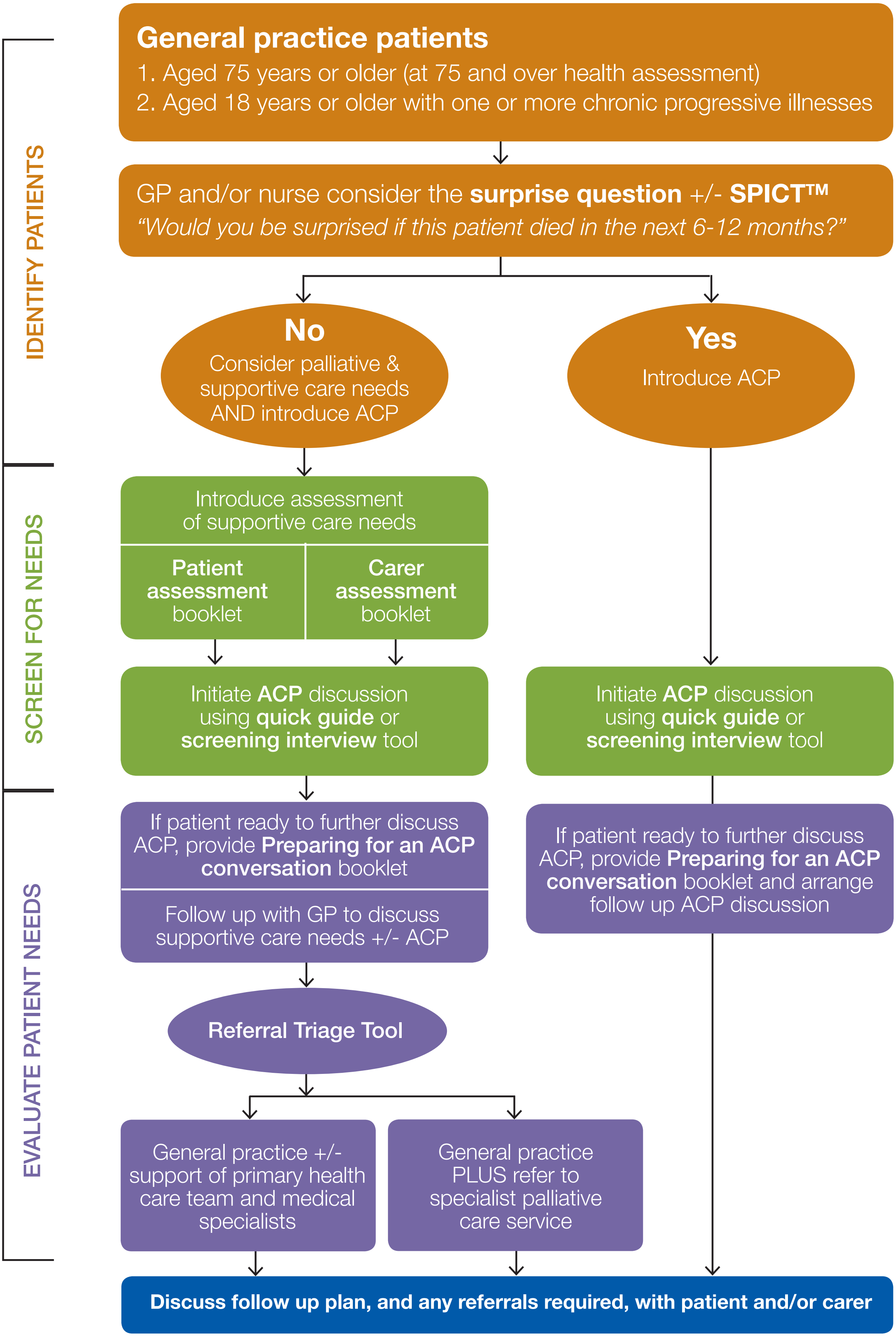
In the second phase, advance care planning is introduced and the patient’s and/or carer’s supportive care needs are assessed, where appropriate.

In the third phase, the results from the patient’s and/or carer’s needs assessments are evaluated by the GP, further discussions about advance care planning are held if the patient is ready to discuss this, and any requirements for additional support are considered.

The Advance Project Guide

Initiating advance care planning (ACP) and palliative care in general practice

The Advance> Project



IDENTIFY PATIENTS

General practice patients

1. Aged 75 years or older (at 75 and over health assessment)
2. Aged 18 years or older with one or more chronic progressive illnesses

GP and/or nurse consider the **surprise question** +/- **SPICT™**

"Would you be surprised if this patient died in the next 6-12 months?"

No
Consider palliative & supportive care needs AND introduce ACP

Yes
Introduce ACP

SCREEN FOR NEEDS

Introduce assessment of supportive care needs

Patient assessment booklet

Carer assessment booklet

Initiate **ACP** discussion using **quick guide** or **screening interview** tool

Initiate **ACP** discussion using **quick guide** or **screening interview** tool

EVALUATE PATIENT NEEDS

If patient ready to further discuss ACP, provide **Preparing for an ACP conversation** booklet

Follow up with GP to discuss supportive care needs +/- ACP

If patient ready to further discuss ACP, provide **Preparing for an ACP conversation** booklet and arrange follow up ACP discussion

Referral Triage Tool

General practice +/- support of primary health care team and medical specialists

General practice PLUS refer to specialist palliative care service

Discuss follow up plan, and any referrals required, with patient and/or carer

Section 3

Tools for initiating advance care planning

These tools are relevant for initiating conversations about advance care planning with any patient aged 75 years or over, or any patient aged 18 years or over with a chronic progressive illness. This section contains the following tools, as well as background information and tips for how to use these tools during routine health assessments, care plan reviews, and routine consultations:

- The Advance Care Planning Screening Interview (clinician resource)
- Quick guide to introducing advance care planning (clinician resource)
- ‘Preparing for an advance care planning conversation. *A guide to help you prepare for a conversation with your family or health care team about your wishes for future health and personal care*.’ (patient resource)
- ‘Who will speak for you if you can’t speak for yourself? *A guide for choosing a substitute decision-maker for health care decisions*.’ (patient resource).

Section 3 - Tools for initiating advance care planning

The Advance Care Planning Screening Interview (clinician resource)

The Advance Care Planning Screening Interview aims to:

- Introduce the topic of advance care planning
- Determine a patient's preferred substitute decision-maker
- Ensure the general practice is aware of any advance care planning already completed by the patient
- Assess a patient's readiness to further discuss advance care planning.

Who completes the Advance Care Planning Screening Interview and how is it used?

The Advance Care Planning Screening Interview is a structured interview that can be conducted by a nurse or GP during a consultation with a patient. There are spaces within the tool to record the patient's responses to the questions. The interview can be conducted with an adult patient who either has a chronic progressive illness or is aged 75 years or over. It could be incorporated into a 75 years and over health assessment, a chronic disease management plan review, or a routine consultation. The tool can be scanned and added to the patient's practice records.

More information about the Advance Care Planning Screening Interview

The Advance Care Planning Screening Interview was developed in Australia. It has been found to be a feasible and acceptable tool for initiating advance care planning (Cheang *et al*. 2014).

Tips for introducing the Advance Care Planning Screening Interview

It may feel foreign to introduce the Advance Care Planning Screening Interview. Health care professionals can feel uncomfortable discussing these issues and perceive that their patients do also. However, patients and carers mostly welcome the opportunity to talk about advance care planning. Tips for completing this interview include:

- Introduce the conversation about advance care planning in a clear, straightforward way. Normalise it by saying that the practice asks everyone who is having either a 75 years and over health assessment or a chronic disease management plan review about advance care planning. For example: *"As part of the annual check-up, we also ask everyone about their future health wishes."*
- Ask for permission to talk with the patient about their future health wishes. For example: *"Are you OK to talk with me about this for 5 to 10 minutes?"* OR *"In the next 5 to 10 minutes, could I ask you some questions about your future health wishes?"*
- If the patient wants further information, you could add: *"Your answers will give me useful information about your needs and wishes and allow me to work out the best way to help you with future health care planning."*
- An example of a way to describe advance care planning when talking to patients is: *"Advance care planning is a process that helps you to plan for your future medical care. It involves thinking and talking about your values and beliefs – what's important to you - and your wishes about the medical care you would like to have if you became critically ill or injured."*
- If the patient indicates they are ready to discuss advance care planning during the Advance Care Planning Screening Interview, they could be provided with the 'Preparing for an advance care planning conversation' booklet (see pages 24-36) to review and consider prior to coming back for a follow-up appointment to further discuss advance care planning.
- In case you need to provide further information about how to appoint a substitute decision-maker during the Advance Care Planning Screening Interview, an information brochure about this is available (see pages 38-42).

Example

A shorter video of a general practice nurse conducting the Advance Care Planning Screening Interview with a patient is shown at: https://vimeo.com/174983055/1ce6870b4e

The full version of this video is shown at: https://vimeo.com/170468999/045cc9c99c

Reference

Cheang F, Finnegan T, Stewart C et al. 2014. Single-centre cross-sectional analysis of advance care planning among elderly patients. Internal Medicine Journal 44: 967-974. Abstract available at http://www.ncbi.nlm.nih.gov/pubmed/25109312

Advance Care Planning Screening Interview

Notes for Interviewer

Suggested introduction

"As part of the seniors annual check up we ask everyone about their future health wishes. Are you OK to talk with me about this for 5 to 10 minutes?"

OR

"In the next 5 to 10 minutes, could I ask a few questions about your future health wishes?"

FOLLOWED BY:
"Your answers will give me useful information about your needs and wishes and allow me to work out the best way to help you (with Advance Care Planning)".

What is Advance Care Planning?

Advance care planning is a process that helps you to plan for future medical care. This process involves thinking about your values and beliefs and your wishes about the medical care you would like to have if you became critically ill or injured. It is a way to make sure that people involved in your life understand your wishes about medical treatment and care. You may choose to write down an Advance Care Directive that records your specific wishes in the event of serious illness, and any treatments you would refuse.

Instructions for use

The unshaded sections in the Tables on pages 2 to 3 are questions for the interviewer to ask the patient, and record the response. The shaded sections in the Tables on pages 2 to 3 are prompts for the interviewer, with some prompts also requiring a written response. On page 4 there is space to write any additional notes about the patient's wishes or other topics that come up during the interview.

For further information about advance care planning, and substitute (or surrogate) decision making legislation and the appointment of formal legal medical enduring guardians (or equivalent) in your state please refer to:

Advance Care Planning Australia

http://advancecareplanning.org.au

RACGP Advance Care Planning

http://www.racgp.org.au/your-practice/business/tools/support/acp

Patient Name: **Date:**			
1. Have you ever thought about who you would like to make medical decisions for you in an emergency if you were too unwell to speak for yourself? If so, who? a. Spouse b. Family/friend carer c. Relative d. Friend e. Not sure f. No-one identified			
Is this person's name and contact details listed below or clearly recorded in the practice records? Preferred Substitute Decision Maker's Name: ___________________________ First contact number ______________________________ Second contact number ______________________________	Yes	No	N/A
2. Have you ever signed a legal document to appoint someone to make health decisions on your behalf if you were unable to?	Yes	No	
Note: • There are different terms for this in each state • This is different to appointing someone to make money or finance decisions			
If so, is a copy of the documentation available in the patient's practice records?	Yes	No	N/A
If so, is this person's contact details listed above or in the practice records?	Yes	No	N/A
If not, consider providing information about how to do this in your state, especially if the patient's preferred substitute decision maker is someone who might not automatically be consulted according to the hierarchy in your state. See state specific information available at *http://advancecareplanning.org.au or* *http://www.racgp.org.au/your-practice/business/tools/support/acp/*			
3. Have you talked *to anyone in your family or a close friend* about your wishes, values and beliefs about medical treatment and care in case you become seriously ill or unable to make your own decisions?	Yes	No	
If yes, with whom?			
4. Have you talked to *a doctor* about your wishes, values and beliefs about medical treatment and care in case you become seriously ill or unable to make your own decisions?	Yes	No	
If yes, with whom?			
5. Have you ever *written down* your wishes, values and beliefs about medical treatment and care in case you become seriously ill or unable to make your own decisions?	Yes	No	
If so, in what type of document?			
If so, when was this last reviewed?	Date		
Where do you keep a copy?			
Is a copy available in the practice record?	Yes	No	N/A

Patient Name: **Date:**			
Is a copy available in your My Health Record?	Yes	No	N/A
6. Have you heard of Advance Care Planning or Advance Care Directives?	Yes	No	
Explain to the patient about Advance Care Planning using the script on page 1 as necessary.			
7. Would you like an information brochure about Advance Care Planning?	Yes	No	
If so, has a copy of this been provided?	Yes	No	
8. Would you be comfortable if a member of the practice were to further discuss Advance Care Planning with you?	Yes	No	
8i. If so, who would you like to discuss this with? a. *GP* b. *General Practice Nurse* c. *Other* ______________________________			
8ii. If so would you like to discuss this with a family member, friend or someone who cares for you also present? If so with whom?	Yes	No	
Record this person(s) name and relationship to the patient: ____			
9. Is there anything else you would like the practice to know about your wishes or priorities when it comes to your health care? *(record details here or on the next page if more space is required)*	Yes	No	
10. Please rate your level of comfort with our conversation today. a. Very comfortable b. Somewhat comfortable c. Uncomfortable			
Was their preferred substitute decision maker present during the screening interview?	*Yes*	*No*	
Was anyone else present?	*Yes*	*No*	
If so, what was their relationship to the patient?			
Time taken to complete the interview (minutes)			
Completed by:	**Date:**		

Patient Name:

Date:

Notes about the patient's wishes or other topics that come up during the interview:

Completed by:	**Date:**

Quick guide for introducing advance care planning (clinician resource)

GPs and some nurses may prefer to use a quick conversation guide instead of the Advance Care Planning Screening Interview tool for introducing advance care planning. This guide includes suggested phrases to introduce the topic, questions to ask during the initial conversation, and prompts for the clinician to consider. Unlike the Advance Care Planning Screening Interview tool, it does not provide spaces for recording the patient's responses to the screening questions. So, GPs or nurses who use the quick guide would need to document the discussion directly into the practice software or paper medical records.

If the patient indicates they are ready to discuss advance care planning during the initial conversation, they could be provided with the 'Preparing for an advance care planning conversation' booklet (see pages 24-36) to review and consider prior to coming back for a follow-up appointment to further discuss advance care planning.

In case you need to provide further information about how to appoint a substitute decision-maker during the introductory advance care planning discussion, an information brochure about this is available (see pages 38-42).

Example

An example of a GP introducing advance care planning using the quick guide is shown at: https://vimeo.com/287510278/65e03d96b6 (this occurs in the context of a consultation with a young person with a progressive illness, after he has raised concerns about what will happen if he became really sick).

Quick guide to introducing Advance Care Planning in routine consultations or health assessments

“As part of the annual check up we ask everyone about their future health wishes. Are you OK to talk with me about this for 5 to 10 minutes?” OR

“In the next 5 to 10 minutes, could I ask a few questions about your future health wishes?”

Consider adding: “This will help me to work out the best ways to help you with your future care.”

Purpose of the question	Suggested questions to ask the patient	Prompts for the clinician
Determine the patient’s preferred substitute decision maker	Have you ever thought about who you would like to make medical decisions for you in an emergency if you were too unwell to speak for yourself? If so, who?	• Record persons’ preferred substitute decision maker in practice record
Determine if the patient has a legally appointed substitute decision maker	Have you ever signed a legal document to appoint someone to make health decisions on your behalf if you were unable to?	• If so, request copy for practice record • If not, provide information about how to do this, especially if the patient’s preferred substitute decision maker is someone who might not automatically be consulted according to the hierarchy in your state.
Determine the patient’s previous involvement in Advance Care Planning	Have you talked *to anyone in your family or a close friend* about your wishes, values and beliefs about medical treatment and care in case you become seriously ill or unable to make your own decisions? • Have you spoken to a doctor or other health professional about this? • Have you ever written down your wishes?	If written down: • In what type of document? • When was it last reviewed? • Is a copy available in practice record or my health record?
Determine the patient’s understanding of Advance Care Planning and whether they wish to know more	Have you heard of Advance Care Planning or Advance Care Directives? Would you like to know more?	• Explain what ACP is (see definition overleaf) • Provide information brochure about ACP in your state if appropriate
Determine the patient’s readiness to discuss Advance Care Planning	Would you be comfortable if I *(or another member of the practice)* were to further discuss Advance Care Planning with you?	If so: • Find out which clinician they’d like to discuss it with • Suggest they consider bringing their preferred substitute decision maker with them to the consultation
Explore the patient’s wishes or priorities for future care.	Is there anything else you would like me (*or your health care team or the practice*) to know about your wishes or priorities when it comes to your future health care?	• Summarise key points and reflect back to patient to make sure you have understood • Write summary in practice record

Next steps:

- Arrange further follow up to discuss ACP as appropriate
- Consider giving the patient the “Preparing for an advance care planning conversation” guide to take home and discuss with their family prior to the follow up appointment
- Consider providing information about formally appointing a substitute decision maker relevant to your state or territory.

The Advance> Project

Definitions and further information

What is Advance Care Planning?
Advance care planning is a process that helps you to plan for future medical and personal care. It includes thinking about your values and clarifying your preferences for care if you became critically ill or injured. It is a way to make sure that people involved in your life understand your wishes about medical treatment and care. You may choose to write down an Advance Care Directive that records your specific wishes in the event of serious illness, and any treatments you would refuse.

For further information about advance care planning, substitute decision making legislation and the formal appointment of substitute decision maker (terminology varies throughout Australia) in your state please refer to:

Advance Care Planning Australia

http://advancecareplanning.org.au

RACGP Advance Care Planning

http://www.racgp.org.au/your-practice/business/tools/support/acp

Preparing for an advance care planning conversation (patient resource)

This booklet was developed after feedback from nurses in the initial phase of the Advance Project that suggested it would be helpful to have a booklet to guide patients through the next steps in the advance care planning process.

If the introductory advance care planning conversation (using either the Advance Care Planning Screening Interview or quick guide) suggests the patient is ready and interested to further discuss advance care planning, the patient could be provided with the 'Preparing for an advance care planning conversation' booklet and a follow-up consultation arranged to have a more in-depth advance care planning discussion with the GP or nurse.

This booklet is designed to help the patient to think about their own values and preferences for future care, and to facilitate further conversations about this with their family and/or health care team.

It was developed by HammondCare, with input from the Advance Project Advisory Group and consumers.

It is important to realise that the 'Preparing for an advance care planning conversation' booklet does not contain an Advance Care Directive form.

If the patient is interested in documenting their preferences in a legally-binding way, this should be done using the Advance Care Directive forms that are relevant to your state or territory. For more information you can visit: https://www.advancecareplanning.org.au/resources/advance-care-planning-for-your-state-territory

The Advance> Project

Patient Resource

Preparing for an advance care planning conversation

A guide to help you prepare for a conversation with your family or health care team about your wishes for future health and personal care

What is advance care planning?

Advance care planning is about having conversations and planning for your future health and personal care so that you, your family or close friends, and health care team know your values and preferences.

If you were very sick and could not make or communicate your own decisions, who would you want to speak for you? What would you want them to say on your behalf?

Advance care planning helps to ensure that your loved ones and your health care professionals know what your health and personal preferences are. This can bring comfort and peace of mind to you, your family and your health care team who may have to make health care decisions for you.

Who is this guide for?

If you would like to start thinking and talking about your future care, this guide is for you. It will prompt you to think about what is important to you now and what you might want in the future.

It includes thinking about the type of care you might want or not want if you were very sick or suddenly injured. It also includes thinking about things you would want people to know about the care you may want before and after you die.

Any adult might like to complete this guide. None of us can predict what might happen with our health. One is never too young or old to begin thinking and talking about what would be important to them if they became suddenly unwell.

This guide may be particularly relevant for people who are older or people who have a chronic or serious illness or multiple health problems.

Why complete this guide?

Talking about the future and your wishes for end-of-life care can be hard. It can also bring you closer to the people you love and help them feel more comfortable about any decisions they might have to make for you in the future. It provides a way for you to have a say about the care you receive in case you are ever in a situation where you are unable to make decisions for yourself.

People will only know what is important to you if you tell them. Thinking and talking about these things will help to ensure you receive the kind of care you would like, and it guides your loved ones with what may otherwise be stressful decisions.

The purpose of this guide

This guide includes a number of questions to help you explore your values and beliefs that could influence your future health care decisions. It's a useful tool to help you start thinking about advance care planning and preparing for conversations with your family and health care professionals.

Thinking about some of these questions might be hard but it will allow you to start processing your thoughts and preferences. You may change your mind about how you feel about these questions over time and that is okay, it is part of the process.

There are spaces to write down your thoughts in this guide if you want to. You can change your answers at any time.

There are no right or wrong answers to these questions. **You do not have to answer all of the questions and you can complete the questions in any order that you like.**

After thinking about the questions in this guide it is important to share your thoughts with the people who might be called upon to make decisions for you in the future, including your close family or friends and your doctor and nurse. You may like to show them your answers to the questions in this guide.

The conversations you have with your family and loved ones about advance care planning are important even if you never write down your preferences for future care. After having these conversations about advance care planning, you may choose to record your preferences in a legal document called an *Advance Care Directive*. Information about how to do this, if you want to, is on page 12 of this guide. On page 12, there are also suggestions for the next steps in the advance care planning process after you have thought about the questions in this guide.

Below you may like to record your name and the date(s) you reviewed or updated this guide.

My name:

Date I initially completed this guide:

Date(s) I reviewed this guide:

1. What I want my health care team and family to know about me and what matters to me

The sorts of questions you might want to consider are:

- What brings you the greatest joy?
- Who are the most important people in your life?
- How do you like to spend your time?
- Are there any routines that are important to you?
- How would you like to be remembered?
- Are there any cultural, religious or family traditions that are important to you?

2. The medical information I would want to know

Some people would want to know all the details about their illness if they became very sick, others would prefer as few details as possible. Please circle on a scale from 1 to 5, the number which best represents what you think your preference for information would be about your illness if you were very sick.

Prefer as few details as possible	**1**	**2**	**3**	**4**	**5**	Prefer as many details as possible

3. How I would want medical treatment decisions to be made

Some people like to be involved in medical treatment decisions, others would prefer to leave decisions about medical treatment up to their doctors. Others might want their family or friends to decide about the best treatments for them with their doctors, even if they were still able to decide for themselves.

a) How involved do you think you would want to be in decisions with your doctors about medical treatments if you became very unwell?

☐ I want to decide about medical treatment after hearing about the options

☐ I want to share decisions about medical treatment with my doctors

☐ I want my doctors to decide what medical treatments would be best for me

b) If you became very unwell and **could still make decisions for yourself**, how involved would you like your close family or friends to be in decisions about your medical treatments?

☐ I want to make decisions about medical treatments on my own or with my doctors

☐ I want my close family or friends to share decisions about my medical treatments with me

☐ I want my close family or friends to make decisions about my medical treatments for me or with input from my doctors

If there are other things you would want your loved ones or health care professionals to know about how you would want medical treatment decisions to be made if you were very unwell, you can write them here. For example, there may be a particular family member(s) or friend(s) that you would want to share medical decisions with.

4. Who could make medical decisions for me if I couldn’t

Can you think of any family members or friends who might be able to make medical decisions for you in case you became **too unwell to make decisions for yourself?**

☐ Yes or maybe. The name(s) of this person or people are:

☐ No

Depending on your situation, it may be important to legally appoint one or more people to make medical decisions for you. More information about how to do this is available in the accompanying resource called *“Who will speak for you if you can’t speak for yourself?”*. Information specific to your state or territory is available from www.advancecareplanning.org.au

5. My past experience with serious illness

You may remember someone close to you who was very sick or dying. Or you may have even experienced a serious illness yourself. Think about what went well and what did not go well. Is there anything you would or would not want for yourself based on these experiences?

6. My current and future health

You may be healthy now or you may have health problems. Do you have any questions, fears or concerns about your current or future health? If so, you might like to write them down here and discuss them with your doctor or nurse.

7. My personal goals

Some people have a list of things they would like to do or see, or people they would like to spend time with before they die. Is there anything you would wish for?

8. My preferences for care at the end of life

a) People have different views about medical treatments if they became very sick. Some people would want all treatments that would be available to them to prolong their life as long as possible, even if there were significant side effects. Others would only want treatments to make them comfortable, even if this meant they may live for a shorter period. Others are somewhere in between.

If you had to decide now about the medical treatments you would want if you were very sick, where would you put yourself on this scale? (tick a box on the scale which best indicates how you feel)

☐ ☐ ☐ ☐ ☐

←——————————————————————————→

Quality of life I only want treatments to make me comfortable	Equally important	Length of life I want treatments to prolong my life as long as possible

☐ **I am not sure**

b) Some people would want to stop receiving medical treatments to prolong their life if their circumstances changed. For example, if they were no longer able to live in their own home, use the toilet independently or have a conversation with their family. Are there any circumstances where you would want your doctors to stop (or not start) any treatments that may prolong your life and instead allow you to die naturally? If so, what are these circumstances?

c) Are there any treatments that you would definitely **not** want at any time in the future? If so what treatments?

d) If you were dying, where would you prefer to be cared for (if possible)?

☐ At home

☐ In an aged care home

☐ In hospital

☐ In a palliative care hospital

☐ Other ____________________

e) How important is it to you that you die in the place that you selected above?

☐ Not important

☐ Somewhat important

☐ Very important

Is there anything else you would want your family or health care professionals to know about your preferences for where you are cared for, if you were very sick or dying? If so, you can write your thoughts here.

f) Are there any religious, spiritual or cultural beliefs that you would like your family and health care team to know and consider if you were sick or dying?

g) Is there anything else you would want your family and health care team to know about how you would like to be cared for if you were very sick or dying? For example, some people would want privacy, others would want to be surrounded by their family and friends. Some people would want music playing, others would want peace and quiet.

h) Some people decide to donate their organs or body parts (tissues) when they die. What are your views on this?

☐ I want to donate my organs or body parts (if it were an option for me)

☐ I do not want to donate my organs or body parts

☐ I am not sure

You can also make your wishes known about this on the Australian Organ Donor Register. If you would like more information about organ and tissue donation, ask your doctor or visit www.donatelife.gov.au

If there is any other information you would like your health care team or family to know about your views on organ or tissue donation you could write this here.

9. How I would want to be cared for after I die

What would you want your health care team and family to know about how you want to be cared for after you die? Things to consider:

- Are there any rituals you want?
- Would you prefer to be buried or cremated?
- Do you have any special requests or plans for your funeral?

10. Other questions or things I would like to discuss with my doctor, nurse or family about my future care

Next steps

- Speak to your close family or friends and health care professionals about your answers to the questions in this guide. Also speak to them about any other thoughts or preferences you may have about your future care.
- Ask your doctor or nurse any questions you have to help you think through your preferences.
- Think about appointing a substitute decision-maker for health care decisions.
    - See the accompanying resource, called “Who will speak for you if you can’t speak for yourself?”, for things to consider when choosing a substitute decision-maker for health care decisions and how to do this. Also think about how much flexibility you would want them to have when making decisions for you.
- Consider writing down your preferences in an Advance Care Directive.
    - An Advance Care Directive is a legal document that formally records your preferences. It only goes into effect if you are unable to make decisions for yourself. Your doctor can provide you with further information about this. If you do complete an Advance Care Directive, it needs to be shared with your health care team and preferred substitute decision-maker and any other family members you would want to have access to it. It is also important to review it from time to time if your preferences change and share any changes with the people who have a copy of your Advance Care Directive. You can also upload and update your Advance Care Record in My Health Record https://www.myhealthrecord.gov.au/

For more information and assistance

- Speak to your local doctor or nurse
- You can access further advice and documents for your state or territory from Advance Care Planning Australia www.advancecareplanning.org.au or the National Advance Care Planning advisory service on 1300 208 582

Acknowledgements

This resource was produced by The Advance Project team. The Advance Project team is funded by the Australian Government Department of Health. The Advance Project is led by HammondCare in collaboration with University of Sydney, Flinders University (CareSearch), Austin Health (Advance Care Planning Australia), University of Queensland, University of Wollongong, University of Technology Sydney, and La Trobe University.

In collaboration with

Who will speak for you if you can’t speak for yourself? (patient resource)

This is an information booklet to assist patients with choosing a substitute decision-maker for health care decisions.

It may be a useful resource if you need to provide further information about how to appoint a substitute decision-maker during the introductory advance care planning discussion. This patient information brochure is relevant to all states and territories.

It was developed by HammondCare in collaboration with Advance Care Planning Australia and with input from the Advance Project expert advisory group and consumers.

Alternatively, state-specific information about substitute decision-making can be found at: https://www.advancecareplanning.org.au/resources/advance-care-planning-for-your-state-territory

The Advance> Project

Patient
Resource

Who will speak for you if you can't speak for yourself?

A guide for choosing a substitute decision-maker for healthcare decisions

What is advance care planning?

Advance care planning is about your future health and personal care. It gives you the opportunity to plan for what you would want, if you were unable to say it yourself. This guide is about choosing someone to make decisions for you in case you couldn't speak for yourself.

Your substitute decision-maker

If you lose the ability to make decisions about your health care – either because of an accident, sudden illness or a progressive illness – the treating doctors and health care team will need to ask someone else to make decisions for you. This person is called a 'substitute decision-maker'.

There are laws in each state and territory setting out a priority order of substitute decision-makers. The treating doctors will need to interpret these laws to work out who would be your substitute decision-maker. However, you can appoint a different person if you want to, to ensure that the person you would select has the authority to make decisions on your behalf. This person does not have to be a family member.

'Identifying and appointing someone who will make decisions on your behalf, is an important part of planning ahead.'

Persons identified in state or territory laws to be your substitute decision-maker

The laws that decide who will be your substitute decision-maker vary across the states and territories of Australia. The first person on the list in all states and territories is someone you have legally appointed. After that, the list involves certain types of people.

For example, the order in the list might be:

1. an appointed substitute decision-maker
2. a spouse
3. an unpaid person who provides care and assistance
4. a close family member or friend

Specific information for your state or territory can be found at www.advancecareplanning.org.au

Is this the person you would have chosen for yourself?

In many cases, the person automatically identified as your decision-maker is the same person that you would have chosen yourself. But this is not always the case. The treating doctors might find it difficult to work out who to ask if you have multiple family members or close friends especially when decisions need to be made urgently. For example, you might want your daughter or neighbour as your substitute decision-maker but the hospital may contact your brother or sister during an emergency.

Legally appointing your decision-maker

If the person who may be contacted by the treating doctors to be your substitute decision-maker is different to the person you would choose, you can legally appoint your preferred person. That person will then have the authority to act on your behalf. Even if the person automatically identified as your decision-maker is the same person you would choose yourself, you may still want to legally appoint them if you would like them to be able to refuse medical treatments on your behalf. In most states and territories, only a legally appointed substitute-decision maker can refuse treatments.

Legally appointing your decision-maker can give you peace of mind as you will know decisions will be made by someone you trust and who you would want to make decisions for you.

It is important that you access information from your state or territory to ensure you have the correct forms for legally appointing your substitute decision maker. You also need to check any requirements for completing the form in your state or territory, including who can witness the signatures on the form. Further information is available from www.advancecareplanning.org.au

Things to consider when choosing a substitute decision-maker

This is a very important role and something you should consider carefully. Ideally, the person (or people) you choose:

- would be willing to speak on your behalf
- can separate their own feelings from yours
- is available (preferably living nearby)
- knows you well and understands what's important to you

- will talk with you now about sensitive issues, and listen and act on your preferences in the future
- will likely be around for some time into the future
- can confidently speak with health professionals and other family members about your preferences.

‘The most important consideration is to have someone you trust.’

How to appoint your substitute decision-maker

You will need to complete documents from your Australian state or territory. It is best to complete these while you are well as you need to be ‘legally competent’. Being competent means you are able to understand the document you are signing, and the implications of this.

A person appointed by you as your substitute decision-maker only takes on this role if you lose capacity to make your own decisions. In most states and territories, this person does not have the power to manage your financial affairs. If you want them to manage your financial affairs, you may need to appoint them separately to have that role.

In most states or territories, you can appoint more than one person. You can give them the power to act alone or together in making decisions. However, if they need to act together this can have implications if they don’t agree on a course of action.

It is recommended that you explain to others who may expect to have a say in your care:

- who you have nominated and why, and
- ask these people to support the person(s) you have appointed.

Supporting your substitute decision-maker

You can help your substitute decision-maker perform their role by:

- Checking that they are happy to do it. For example you could say “If I got really sick in the future and could not make my own decisions, would you work with my doctors and help make medical decisions for me?”
- Talking with them about your preferences for future care.
- Ensuring they have copies of any relevant documents, such as your Advance Care Directive.

- Thinking about how much flexibility you would want to give them in making decisions for you and make sure this is clear on your Advance Care Directive if you complete one. Flexibility gives your substitute decision-maker scope to work with your doctors and possibly change any prior medical decisions you have made. There may be some decisions that you are happy for your substitute decision-maker to change and other things you would never want them to change. Other people may be happy to give their substitute decision-maker total flexibility to work with their doctors if they got really sick and couldn't speak for themselves, rather than make medical decisions ahead of time.

For more information and assistance

- Talk to your local doctor
- Visit www.advancecareplanning.org.au for resources applicable to your state or territory
- Call Advance Care Planning Australia National Advisory Service: 1300 208 582

Acknowledgements

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Section 4

Tools for identifying patients who might be at risk of deteriorating and dying

Identifying when to introduce palliative care into a patient's care can be challenging in general practice. This section contains tools that can be used to identify patients who might be at risk of deteriorating and dying, and who would therefore benefit from an assessment of their palliative and supportive care needs. The following identification tools are included, as well as background information and tips for how to use these tools:

- The 'surprise' question
- The SPICT^{TM}.

Section 4 - Tools for identifying patients who might be at risk of deteriorating and dying

The 'surprise' question

What is the 'surprise' question?

The 'surprise' question is:

"Would you be surprised if the person died in the next 6 – 12 months?"

It can be used to identify patients who might be at risk of deteriorating and dying. For these patients, it is important to assess their palliative and supportive care needs, to explore their priorities for care, and to assess the needs of their carers.

If the answer to the 'surprise' question is "No" – in other words, you think there is a risk the patient may die in the next 6 to 12 months – then this patient would benefit from a full assessment of their palliative and supportive care needs PLUS an introduction to advance care planning.

If the answer to the 'surprise' question is "Yes", the full palliative and supportive care needs assessment is **not** necessary at this stage. However, given that this group of patients is either elderly or has a chronic progressive illness, it is appropriate and timely to begin to discuss advance care planning using the Advance Care Planning Screening Interview or quick guide to initiating advance care planning conversations.

If you are unsure about the answer to the 'surprise' question, the SPICT^{TM} can be used to further assist in identifying patients who might be at risk of deteriorating and dying.

Tips for using the 'surprise' question

This can be a confronting question for health care professionals, but can be a very useful prompt to consider a patient's needs. This question can be answered using clinical knowledge, personal knowledge of the patient (including discussions with them), clinical intuition, or a combination of all of these.

If you are a nurse, you can consider the 'surprise' question on your own or discuss it with the patient's GP. Regardless of the answer to the 'surprise' question, it is still appropriate and timely to begin to discuss advance care planning with all patients who are elderly or have a chronic or progressive illness.

Example

A demonstration video of a general practice nurse and GP discussing the 'surprise' question can be found at: https://vimeo.com/287500130/8726384432

Reference

Scott, I. A., Mitchell, G. K., Reymond, E. J., & Daly, M. P. (2013). Difficult but necessary conversations — the case for advance care planning. *Med J Aust*, *199*(10), 662-6.

The SPICT^{TM}

What is the SPICT^{TM}?

The Supportive and Palliative Care Indicators Tool, or SPICT^{TM} (see page 47) is used to identify people who might be at risk of deteriorating and dying from one or more advanced progressive conditions. It can be used as a second screening tool for any patients for whom you are unsure about the answer to the 'surprise' question.

For patients who might be at risk of deteriorating and dying, it is important to assess their palliative and supportive care needs. It is also important to talk about what is important to them and to start planning their future care with them by initiating a discussion about advance care planning. In addition, it is important to assess the needs of their carers.

The SPICT^{TM} contains:

- Six general indicators of deteriorating health and increasing needs
- Clinical indicators of advanced disease.

There is also a version of the SPICT^{TM} tool called SPICT-4ALL. The SPICT-4ALL (see page 48) uses less medical language and therefore might be useful for practice managers to get an idea of the types of patients in general practice who might be suitable for an assessment of their palliative and supportive care needs.

How is the SPICT^{TM} used to help identify patients?

This tool is used by the GP, or the general practice nurse in consultation with the GP. If you are a nurse, we suggest you discuss the patient with the GP and decide together whether the patient meets enough SPICT^{TM} indicators for being at risk of deteriorating and dying for you both to think that a full palliative and supportive care needs assessment is likely to be helpful.

People identified as needing a full assessment of their needs by the SPICT^{TM} usually have two or more of the general indicators plus indicator(s) of advanced disease from one or more conditions in the second part of the tool. SPICT^{TM} helps health professionals make decisions about who should have an assessment, but does not give an exact "prognosis".

More information about using the SPICT^{TM}

For more information about the SPICT^{TM}, please visit: http://www.spict.org.uk/using-spict/

Tips for nurses when talking with the patient's GP about the SPICT^{TM} and, where indicated, the need to do a full needs assessment with the patient:

- Ensure that you have all the relevant information when speaking to your GP colleague.
- Describing the clinical indicators of declining health that you have identified using the SPICT^{TM} can be a helpful way to explain the rationale for doing a full supportive care needs assessment with a patient.
- Highlight the comprehensive training that you have received. You can point out that the module is funded by the Australian Government and has been prepared in consultation with experts in the field, including general practice nurses and GPs who understand the realities of a busy general practice.
- Being clear and concrete about your plans is important. Many doctors are practical and appreciate ending every meeting with a definite plan for action.

Example

A short demonstration video of a general practice nurse discussing the SPICT^{TM} with the patient's GP can be found at: https://vimeo.com/174632412/15f830d6c3

A longer version of this video can be found at: https://vimeo.com/174991526/e93026858e

An example of a different general practice nurse and GP discussing the 'surprise' question and SPICT^{TM} can be found at: https://vimeo.com/170486390/b18559f2c7

Reference

SPICT^{TM} website. Available at: http://www.spict.org.uk/

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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

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.

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.

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.

Other conditions

Deteriorating and at risk of dying with other conditions or complications that are not reversible; any treatment available will have a poor outcome.

Review current care and care planning.

- 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.

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

SPICT™, April 2017

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

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

Does this person have signs of poor or worsening health?

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

Does this person have any of these health problems?

Cancer

Less able to manage usual activities and getting worse.

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

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Has lost control of bladder and bowel.

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

Frequent falls; fractured hip.

Frequent infections; pneumonia.

Nervous system problems

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

Physical and mental health are getting worse.

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

Chest infections or pneumonia; breathing problems.

Severe stroke with loss of movement and ongoing disability.

Heart or circulation problems

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

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

Lung problems

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

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

Has needed treatment with a breathing machine in the hospital.

Kidney problems

Kidneys are failing and general health is getting poorer.

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

Liver problems

Worsening liver problems in the past year with complications like:

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

A liver transplant is not possible.

Other conditions

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

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

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

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

SPICT-4ALL™, June 2017

Section 5

Tools for screening and evaluating palliative and supportive care needs

Patients who meet either the ‘surprise’ question or SPICT^{TM} criteria would benefit from a full assessment of their palliative and supportive care needs. The tools in this section can be used to facilitate an assessment of the patient’s and their carer’s needs. This section also includes background about the following tools and tips for how to use them:

- The Advance Project Patient Assessment booklet
- The Advance Project Carer Assessment booklet
- The Advance Project Referral Triage Tool (clinician resource).

Section 5 - Tools for screening and evaluating palliative and supportive care needs

The Advance Project Patient Assessment booklet

This booklet is titled ‘Supporting you to live well with a chronic illness’ and is shown on pages 53-61.

This evidence-based assessment booklet is a systematic and person-centred way of assessing the palliative and supportive care needs of a patient who might be at risk of deteriorating and dying.

This booklet includes two assessment tools, the IPOS and NAT-CC Patient tool, which help to see if the patient has any unmet needs and also help the patient to consider their most important concerns and priorities. The booklet uses non-threatening language to gently explore the person’s symptoms and care needs. It does not use the word ‘palliative’, nor does it imply that the patient has limited life-expectancy.

In the initial phase of the Advance Project, we provided the IPOS and NAT-CC as separate tools. Based on feedback received in the evaluation of the initial Advance Project, we amalgamated both tools into the one booklet titled ‘Supportive you to live well with a chronic illness’. This booklet contains simplified instructions for the patient. The new booklet will enable both of these tools to be completed by patients more easily and without assistance, where appropriate.

Who completes the Advance Project Patient Assessment booklet and how is it used?

Patients who have reasonable health literacy and are well enough can be given the Advance Project Patient Assessment booklet: ‘Supporting you to live well with a chronic illness’ to complete on their own at home or possibly in a quiet space in the waiting room while waiting for an appointment. Patients who cannot read or are frail may need assistance from the nurse or a carer, family member, friend, or other trusted person to help them complete the booklet.

The booklet can be introduced by a nurse or GP and a follow-up appointment made with the nurse or GP to review the patient’s responses. Alternatively, a suitably trained administrative staff member could provide the patient with the booklet to complete prior to a health assessment, care plan review, or consultation.

Once completed, the assessment booklet can be used by the nurse and GP to quickly get an indication of the patient’s main symptoms, concerns, questions, and priorities to guide the consultation about the patient’s supportive care needs.

Some GPs may worry that many concerns will be raised by the Advance Project Patient Assessment booklet, which might make it hard to cover everything in a consultation.

The Advance Project Patient Assessment booklet helps patients to identify their concerns about their health and well-being. *It also ranks the relative importance of these concerns*, and indicates when the patient would like to discuss them; it may not necessarily be today. If your patient identifies several concerns to discuss during one appointment, discuss those of most importance to the patient and then suggest another appointment to discuss the rest.

With the patient’s permission, the completed booklet could be scanned and added to the patient’s practice record.

Copies of this booklet can be downloaded from the Advance Project website as a printable PDF. Further information about the individual tools (the IPOS and NAT-CC Patient tool) is given below for those interested.

Tips for introducing the Advance Project Patient Assessment booklet

Tips for administrative staff to introduce the booklet to a patient prior to a consultation, where appropriate and where a GP or nurse has identified that the patient as suitable, are shown on page 79.

Some example phrases for nurses or GPs to introduce the assessment booklet are as follows:

- "*I've noticed that you have been more unwell lately* (OR *"you've had this illness for a long time"* OR "*you've been experiencing a number of health problems"*) *and we'd like to see you to do a thorough check of your symptoms, concerns, and your priorities so we can work out how best to support and help you. I'd like book you in for an appointment and give you a booklet to take home and fill in between now and then. Would that be OK?"*
- *"Thanks for coming in today. The reason we're here is that we'd like to take a step back and ask you some questions to try to understand your concerns, thoughts about how you are going, and your priorities, so that we can make sure that we are providing you with the right support and not missing anything."*
- If more explanation is required: *"We would like to make sure that we know and understand your side of the story, as the person who is going through all the things that you are going through, so that we are all on the same page and that we are doing everything we can to make your life as good as possible. How does that sound to you?"*

Example

A short video of a general practice nurse introducing the need for a full supportive care needs assessment is shown at: https://vimeo.com/174768389/13abdbcec8

A video of a GP introducing the Advance Project Patient Assessment booklet is shown at: https://vimeo.com/287515995/1c801dd127

More about the IPOS tool

The Integrated Patient Outcome Scale (IPOS) is a tool to assess the symptoms and concerns of patients who have one or more chronic debilitating illnesses. The tool contains a series of questions about:

- The three major concerns of the patient, as reported in their own words
- Whether they are affected by common symptoms (e.g., pain, breathlessness, drowsiness)
- Information needs
- Practical problems
- Anxiety and low mood.

The IPOS is part of a family of tools developed and fully tested by the Cicely Saunders Institute, King's College London, to measure patients' main symptoms and concerns in advanced illness. IPOS is a streamlined tool that captures those symptoms, concerns, and problems most commonly reported by patients with advanced illness, while still ensuring an individual's own specific concerns are included. Further information about IPOS is available at: http://pos-pal.org/

More about the NAT-CC Patient tool

The NAT-CC Patient tool is a list of common concerns and questions of people with a chronic illness regarding their health and well-being. It prompts the patient to consider the relative importance of their concerns and whether they would like to discuss them with the GP or other health professional.

The tool contains:

- Information for the patient about the tool
- A list of concerns in the areas of:
    - information issues

    - practical information
    - relationship issues
    - issues about meaning
- A list of suggested questions the patient may like to ask
- Space for the patient to write down their own questions/concerns
- Space for the patient to write down the top three concerns/questions/problems they would like to discuss with the GP.

This tool was adapted by the Advance Project expert advisory group from a similar tool developed for carers of patients with a chronic illness in general practice settings (Burridge et al. 2015; Mitchell et al. 2010) as well as a question prompt list for palliative care patients (Clayton et al. 2003; Clayton et al. 2007).

The Advance> Project

Patient
Assessment

Supporting you to live well
with a chronic illness

About this booklet

Living with a chronic condition can affect how you feel and what you're able to do. You may have symptoms that bother you and you may have questions or concerns about your health.

Your doctor and nurse are experienced in supporting people in similar situations to you. They care about your health. It helps if they know what you are going through and the things that matter to you most. But it can be hard to talk about all the things that are important to you when you go to see your doctor or nurse.

This booklet has a series of questions for you to answer that will help your doctor and nurse to understand the symptoms you are experiencing, along with any questions or concerns you may have about your health. It is like a conversation starter that captures important information about you that you can then talk about in more detail with your nurse or doctor.

The booklet asks about a range of issues that people with a chronic condition often experience. Please select the ones that apply to you. Please complete the questions in the booklet and bring it with you when you next see your doctor or nurse. You may feel some questions are not relevant to you, in which case please skip these.

It might be a good idea to book in a long appointment to see your doctor to go through the booklet. Or you may be asked to complete this booklet prior to a regular health check. It may take more than one appointment to talk about all the things that are important to you. That's okay. What's most important is starting the conversation with your health professionals.

IPOS tool

Your full name:

Date:

What have been your main problems or concerns **over the past week?**

1.

2.

3.

Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick **one box** that best describes how it has **affected** you **over the past week.**

	Not at all	Slightly	Moderately	Severely	Overwhelmingly
Pain	☐	☐	☐	☐	☐
Shortness of breath	☐	☐	☐	☐	☐
Weakness or lack of energy	☐	☐	☐	☐	☐
Nausea (feeling like you are going to be sick)	☐	☐	☐	☐	☐
Vomiting (being sick)	☐	☐	☐	☐	☐
Poor appetite	☐	☐	☐	☐	☐
Constipation	☐	☐	☐	☐	☐
Sore or dry mouth	☐	☐	☐	☐	☐
Drowsiness	☐	☐	☐	☐	☐
Poor mobility	☐	☐	☐	☐	☐

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Please list any **other** symptoms not mentioned above, and tick **one box** to show how they have affected you **over the past week.**

	Not at all	Slightly	Moderately	Severely	Overwhelmingly
1.	☐	☐	☐	☐	☐
2.	☐	☐	☐	☐	☐
3.	☐	☐	☐	☐	☐

Over the past week

	Not at all	Occasionally	Sometimes	Most of the time	Always
Have you been feeling anxious or worried about your illness or treatment?	☐	☐	☐	☐	☐
Have any of your family or friends been anxious or worried about you?	☐	☐	☐	☐	☐
Have you been feeling depressed?	☐	☐	☐	☐	☐

	Always	Most of the time	Sometimes	Occasionally	Not at all
Have you felt at peace?	☐	☐	☐	☐	☐
Have you been able to share how you are feeling with your family or friends as much as you wanted?	☐	☐	☐	☐	☐
Have you had as much information as you wanted?	☐	☐	☐	☐	☐

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	Problems addressed/ No problems	Problems mostly addressed	Problems partly addressed	Problems hardly addressed	Problems not addressed
Have any practical problems resulting from your illness been addressed? (such as financial or personal)	☐	☐	☐	☐	☐

	On my own	With help from a friend or relative	With help from a member of staff
How did you complete this questionnaire?	☐	☐	☐

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NAT-CC – Caring for *you.*

Needs Assessment Tool for people with a chronic condition.

The topics below are often a concern for people with a chronic condition.

1. Please rate how concerned you are about each issue. Tick the box which best describes your level of concern **now**.
2. Tick the topics you want to discuss with your doctor or nurse, either now or at some stage in the future.

Your full name:			**Date:**		
	Level of concern (tick one)			I would like to discuss this with my doctor or nurse? (tick one if applicable)	
Information issues	**None**	**Some**	**A lot**	**Now**	**Later**
Finding general information about my health condition(s)	☐	☐	☐	☐	☐
What to expect during the illness	☐	☐	☐	☐	☐
How to plan for the unexpected things relating to the illness	☐	☐	☐	☐	☐
How to plan for my future	☐	☐	☐	☐	☐
Managing financial matters, e.g. getting Centrelink allowances and other benefits	☐	☐	☐	☐	☐
Legal matters, e.g. preparing or updating a will	☐	☐	☐	☐	☐
Not knowing who to go to with my questions	☐	☐	☐	☐	☐
Providing information to my family/carer about my health condition(s)	☐	☐	☐	☐	☐

Your full name: **Date:**

	Level of concern (tick one)			I would like to discuss this with my doctor or nurse? (tick one if applicable)	
Practical issues	**None**	**Some**	**A lot**	**Now**	**Later**
My ability to look after myself	☐	☐	☐	☐	☐
My medical conditions limit my ability to carry out my usual activities	☐	☐	☐	☐	☐
How to manage my medications or treatment regimes	☐	☐	☐	☐	☐
Relationship issues	**None**	**Some**	**A lot**	**Now**	**Later**
I have problems in close/intimate relationships	☐	☐	☐	☐	☐
I have problems in other relationships	☐	☐	☐	☐	☐
Meaning issues	**None**	**Some**	**A lot**	**Now**	**Later**
The illness and its effects are challenging my beliefs and values	☐	☐	☐	☐	☐
The illness and its effects are challenging because of my culture	☐	☐	☐	☐	☐

Questions you may like to ask (tick any questions you would like to ask)

☐ What can be done to improve my physical symptoms?

☐ What can be done to improve my well-being?

☐ Are there any other care services available that can assist me?

☐ What help, assistance or information is available to support my family?

☐ What can I expect in the future with this condition(s)?

Your own questions or concerns – please list here:

____

____

____

To help your doctor or nurse understand what matters most to you, please write the most important issues that have been raised from filling out this booklet below.

The top three concerns or questions I want to talk about with my doctor or nurse now, or in the near future, are:

1. ______________________________

2. ______________________________

3. ______________________________

Now that you've completed the booklet, book an appointment with your doctor or nurse to talk more about the things that are concerning you.

You may also like to complete a fresh copy of this booklet again in the future, so that you and your healthcare team can monitor how things are going with your symptoms and concerns. You could ask your GP or nurse for a new copy.

Acknowledgements

The Advance Project is funded by the Australian Government Department of Health and led by HammondCare in collaboration with the University of Sydney, Flinders University (Caresearch), University of Queensland, University of Wollongong, University of Technology Sydney, Austin Health, and La Trobe University.

The Advance Project Carer Assessment booklet

The Advance Project Carer Assessment booklet contains an assessment tool for carers called the NAT-CC Carer and a short question prompt list for carers. It includes common concerns and questions of carers of people with a chronic illness, regarding their own health and well-being. It prompts the carer to consider the relative importance of their concerns and whether they would like to discuss them with the GP or other health professional.

Based on feedback from the initial phase of the Advance Project, we have formatted these tools into a booklet that is more user-friendly for carers. It includes revised and simplified instructions.

Who completes the Advance Project Carer Assessment booklet and how is it used?

If the patient is accompanied by their carer, the nurse or GP can suggest that the carer completes the Advance Project Carer Assessment booklet: ‘Looking after you while you care for someone with a chronic illness’. The carer can then make an appointment to see their own nurse or GP to review and discuss this.

Alternatively, you may see a carer of a patient with a chronic illness on another occasion and suggest they complete this tool.

This tool can be completed by the carer, with or without the assistance of a nurse. Some carers may particularly value talking with the nurse about the top three concerns/questions/problems they would like to discuss with their GP or other health professional.

Once completed, the tool can be used by the carer’s nurse or GP to quickly get an indication of the carer’s main concerns and questions to guide their consultation with them.

Having the carer on their own in a consultation aimed at them can facilitate discussion about interpersonal issues that they may not be able to raise in front of the person they are caring for.

After the assessment by the nurse and/or the GP, the tool can be scanned and added to the carer’s practice records (if they are also seen as a patient in your general practice).

The Advance Project Carer Assessment booklet is shown on pages 64-70 and can be downloaded from the Advance Project website as a printable PDF.

Tips for introducing the NAT-CC Carer tool

- Ensure that the carer is in a private area when you start the conversation.
- Introduce the topic gently: *“Caring for someone like (name of the person they care for), who has a chronic condition, is very important and it can have an effect on your own health and well-being.”*
- Normalise the difficulty carers can experience and emphasise the importance of the carer looking after their own health: *“We have a lot of experience with how hard it can be to be a carer, and we can support you in that. Your health matters too, so that you can keep looking after (name of the person they care for).”*

Example

A demonstration video of a general practice nurse discussing the NAT-CC Carer tool with a carer can be found at: https://vimeo.com/174789381/c7fd66dc3e

More about the NAT-CC Carer tool

The tool contains:

- Information for the carer about the tool
- A list of concerns in the areas of:
    - information issues

    - practical information
    - personal health and well-being issues
    - relationship issues
    - issues about meaning
- A list of questions the carer may like to ask
- Space for the carer to write down their own questions or concerns
- Space for the carer to write down the top three concerns/questions/problems that they would like to discuss with the GP.

This tool was previously developed and evaluated for carers of patients with a chronic illness in general practice settings (Burridge *et al*. 2015; Mitchell *et al*. 2010). It was adapted by the Advance Project expert advisory group to include some questions from a question prompt list for carers of palliative care patients (Clayton *et al*. 2003; Clayton *et al*. 2007).

The Advance> Project

Carer
Assessment

Looking after you
while you care for someone with a chronic illness

About this booklet

Caring for someone with a chronic condition is important. It can also be a challenging role that can affect your own health and wellbeing.

Your doctor or nurse knows about these challenges and are experienced in supporting people in similar situations to you. They care about your health and it helps if they know what you are going through and the things that matter to you. But it can be hard to talk about all the things that are important to you when you go to see your doctor or nurse.

This booklet has a series of questions for you to answer that will help your doctor and nurse to understand any concerns you are experiencing, along with any questions you may have about your health or the health of the person you care for. It is like a conversation starter that captures important information about you that you can then talk about in more detail with your nurse and doctor.

The booklet asks about a range of issues that carers often experience. Please select the ones that apply to you. Complete the questions in the booklet and bring it with you when you next see your doctor or nurse. You may feel that some questions are not relevant to you, in which case please skip these.

It might be a good idea to book in a long appointment to see your doctor to go through the booklet. Or you may be asked to complete this booklet prior to a regular health check. It may take more than one appointment to talk about all the things that are important to you. That is okay. What's most important is starting the conversation with your health care professionals.

NAT-CC – Caring for *you.*

Needs Assessment Tool for Carers.

The topics below are often a concern for people close to someone with a chronic condition.

1. Please rate how concerned you are about each issue. Tick the box which best describes your level of concern **now**.
2. Tick the topics you want to discuss with your doctor or nurse, either now or at some stage in the future.

Your full name:

Date:

	Level of concern (tick one)			I would like to discuss this with my doctor or nurse? (tick one if applicable)	
Information issues	**None**	**Some**	**A lot**	**Now**	**Later**
Finding general information about the person I am caring for and their condition(s)	☐	☐	☐	☐	☐
Finding specific information to give to the person I am caring for about their condition(s)	☐	☐	☐	☐	☐
What to expect during their illness	☐	☐	☐	☐	☐
How to plan for the unexpected things relating to the illness	☐	☐	☐	☐	☐
How to plan for my future	☐	☐	☐	☐	☐
Ways to care for the person at home, e.g. techniques, equipment or diet	☐	☐	☐	☐	☐
Managing financial matters, e.g. getting Centrelink allowances and other benefits	☐	☐	☐	☐	☐
Accessing support services for the person I am caring for, e.g. community nursing or aged care services	☐	☐	☐	☐	☐
Legal matters, e.g. preparing or updating a will	☐	☐	☐	☐	☐
Not knowing who to go to with my questions	☐	☐	☐	☐	☐
My ability to give information to the person I am caring for	☐	☐	☐	☐	☐

Your full name: **Date:**

	Level of concern (tick one)			I would like to discuss this with my doctor or nurse? (tick one if applicable)	
Practical issues	**None**	**Some**	**A lot**	**Now**	**Later**
My ability to look after myself	☐	☐	☐	☐	☐
My ability to look after the person I am caring for	☐	☐	☐	☐	☐
My medical conditions limit my ability to do things I have to do	☐	☐	☐	☐	☐
The person I am caring for has symptoms that limit their ability to function	☐	☐	☐	☐	☐
The person I am caring for is having difficulty looking after him/herself	☐	☐	☐	☐	☐
My skills limit what I want to do for the person I am caring for	☐	☐	☐	☐	☐
Other issues limit my ability to do what I want to do	☐	☐	☐	☐	☐
Personal health and well-being issues	**None**	**Some**	**A lot**	**Now**	**Later**
My own physical health is a concern	☐	☐	☐	☐	☐
I have problems with tiredness or lack of energy	☐	☐	☐	☐	☐
Being a carer impacts on my choices	☐	☐	☐	☐	☐
Being a carer impacts on my happiness	☐	☐	☐	☐	☐
Being a carer impacts on my self-confidence	☐	☐	☐	☐	☐

Your full name: **Date:**

	Level of concern (tick one)			I would like to discuss this with my doctor or nurse? (tick one if applicable)	
Relationship issues	**None**	**Some**	**A lot**	**Now**	**Later**
I have problems in close/intimate relationships with the person I am caring for	☐	☐	☐	☐	☐
I have problems in other relationships	☐	☐	☐	☐	☐
My ability to communicate with the person I am caring for is limited	☐	☐	☐	☐	☐
My ability to communicate with others is limited	☐	☐	☐	☐	☐
The person I am caring for has problems in close/intimate relationships	☐	☐	☐	☐	☐
The person I am caring for has problems in other relationships	☐	☐	☐	☐	☐
The person I am caring for has limited ability to communicate with others	☐	☐	☐	☐	☐
Meaning issues	**None**	**Some**	**A lot**	**Now**	**Later**
The illness and its effects are challenging my beliefs and values	☐	☐	☐	☐	☐
The illness and its effects are challenging the beliefs and values of the person I am caring for	☐	☐	☐	☐	☐
The illness and its effects are challenging because of my culture, or the culture of the person I am caring for	☐	☐	☐	☐	☐

Questions you may like to ask your doctor or nurse (tick any questions you would like to ask)

☐ What can be done to improve my well-being?

☐ Are there any other care services available that can assist me to care for my relative/friend?

☐ What help, assistance or information is available to support the person I am caring for?

☐ What help or support is available for me and other members of the family?

☐ What can the person I am caring for expect in the future with their condition(s)?

Your own questions or concerns – please list here:

To help your doctor or nurse understand what matters most to you, please write the most important issues that have been raised from filling out this booklet below.

The top three concerns or questions I want to talk about with my doctor or nurse now, or in the near future, are:

1.

2.

3.

Now that you've completed the booklet, book an appointment with your doctor or nurse to talk more about the things that are concerning you.

Acknowledgements

The Advance Project is funded by the Australian Government Department of Health and led by HammondCare in collaboration with the University of Sydney, Flinders University (Caresearch), University of Queensland, University of Wollongong, University of Technology Sydney, Austin Health, and La Trobe University.

Reference for the IPOS tool

IPOS (Integrated Patient Outcome Scale). Palliative care Outcome Scale website. Available at: http://pos-pal.org/

References for NAT-CC Patient and Carer tools

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Mitchell G, Girgis A, Jiwa M et al. 2010. A GP Caregiver Needs Toolkit versus usual care in the management of the needs of caregivers of patients with advanced cancer: a randomized controlled trial. Trials 11:115. Full article available at: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3009964/

The Advance Project Referral Triage Tool (clinician resource)

The Advance Project Referral Triage Tool identifies additional support that might be required by a patient and/or carer. This includes whether the patient may benefit from early referral to a specialist palliative care service.

The Advance Project Referral Triage Tool contains:

- A question to determine whether the supportive care needs of the patient and carer can be met by the general practice with current support
- Questions about whether referral to other services is required, including specialist palliative care
- A list of triggers or indicators for referral to a specialist palliative care service
- A question about when further follow-up is required with the general practice nurse and/or the GP.

Who completes the Advance Project Referral Triage Tool and how is it used?

This tool can be completed by a nurse or GP after the patient and/or carer have completed the Advance Project Assessment booklet(s) and seen the GP and/or nurse to review the responses and develop the care plan. The tool can be scanned and added to the patient's practice records after any required referrals and follow-up appointments have been made.

Alternatively, the GP or nurse may like to simply review the tool as a prompt or educational tool and use the practice software or records to record any referrals required for a particular patient.

If the patient requires referral to specialist palliative care services, this must be discussed with the patient and/or their carer. Some tips for discussing referral to specialist palliative care services are shown in Section 6 (page 77).

Example

A short demonstration video of a general practice nurse discussing the Advance Project Referral Triage Tool with the patient's GP can be found at: https://vimeo.com/174791491/0711ffa5dd

A longer version of this video can be found at: https://vimeo.com/174752455/4145466287

The Advance Project Referral Triage Tool:
Supportive and palliative care in general practice

Patient Name:

1. After assessment by the practice nurse and GP consider: Can this patient's and their family/carer's supportive care needs be met at present by the GP practice and the current support systems in place?	Yes	No

If No, consider what additional support is needed (see questions 2. and 3. below)

If either Yes or No, complete question 4.

2. Are any of the following support or referrals required?:		
Practical support (eg. Meals on Wheels, equipment, assistance in the home – shopping, domestic help, transport, personal care) ………………..	Yes	No
Community nurse ………………………………………………………………	Yes	No
Counsellor or Psychologist.……………………..……………………………....	Yes	No
Social worker …………………………………………..…………………….....	Yes	No
Physiotherapist ……..……………………………………………………………..	Yes	No
Occupational therapist ……………………………………………………….....	Yes	No
Aged Care Assessment Team (ACAT)………………………………………	Yes	No
Other medical specialist: ______________________________		
Other: ____		
3. Is referral to a specialist palliative care service required?	Yes	No

Consider referral to specialist palliative care service for either a one off assessment or ongoing care, if one or more of the following are present:

- *Unresolved physical symptoms*
- *Unresolved psychological symptoms or existential/spiritual distress*
- *Unresolved carer/family distress*
- *Anticipated difficulties with end of life planning or care in the coming months*
- *Likely to require, or a preference for, terminal care in a specialist palliative care inpatient unit in the coming months*

If referral to specialist palliative care is required:

- *information about services available in your local area can be found at http://palliativecare.org.au/directory-of-services/*
- *communication tips for discussing referral to specialist palliative care teams with patients / families are shown in the Advance Project Toolkit, which is available from www.theadvanceproject.com.au*

4. When does the patient and/or carer next need follow up by the general practice?
   a. *General Practice Nurse follow up* _____________________
   b. *GP* follow up _____________________

Completed by:

Date:

Section 6

Other resources

This section contains the following resources to assist with implementation of the Advance Project toolkit:

- Communication tips for clinical staff
    - tips for introducing referral to specialist palliative care if required
    - links to demonstration videos
- Communication tips for general practice administrative staff
- How to successfully implement the Advance Project Toolkit.

Section 6 - Other resources

Communication tips for clinical staff when introducing the Advance Project Assessment tools to patients and/or carers

It may feel foreign to introduce the need for an assessment of a patient or carer's supportive care needs or introduce a discussion about advance care planning. Health care professionals can feel uncomfortable discussing these issues and perceive that their patients do also. However, patients and carers mostly welcome the opportunity to talk about their symptoms, problems, concerns, and priorities and to discuss advance care planning.

The principles of good communication apply when introducing these assessment tools, as they do for all areas of your nursing or medical practice. It is important to show empathy, care, and compassion when you are doing these assessments with patients and their carers.

Introducing the topic of advance care planning using either the Advance Care Planning Screening Interview or the quick guide for introducing advance care planning

If the patient does not require a full assessment of their palliative and supportive care needs and you are incorporating the Advance Care Planning Screening Interview or quick guide to introducing advance care planning as part of a 75 years and over health assessment, chronic disease management plan review, or routine consultation, some tips for introducing this include:

- Introduce conversation about advance care planning in a clear, straightforward way. Normalise it by saying that the practice asks everyone who is having either a 75 years and over health assessment or a chronic disease management plan review about advance care planning. For example: *"As part of the annual check-up, we also ask everyone about their future health wishes."*
- Ask for permission to talk with the patient about their future health wishes. For example: *"Are you OK to talk with me about this for 5 to 10 minutes?"* OR *"In the next 5 to 10 minutes, could I ask you some questions about your future health wishes?"*
- If the patient wants further information you could add: *"Your answers will give me useful information about your needs and wishes and allow me to work out the best way to help you with future health care planning."*
- An example of a way to describe what advance care planning is when talking to patients about advance care planning is as follows: *"Advance care planning is a process that helps you to plan for your future medical care. It involves thinking and talking about your values and beliefs – what's important to you - and your wishes about the medical care you would like to have if you became critically ill or injured."*

If advance care planning is introduced as part of a full assessment of the patient's palliative and supportive care needs, we suggest you introduce this first (see below) and then introduce advance care planning with a statement such as *"Would it be alright if I start by asking you some questions about your future health wishes?"*

Example

A shorter video of a general practice nurse conducting the Advance Care Planning Screening Interview with a patient is shown at: https://vimeo.com/174983055/1ce6870b4e

The full version of this video is shown at: https://vimeo.com/170468999/045cc9c99c

An example of a GP initiating a conversation about advance care planning is shown at: https://vimeo.com/287517611/d99f26f091

Another example of a GP initiating a conversation about advance care planning using the quick guide is shown at: https://vimeo.com/287510278/65e03d96b6 (this occurs in the context of a consultation with a young person with a progressive illness, after he has raised concerns about what will happen if he became really sick).

Introducing the need for an assessment of the patient's supportive care needs

Patients whose death in the next 6 to 12 months would not surprise you and/or who meet the SPICT^{TM} criteria for being at risk of deteriorating and dying will benefit from a full assessment of their palliative and supportive care needs. This assessment will help to see if the patient has any unmet needs and also help them to consider their most important concerns and priorities. Some example phrases for introducing the supportive care needs assessment are as follows:

- "*I've noticed that you have been more unwell lately (*OR *"you've had this illness for a long time"* OR "*you've been experiencing a number of health problems"*) *and we'd like see you to do a thorough check of your symptoms, concerns, and priorities so we can work out how best to support and help you. I'd like book you in for an appointment and give you a booklet to take home and fill in between now and then. Would that be OK?"*
- *"Thanks for coming in today. The reason we're here is that we'd like to take a step back, and ask you some questions to try to understand your concerns, thoughts about how you are going, and your priorities, so that we can make sure that we are providing you with the right support and not missing anything."*
- If more explanation is required: *"We would like to make sure that we know and understand your side of the story, as the person who is going through all the things that you are going through, so that we are all on the same page and that we are doing everything we can to make your life as good as possible. How does that sound to you?"*

Example

A short video of a general practice nurse introducing the need for a full supportive care needs assessment is shown at: https://vimeo.com/174768389/13abdbcec8

A video of a GP introducing the Advance Project Patient Assessment booklet is shown at: https://vimeo.com/287515995/1c801dd127

Tips for introducing the Carer Assessment

- Ensure that the carer is in a private area when you start the conversation
- Introduced the topic gently: *"Caring for someone like (name of the person they care for), who has a chronic condition, is very important and it can have an effect on your own health and well-being."*
- Normalise the difficulty carers can experience and emphasise the importance of the carer looking after their own health: *"We have a lot of experience with how hard it can be to be a carer, and we can support you in that. Your health matters too, so that you can keep looking after (name of the person they care for)."*

Example

A demonstration video of a general practice nurse discussing the Carer Assessment can be found at: https://vimeo.com/174789381/c7fd66dc3e

Endorsing the value of the Advance Project Assessment booklets

If another member of the general practice team introduces the need for the supportive care needs assessment, it is important for the GP to also endorse the value of the assessment to the patient or carer and review the completed assessment booklet during the patient or carer's next consultation. Patient and carer concerns and questions booklets are more effective when endorsed by the doctor. For example: *"Thank you for taking the time to fill out the booklet. The questionnaires in the booklet help me to make sure I haven't missed anything and also let you share how you are going. Would it be alright if I read through your answers, and then we can talk about it?"*

Some GPs may worry that many concerns will be raised by the Advance Project Patient or Carer Assessment booklets, which may make it hard to cover everything in a consultation. The Assessment booklets help patients and carers to identify their concerns about their health and well-being. They also rank the relative importance of these concerns, and indicate when the patient or carer would like to discuss them; it might not necessarily be today. If the patient or carer identifies several concerns to discussion during one appointment, discuss those of most importance to the patient or carer and then suggest another appointment to discuss the rest.

Example

An example of a GP endorsing the value of a Carer Assessment booklet that was previously introduced by a nurse is shown at: https://vimeo.com/287512164/f5361d95c8

Tips for introducing referral to specialist palliative care services

If the patient requires referral to specialist palliative care services, the GP or nurse can discuss this with the patient. If the patient is being referred to specialist palliative care, this requires sensitive communication as patients may have fears, concerns, and misunderstandings about palliative care. It can be daunting as a health professional to explain palliative care to patients. Some tips for discussing referral to specialist palliative care services are shown below.

- Initially, it can be helpful to ask the patient about their understanding of palliative care, as many patients have misconceptions about it: *"Have you heard of palliative care? Or do you know anyone who has received palliative care?"*
- Offer to provide an explanation about palliative care, such as: *"Would it be useful if I explained a little about palliative care?"*
- Explain what specialist palliative care could offer in a clear and straightforward way. Some example phrases are as follows:
    - "*Extra help and support from the palliative care service might be useful now, especially if we are to give you the best care possible."*
    - *"The palliative care doctor can give us advice about the best medicines for symptoms like your itch and pain."*
    - *"The palliative care team can provide extra support to you and your family and help optimise your comfort and your ability to do the things you want to do."*
- Reassure the patient that she/he will still be cared for by the general practice team. Some example phrases are as follows:
    - "*We aren't going anywhere. We'll still be very much involved in looking after you.*"
    - "*The palliative care team will be able to provide extra support or advice with the best medicines for your pain. I or Dr (name of GP) will still be your main doctor, and we'll be coordinating everything.*"
- You may need to clarify and correct misconceptions about palliative care services (particularly that it is not solely for people who are dying or associated with imminent death).
- If appropriate, explain that the patient can be linked up with the palliative care team at the same time as receiving treatments directed at the underlying disease (e.g., chemotherapy).

Example

A demonstration video of a general practice nurse discussing referral to specialist palliative care services with a patient can be found at: https://vimeo.com/174757407/0d0f744856

A demonstration video of a GP discussing referral to specialist palliative care services with a patient can be found at: https://vimeo.com/287501967/4d949a99bd

Further communication tips can be found in the following freely available guidelines:

Clayton JM, Hancock KM, Butow PN, Tattersall MHN, Currow DC. Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers. Medical Journal of Australia 2007; 186 (12): S77- 108. This is available for free at: https://www.mja.com.au/journal/2007/186/12/clinical-practice-guidelines-communicating-prognosis-and-end-life-issues-adults

Communication tips for administrative staff when introducing the Advance Project Assessment booklets to patients and/or carers

Some practices may feel comfortable training their administrative staff to hand out the Advance Project Assessment booklets to patients or carers to complete prior to a consultation or health assessment. Some tips for administrative staff when doing this are shown here:

- The patient or carer would need to first be identified as suitable by the GP or nurse.
- An example script is as follows *"As a part of the annual health check, we ask patients to complete a series of questionnaires to help us to better understand how they are going and what is important to them at the moment. This will help (name of GP or nurse) to focus on the right things when they see you. … Please feel free to just answer what you can, and if you have any questions, you can ask (name of GP or nurse) when you see them."*
- If feasible, find a quieter or more private area in the waiting room for the patient or carer to complete the booklet.

Example

A demonstration video of an administrative staff member handing out the Advance Project Patient Assessment booklet to a patient prior to a health assessment is shown at: https://vimeo.com/287513013/321b888fcd

How to successfully implement the Advance Project Toolkit

Introducing the Advance Project Toolkit within your practice

There are many strategies to ensure that the implementation of the Advance Project Toolkit within your general practice is a success. These include:

- Reflect on how the tools might be integrated into current practice and/or what changes might be required
- Inform everyone in the practice about the benefits of what you are trying to do
- Seek support from colleagues in your practice
- If you are a nurse or practice manager, seek support from GPs and perhaps identify a ‘champion’ GP
- If necessary, negotiate a change in work organisation to create time to initiate the assessments
- Identify a private space to conduct assessments
- Allocate time to undertake assessments with patients to ensure successful completion
- Ensure there is clarity and shared understanding about the billing arrangements.

Practical ideas

Further practical ideas include:

- Volunteer to do a short presentation at the next regular practice meeting to inform everyone about the benefits of the project
- If you are a nurse or practice manager who has one GP who is very interested in the project, ask him/her to give a short talk to other GPs in the practice
- Try to find a room where privacy is guaranteed. For instance, there might be a consulting room that is not being used on a particular day. Avoid conducting follow-up assessments in public or shared spaces (e.g., the treatment room), where other staff may pop in and out or interrupt your conversations.

Section 7

More about the Advance Project

This section contains the following information about the Advance Project:

- Further training options
- The Advisory Project Advisory Group members and team members.

Section 7 - More about the Advance Project

Further training opportunities

To get the most out of your learning, we encourage you to practise your skills in sensitively promoting awareness of advance care planning and screening for patients' and carers' supportive and palliative care needs, utilising the tools in the Advance Project Toolkit, as soon as possible after the completion of the online training program.

One-on-one telephone mentoring – A palliative care nurse is available to provide individual and small group mentoring and coaching for nurses, GPs, practice managers, and other primary care clinicians regarding implementing the skills into practice. If you are interested in speaking with our nurse, please contact AdvanceProject@hammond.com.au

Further information on training opportunities can be found at: www.theadvanceproject.com.au

The Advance Project Advisory Group members and team members

The Advance Project is led by HammondCare (http://www.hammond.com.au/) in collaboration with various universities and health organisations.

HammondCare team members:

- Project Director and Chair of the Advisory Group: Prof Josephine Clayton, Palliative Care Physician, HammondCare and Professor of Palliative Care, University of Sydney
- Project Coordinator and Evaluation Coordinator: Dr Srivalli Nagarajan, HammondCare
- General Practitioner Education Lead: A/Prof Joel Rhee, General Practitioner, HammondCare and Associate Professor, University of Wollongong
- Clinician Mentor: Kelly Arthurs, Clinical Nurse Consultant in Palliative Care

CareSearch team members:

- Prof Jennifer Tierman, Director of CareSearch (https://www.caresearch.com.au/), Flinders University, and member of the Advisory Group
- Online Module Consultant: Sue Stoecker and previously Dr Karen Cooper
- Website Administrator: Ruth Murton, CareSearch
- Website Assistant: Heather Grigg, CareSearch
- Project Officer: Madelaine de Valle, CareSearch

Other Advisory Group members:

- Prof Geoffrey Mitchell (Professor of General Practice and Palliative Care), University of Queensland
- Prof Jane Phillips (Professor of Palliative Care Nursing), University of Technology, Sydney
- Prof Elizabeth Halcomb (Professor of Primary Healthcare Nursing), University of Wollongong
- Dr Karen Detering (Medical Director), Department of Advance Care Planning, Austin Health
- A/Prof Virginia Lewis (Director, Australian Institute for Primary Care & Ageing), La Trobe University
- A/Prof Rachael Morton (Director of Health Economics, Sydney Medical School), University of Sydney

International advisors:

- SPICT$^{\text{TM}}$ tool: Prof Scott Murray and Dr Kirsty Boyd, University of Edinburgh, UK
- IPOS tool: Prof Felicity Murtagh, Cicely Saunders Institute, Kings College, London, UK
- International palliative and end-of-life care nursing perspective: Prof Jane Seymour, The University of Sheffield, UK

Further information, brief biographies, and photos of the Advisory Group and Team Members can be found at: www.theadvanceproject.com.au

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