Host Agency Information Kit - ATTACHMENTS

Advance Care Planning Volunteer Ambassadors Program

CENTRAL HUME Primary Care Partnership

Mercy Health
Care first

Advance Care Planning Initiative

(East Hume and Border)

2016

Acknowledgements

Many thanks to the Advance Care Planning Initiative (East Hume and Border) members and Mercy Health Palliative Care Volunteers for their support and contribution to this program

We would also like to thank the Austin Health – Respecting Patient Choices Volunteer Ambassadors and Western NSW Local Health District (Dubbo) Palliative Care Service for sharing their volunteer documents.

The Advance Care Planning Initiative (East Hume and Border) has been funded by Networking Health Victoria in partnership with the Department of Health and Human Services and auspiced by the Central Hume Primary Care Partnership.

VERSION: August 2016

For further information: admin@centralhumepcp.org

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Attachment 1- ACP Volunteer Ambassador Expression of Interest

EXPRESSION OF INTEREST

[Host Agency Name]

Please complete and return to:

[Agency Contact Person
Preferably Volunteer Coordinator
Name, Address, Email
By DUE DATE]

The main **aim** of the ***Advance Care Planning Volunteer Ambassadors*** program is to improve community awareness of advance care planning in an accessible and sustainable way by supporting volunteers to present 'Introduction to Advance Care Planning' information to interested groups in their local community.

For further information:
Advance Care Planning Volunteer Ambassador – Position Description

DATE:

VOLUNTEER DETAILS

NAME.....

ADDRESS.....

SUBURB ..... STATE ..... POSTCODE.....

DATE OF BIRTH .....

TELEPHONE: HOME or MOBILE .....

E-MAIL .....

LANGUAGES SPOKEN: .....

EXPERIENCE

OCCUPATION / PREVIOUS OCCUPATION.....

.....

PREVIOUS VOLUNTEER EXPERIENCE: .....

.....

.....

PREVIOUS VOLUNTEER TRAINING: .....

.....

DO YOU HAVE ANY TRAINING OR EXPERIENCE RELATED TO ADVANCE CARE PLANNING OR PLANNING FOR END-OF-LIFE? IF YES PLEASE SPECIFY

.....

NAME SOME OF THE PERSONAL SKILLS YOU FEEL YOU COULD OFFER TO THE ***ADVANCE CARE PLANNING VOLUNTEER AMBASSADORS*** PROGRAM?

.....

ARE THERE SPECIFIC LIMITATIONS ON YOUR VOLUNTEERING AVAILABILITY FOR THE ***ADVANCE CARE PLANNING VOLUNTEER AMBASSADORS*** PROGRAM?
(e.g. time, previous life experiences, present commitments).

.....

SIGNATURE

APPLICANTS SIGNATURE: .....

DATE.....

SELECTION CRITERIA

- ✓ An interest in promoting advance care planning (ACP)
- ✓ Effective communication skills, including listening skills and basic word processing
- ✓ A capacity to communicate ideas effectively to other people
- ✓ An ability to respond empathically to the experiences of local community members whilst keeping a focus on the core messages of the 'Introduction to ACP' material
- ✓ An understanding of when to refer a question to ACP health professionals
- ✓ Previous training in basic volunteering e.g. role of volunteers, confidentiality, volunteer insurance, ethics, communication, loss and grief
- ✓ Ability to work in a team and within host agency requirements
- ✓ Ability to recognise when additional supervision and debriefing is necessary
- ✓ Completion of ACP Volunteer Ambassador training
- ✓ Availability and capability to present 'Introduction to ACP' information package to local community groups (5-30 people) with an ACP Volunteer Ambassador buddy
- ✓ Availability to participate in ongoing support gatherings and evaluation processes
- ✓ Agreement not to reveal to any person or entity any confidential information relating to patients and employees, policies, processes and dealings and not to make public statements relating to the affairs of [HOST AGENCY] without prior authority of the [VOLUNTEER COORDINATOR]
- ✓ Active participation in the ongoing identification, assessment, treatment and prevention of risks.
- ✓ Over 18 years of age and in good general health
- ✓ Hold a current driver's license and use of a fully insured private vehicle

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Attachment 2 – ACP Volunteer Ambassador Position Description

POSITION DESCRIPTION

General Introduction

Advance Care Planning is the process of planning for future health and personal care whereby a person's values, beliefs and preferences are made known so they can guide clinical decision making at a future time when that person cannot make or communicate their decisions due to lack of capacity (Department of Health and Human Services, Advance Care Planning: A strategy for Victorian Health Services 2014-2018, p11).

Advance Care Planning has been shown to improve quality of care at the end of life and increase the likelihood of a person's wishes being known and respected. Advance Care Planning improves the end-of-life care experience. Clients and families report being more satisfied with the end-of-life care provided. Symptoms of anxiety, depression and post-traumatic stress in the surviving family members are reduced (Detering et al. 2010 in DHHS 2014: 18).

Regional Context

The ***Advance Care Planning – Volunteer Ambassadors Program*** arose out of feedback from community members attending an Advance Care Planning forum organised by the Advance Care Planning Initiative (East Hume & Border) and Mercy Health Palliative Care Volunteers in late 2015. Feedback identified a preference for advance care planning information to be taken out to the community and provided in existing groups and meeting places; for example - retirement villages, chronic health support groups, service groups, Country Women's Association, Men's Sheds, University of the 3rd Age, Returned Soldiers Leagues.

The *Advance Care Planning – Volunteer Ambassadors Program* (ACP VAP) will promote advance care planning (ACP) in the general community.

The aim of this program is to improve community awareness of advance care planning in an accessible and sustainable way by supporting volunteers to present 'Introduction to Advance Care Planning' information to interested groups in their local community.

The Advance Care Planning Initiative (ACPI) is leading and supporting the program; including the development of training material and support systems, initial training, evaluation, and subsequent dissemination of an Advance Care Planning – Volunteer Ambassadors Program toolkit for use by other agencies and communities.

The ACPI (East Hume & Border) is funded by Networking Health Victoria in partnership with Department of Health and Human Services and focuses on the communities of Albury, Wodonga, Towong, Indigo, Alpine, Wangaratta, Benalla and Mansfield local government areas.

Mercy Health Palliative Care Volunteers were instrumental in identifying a need for this project and are continuing to be involved by providing input into the development of the project materials and piloting the initial training and 'Introduction to ACP' information sessions.

Interest in the project has also been expressed by the Alpine Independent Age Care Advocates, Northeast Health Wangaratta (volunteer program), Tallangatta Health Service (volunteer and consumer advocates) and Benalla Health (palliative care volunteers).

The development of the ACP VAP (East Hume & Border) has benefited from the ideas and experiences of the Austin Health – Respecting Patient Choices Volunteer Ambassadors and Western NSW Local Health District (Dubbo) Palliative Care Service.

Host Agency Organisational Context

The ACP VAP will be implemented in partnership with local Host Agencies.

To participate in the ACP VAP each Host Agency will need to have an existing volunteer program and a focus on Advance Care Planning as an integral part of services provided to their community.

The ACP VAP is aimed to benefit Host Agencies by contributing to patient well-being and quality assurance commitments related to client directed care and community engagement.

Participating in the ACP Volunteer Ambassador program will involve:

- ✓ Providing ACP Volunteer Ambassador training, induction and support
- ✓ Promoting 'Introduction to ACP' sessions through local papers, newsletters, website and/or social media
- ✓ Providing an administrative booking system for 'Introduction to ACP' sessions in their catchment
- ✓ Collating the 'feedback form' data after each session and sharing this with volunteers and the Advance Care Planning Initiative (East Hume & Border)
- ✓ Supporting at least two peer support and debriefing meetings annually to provide ACP updates, identify 'what's working' and 'what needs improving' as a basis for continuous improvement

The Host Agency (Volunteer Coordinator) will be responsible for the recruitment and training of the ACP Volunteer Ambassadors who would be drawn from the general pool of agency volunteers after they have met the host agency basic volunteer training and Mandatory Screening requirements.

The ACP Volunteer Ambassadors will work under the supervision of a volunteer co-ordinator.

It is anticipated the Volunteer Coordinator will

- arrange ongoing on-site support and de-briefing as required
- meet on a regular basis with all ACP Volunteer Ambassadors and provide program-specific support, clinical input and supervision as required; and ensure that the volunteers are informed of key program developments.

ACP Volunteer Ambassador Role

Volunteers will be conducting community information sessions about advance care planning utilising resources developed by the Advance Care Planning Initiative (East Hume and Border).

Initially ACP Volunteer Ambassadors will not be expected to assist directly with the completion of individual advance care plans/directives, but rather provide a source of information and clarification about the process, available legal instruments and so on. Volunteer Facilitators will be able to provide advice consistent with the endorsed resources developed (e.g. FAQ's) and to seek assistance from the Volunteer Coordinator where indicated.

The potential for extending the ACP Volunteer Ambassador role to help discuss and complete an advance care plan/directive will be further explored as the program unfolds.

ACP Volunteer Ambassador criteria – skills and attributes

- ✓ An interest in promoting advance care planning (ACP)
- ✓ Effective communication skills, including listening skills and basic word processing
- ✓ A capacity to communicate ideas effectively to other people
- ✓ An ability to respond empathically to the experiences of local community members whilst keeping a focus on the core messages of the 'Introduction to ACP' material
- ✓ An understanding of when to refer a question to ACP health professionals
- ✓ Previous training in basic volunteering e.g. role of volunteers, confidentiality, volunteer insurance, ethics, communication, loss and grief
- ✓ Ability to work in a team and within host agency requirements
- ✓ Ability to recognise when additional supervision and debriefing is necessary.
- ✓ Completion of ACP Volunteer Ambassador training
- ✓ Availability and capability to present 'Introduction to ACP' information package to local community groups (5-30 people) with an ACP Volunteer Ambassador buddy
- ✓ Availability to participate in ongoing support gatherings and evaluation processes
- ✓ Agreement not to reveal to any person or entity any confidential information relating to patients and employees, policies, processes and dealings and not to make public statements relating to the affairs of [*HOST AGENCY*] without prior authority of the [*VOLUNTEER COORDINATOR]*
- ✓ Active participation in the ongoing identification, assessment, treatment and prevention of risks
- ✓ Over 18 years of age and in good general health
- ✓ Hold a current driver's license and use of a fully insured private vehicle

Supervision and Support

Debriefing sessions are an important aspect of a healthy working environment and volunteers will have the opportunity to debrief, reflect on their role and, receive support and recognition.

A performance appraisal will initially take place approximately 3 months then annually with the Volunteer Coordinator.

Out of Pocket Expenses

Volunteers will not be required to purchase any item for the delivery of a promotion event. If a volunteer requires additional resources this can be discussed with the Volunteer Coordinator who will seek approval for the purchase from the host agency.

Insurance

Once a Volunteer has completed the mandatory training they are covered by the host agency insurance policy whilst carrying out activities as outlined in the job description.

Conclusion of Services

A Volunteer may resign their position at any time although it is preferable that they submit their written notice to their coordinator before resigning to enable debriefing and discussion.

Volunteers who do not adhere to the policies and procedures of the host agency or fail to perform in their role in a satisfactory manner will have their position concluded. A Volunteers service will not be concluded without prior discussion with their coordinator and an opportunity given to address any of the issues.

Attachment 3 – Advertisement to recruit ACP Volunteer Ambassadors

ADVERTISEMENT TO RECRUIT ADVANCE CARE PLANNING VOLUNTEER AMBASSADORS

Are you interested in helping people communicate their future health care preferences?

Would you like to provide Advance Care Planning information to local community groups?

Advance Care Planning is having a conversation with family, friends and your doctor about the type of medical care you would want or not want to receive if you became seriously ill or injured and couldn't communicate your wishes.

Advance Care Planning has been shown to

- improve quality of care at the end of life
- increase the likelihood of a person's wishes being known and respected
- improve the end-of-life care experience
- result in clients and families being more satisfied with the end-of-life care provided
- reduce symptoms of anxiety, depression and post-traumatic stress in the surviving family members

The Advance Care Planning – Volunteer Ambassadors Program aims to improve community awareness of advance care planning in an accessible and sustainable way by supporting volunteers to present 'Introduction to Advance Care Planning' information to interested groups in their local community.

We [*Host Agency*] are looking for Volunteer Ambassadors to help us take Advance Care Planning information out to existing community groups and meeting places such as retirement villages, chronic health support groups, service groups, Country Women's Association, Men's Sheds, University of the 3rd Age, Returned Soldiers Leagues.

Volunteers come from all walks of life, are male/female, young/mature age, and varied paid and unpaid workers. Volunteers are as unique as the people in local community groups.

[*Host Agency*] is seeking Expressions of Interest by **[***Date*] from people who would like to be trained and supported to be ***Advance Care Planning – Volunteer Ambassadors.***

Successful applicants would then participate in a 3 hour training workshop on [*Date*] in [*Place*].

For further enquiries, please contact [*Volunteer Coordinator*] on [*telephone or email*].

Attachment 4: Introduction to ACP Information Session – GP Letter

[*Host Agency letterhead*]

Date:

Dear Doctor

Re: Introduction to Advance Care Planning Information Session

I am writing to inform you that the [*Host Agency*] ***Advance Care Planning Volunteer Ambassadors*** are providing 'Introduction to Advance Care Planning' information sessions to community groups in your area during the next few months.

[O*r provide specific session information if relevant*]

Participants will be given information about Advance Care Planning and encouraged to 'have the advance care planning conversation' with their loved ones and health care providers.

If you have patients who would benefit from attending please do not hesitate to inform them of this event – please see the attached flyer for further details.

We hope you will see an increase in people making appointments to discuss their advance care plans as a result.

Thank you for your attention to this matter and we hope it meets with your support.

If you have any queries or require further information please do not hesitate to contact [*Volunteer Coordinator*] at [Host Agency] via email [*xxxxxxxx*] or on [*#######*].

Yours Sincerely

Attachment 5 – 'Introduction to ACP Information Session' – Booking Template

'Introduction to Advance Care Planning - Community Information Session'

BOOKING DETAILS

Name of Community Group:

Community Group Contact Person:

Contact details:

Reason group is interested in Advance Care Planning information:

Proposed session details:

Date: Room details:

Time: Audio-visual facilities:

Venue:

Size of group:

ACP Volunteer Ambassadors allocated:

Signature (Volunteer Coordinator): Date:

Attachment 6 – 'Intoduction to ACP' Community Information Powerpoint Presentation

A copy of the 'Introduction to ACP' PowerPoint presentation is provided in both hard copy form and on the USB given to all ACP Volunteer Ambassadors attending training.

Attachment 7 – Advance Care Planning – Regional ACP Brochure

Regional ACP Brochure - will be provided separately via email to enable Host Agencies to include their own logos and contact information without losing layout of information

Final details will be available on the USB material being given to all ACP Volunteer Ambassadors Program training participants.

Attachment 8 – Handout – ACP Conversation Starters

Advance Care Planning

Conversation Starters

A guide to having discussions with your family and loved ones
Thinking about what is important to you

If you got really sick, and you couldn't speak for yourself, would your family and doctor know what your wishes are about your healthcare?

There are actions you can take to plan for such times – it's called Advance Care Planning.

The first step is just having a talk about your future healthcare. Letting everyone know what you want is the best way to influence the way you are cared for in times of illness.

Next - it is really important to have arranged a 'substitute decision maker' to speak on your behalf. It is a big responsibility to make medical decisions for another person so talking about what you want is also very important for the people who are caring for you.

The following questions will help you have discussions about your values and preferences with the 'substitute decision maker' and with your loved ones so that everyone is quite clear about what is most important to you. If your 'substitute decision maker' knows what you care about, he or she will be able to make good decisions for you.

You may like to write down your answers to the questions and include it with your advance care directive, or you may prefer just to talk.

The important thing is **having the advance care planning conversation!**

Conversation questions – answer as many or few as you like ....

Q What are the things that are most important to you? What makes life meaningful or good for you now? *For example: spending time with family and friends, going fishing, working, gardening, eating and enjoying food & meal times, conversation, able to complete my own personal care, being in control of my life, living independently and at home, going home*

Q What, if any, religious or personal beliefs do you have about sickness, health care decision-making, or dying? *For example: someone to give communion every week, no blood transfusions, regular meditation, not wanting family to have to decide final treatment if they are worried, cultural considerations such as dying time*

Q Some people feel a time might come when their life would no longer be worth living. Can you imagine any circumstances in which life would be so unbearable for you that you would not want medical treatments used to keep you alive? *For example: not able to recognise family and loved ones, not having control of my bladder and bowels, no longer able to drink or eat food, not able to talk, read or write*

- **Q** What, if any, fears do you have about dying? What preferences do you have about where you would prefer to spend your last days? *For example: prefer being safe in hospital or home is best for as long as possible, don't want to die away from country, want all the bells and whistles until I am gone, afraid of pain, want to be comfortable, don't want to be left on my own or would like to be alone, don't want to be attached to a lot of machines, would like my family to be well supported*

- **Q** If your 'substitute decision maker' ever had to make a medical decision on your behalf, are there people you would want them to talk to for advice or support. *For example: family members, friends, health care workers, clergy, get a second medical opinion*

- **Q** Is there anyone you specifically would NOT want involved in helping to make health care decisions on your behalf? *For example: sometimes specific family members or health care workers, or clergy, people who have been abusive in the past, 'nosy neighbours'*

- **Q** How closely would you want your 'substitute decision maker' to follow your instructions about your wishes, as opposed to doing what they think is best for you at the time decisions are made? Legally the 'substitute decision maker' is required to make decisions in accordance with your wishes. *For example: consider my preferences or let my doctor decide*

- **Q** Should financial or other specific concerns enter into decisions about your medical care? If so, please explain these. *For example: if an expensive drug or treatment was offered, would you want major surgery, are you ready fora long recovery period?*

- **Q** Are there other things you would like your 'substitute decision maker' to know about you, if he or she were ever in a position to make medical treatment decisions on your behalf? *For example: I love you, just do your best, I am not afraid to die, thank you for all you have done for me, please follow my wishes and don't feel guilty when I die, please don't be afraid to let me go when it is time*

Attachment 9 – Handout – Advance Care Plan/Directive Format

It is anticipate ACP Volunteer Ambassadors will use their Host Agency's preferred ACP/D format to promote ACP in their community.

Alternatively, the ACPI Working Group (East Hume and Border) is finalising a regionally endorsed ACP format with input from health professionals and consumers. Please contact Tricia Hazeleger, ACPI Project Manager E: tricia.hazeleger@centralhumepcp.org for an ACP/D format if needed.

Attachment 10 – Handout – Sample ACP Letter

SAMPLE Advance Care Plan letter

Name: 'Jane Doe' DOB: xx/xx/xx

When considering my advance care plan, it is important that health professionals that may be tasked with undertaking my future care needs have a sense of who l am and what is important to me.

I am a mother to four fabulous children and a future daughter in law. I am sister to four of my siblings and although we have not always been close - we are there for each other through thick and thin because we relied on each other when growing up and were each other's friends for so many years due to us growing up in a very small rural town.

The most precious things to me are my children and throughout my life, my constant first priority is them. They are my world.

Should I become incapacitated for any reason I would like health professionals to be very proactive and aggressive with my treatment so I have a full opportunity for an optimum recovery. This is important to me because I want to watch my family grow up and experience life's blessings.

Should I ever be in a position that I require a high level of care to remain independent than I would like this care to be given by an appropriately levelled service, home care package or an appropriate residential facility. I appreciate that my family may feel obligated to care for me but I have seen the impact this has on carers and their families - this is not what I would want for them, especially if they are thrown into this reality at a young age. I would prefer for them to continue living and to visit me when they are able and that they include me in their lives through visits, holidays, Skype, and lots more.

If at any time I require life support, I want to be given the full opportunity for treatment and recovery.

If improvement is considered unlikely I would like to be given a window of two weeks to recover or show positive improvement. Should I not show any sign of improvement in this time then I am happy to then move into the next stages of life and have the life support treatment withdrawn.

Should I ever be in a life ending situation I would like to have my precious family around me at this time. This includes my beautiful children and their significant loved one. This will give me the opportunity to express my sincere and everlasting love for them.

I would appreciate seeing the following people leading up to this time - my mother so l have the opportunity to express my deepest gratitude to her for everything she has done for me and to show my thanks. I would also appreciate seeing my best friends Peter and Mary who have provided me with endless friendship, love and support over many years.

Should I be requested to donate my organs this is only agreed to after every possible life saving option has been exhausted - in this situation only am I happy to donate my organs as deemed useful to others in the hope of improving other people's lives and longevity. **This is with the exception of my eyes (and any part of) as they are the windows to my soul and will remain with me forever.**

To my substitute decision makers:

Abigail (phone number) my loving sister and Anthony my precious son I have tried my hardest to provide you with a guide to support your decision making into my future care needs. Know that I trust and love you both to the ends of the earth and that I have complete confidence in you. I know this is a very hard thing for anyone to do so for that reason **I allocate all final decisions to be made by Abigail following collaboration with Anthony**. This is not because I don't love you Anthony, this is because it is unfair of me to expect you to make these hard calls and I want to protect you and your siblings.

To my precious children I love you always and to the moon and back. I am always with you even when you don't see me and you are the very best things that life gave me second to none. Love each other always because that's what family does, blood runs deep in us all and just like a stream or river we all flow towards home.

My funeral:

Footprints in the sand please have this as part of my service.

I would appreciate a full Catholic service at Timbuctoo with Rev Day delivering the service if able. I went to a catholic school and although I don't attend church regularly religion and faith is very important to me.

I have always seen myself as being buried at Timbuctoo Cemetery should I die but now that this seems more like a reality and I am now on my own, I think I would rather be cremated so I can come with you all rather than be alone. If that is not too creepy for you all.

The Last Will and Testament for myself is currently a hand written and witnessed document that is sitting with Abigail, (phone number)

I do not have a current enduring and medical power of attorney as they are now superseded by my recent will. I will endeavour to update these details and Abigail and Anthony will be appointed my medical, financial and enduring power of attorney in a shared role across these three positions. In the interim they are named and recorded as my substitute decision makers within my current advance care plan.

To Abigail and Anthony,

Thank you for being my strength and advocating to support my wishes, I love you dearly and just remember not to be afraid to fight for what is true and right. There is a time to be quiet and a time to be heard, you will know this when you get there.

Xoxo Thank you.

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Attachment 11- Handout – ACP Frequently Asked Questions

ADVANCE CARE PLANNING

FREQUENTLY ASKED QUESTIONS

Adapted from http://advancecareplanning.org.au/frequently-asked-questions on 25 May 2016

What is advance care planning?

Advance care planning provides an opportunity for people to think, discuss and plan for the medical treatment they would prefer if they became too ill in the future to express their wishes.

Advance care planning is not euthanasia. It is about people taking control of their health care wishes.

Who needs to do advance care planning?

Everyone should consider advance care planning, regardless of their age or health. But, it is particularly important for people who have ongoing health problems.

What is an advance care plan/directive?

This is a written document that records the medical treatment wishes of a person, which can then be used if a person is unable to speak for themselves due to illness or injury. The document may also appoint a substitute decision maker and include non-medical wishes for end of life such as spiritual care.

When is an advance care plan or directive used?

These are only used if a patient or client is unable to make or communicate his or her own decisions. The directive would then be used to guide the decision making of the medical staff, substitute decision maker if one has been nominated, and your family.

Who can make an advance care plan/directive?

Any person over 18 years of age can make an advance care plan/directive, unless they are already unable to make their own decisions about medical treatment due to a disability, illness or injury.

Do I need a lawyer to complete an advance care plan/directive?

No, the law does not require a lawyer to complete an advance care plan/directive. Your doctor or someone experienced in advance care planning can help you to complete this document.

Do I need a doctor to complete an advance care plan/directive?

No, but ideally you should discuss your advance care plan/directive with your doctor. This means that any decisions you make will be made on the basis of good information.

Your doctor, or any other doctors treating you in the future, will understand that you were informed prior to making your decisions and this will help them to follow your plan/directive with confidence.

Why is it helpful to make an advance care plan/directive?

Taking part in advance care planning gives people the opportunity to talk to their family and doctor about future medical care. After these discussions, a person's wishes can then be written down and a trusted person nominated to make decisions for you if you are unable to do so yourself in the future.

Having done this often reassures many people and their families as they have a clear idea of what would need to be done in the event of a loved one becoming too ill or injured to speak for themselves.

Who do I talk to?

Your family – Close and loving relationships don't necessarily always mean that loved ones know or understand the wishes of a person in relation to future medical care. These wishes should be talked about with the people who would most likely be involved in making decisions on your behalf.

Your doctor/s – Doctors can help you to understand your current health and what you might need in the future. They can also provide information about the potential outcomes of treatment, which you can then take into account in deciding if you would want some treatments if they meant that you did not return to your previous quality of life. Doctors can also help you to make an advance care plan/directive and then should keep a copy of your plan/directive on file.

People experienced in advance care planning – there are community based health care workers who can help you and, in some hospitals, specialist staff.

Can I select someone I trust to make decisions for me if I can't in the future?

Yes, you can nominate a substitute decision-maker everywhere in Australia except the Northern Territory.

What authority does a substitute decision maker have?

There are some differences between Australian states, but generally substitute decision makers can consent to medical treatment on your behalf if you are unable to do so yourself. In some states, they can also legally refuse medical treatment if you have made your wishes in that regard clear in an advance care plan/directive.

Who should I choose to be my substitute decision maker?

Your substitute decision maker is expected to act in your best interests and make the same decisions they believe you would have made yourself.

They should, therefore, be someone who you trust to listen carefully to your wishes for future medical treatment and to then faithfully represent you when you can no longer speak for yourself.

He or she may be required to make difficult decisions in difficult situations so you need to be reassured that they will be able to do so.

Often, these people are family members but they can be any person who you believe can fulfil this role, who is over 18 years of age.

The names and authorities of people in this role can vary depending on where you live. Check the State or Territory where you live on www.advancecareplanning.org.au to find out more.

Can my advance care plan/directive be changed or revoked?

Yes, you can change or revoke your advance care plan/directive while you are still able to make medical decisions for yourself. If you want to either make changes or revoke your plan/directive, the best avenue is to make a new plan/directive and destroy any old ones.

Make sure you tell everyone who had a copy of your previous plan/directive that you have done this and give them a copy of your new plan/directive.

Is this euthanasia?

No, definitely not. Euthanasia is the deliberate action of causing the death of someone who otherwise would not die. This is completely different from the withdrawal of a treatment that is regarded by the patient, the doctors, the substitute decision-maker or family as futile or overly burdensome. In this circumstance the patient is dying from the underlying illness and nature is being allowed to "take its course".

NOTE: In all Australian states and territories euthanasia is illegal.

Advance Care planning can also be about the health care you would like to receive. Doctors will take these wishes into account when deciding what the best health care is or what care is futile.

What if I become ill or are injured while away from home?

If you have discussed your wishes with your substitute decision maker and family, they will be able to pass on this information to medical staff as they will be the ones contacted to discuss your condition.

They will also be able to provide your advance care plan/directive to whoever is responsible for your care.

What happens in an emergency?

When there is an emergency and your advance care plan/directive is available, medical decisions will be made by reviewing your wishes and discussing your situation with your substitute decision make and family.

If your plan/directive is not immediately available, life-prolonging measures may be started until medical staff can contact your family. If it is clear after discussions with your substitute decision maker and family that your wishes would be to stop treatment, this can then occur.

What happens if I don't have an advance care plan/directive?

If you become unwell and cannot communicate for yourself, doctors will make treatment decisions based on your best interests. This could include treatments that you might not want. If you feel strongly about certain types of treatment that you would not want to receive, than an advance care plan/directive is a good way to communicate those wishes.

Do I have the right to refuse medical treatment?

Yes, you can legally refuse treatment or ask for some types of treatment to be withdrawn. In some states, nominated substitute decisions makers can also refuse treatment if they know or believe that to be your wish.

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Attachment 12 – 'Introduction to ACP Information Session' – Feedback Form

Introduction to Advance Care Planning

INFORMATION SESSION FEEDBACK

[*Information session details: community group, location, date*]

Please give us your feedback on today's session to help us keep improving

1. ***Who attended:*** Are you a Community Member or Health Professional or both?

Community Member	
Health Professional	

2. ***Describe your understanding of advance care planning <u>before</u> the session***

	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
I already have a good understanding of Advance Care Planning					

3. ***What topic(s) did you find helpful?***

What is advance care planning?	
Why is advance care planning important?	
Advance care planning stories	
Having the advance care planning conversation	
What is an advance care plan/directive?	
Legally appointing a Substitute Decision Maker	
Frequently Asked Questions	
Discussion	
Handouts	

4. *Please describe your understanding <u>after</u> attending*

	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
I have gained a greater understanding of Advance Care Planning					

5. *Do you feel comfortable to have the Advance Care Planning Conversation?*

Yes		No		Not Sure	

6. *If we were to organize more sessions, what would you like to know about?*

7. *How did you find out about the information session?*

TV		Radio	
Word of Mouth		Poster	
Newspaper		Social Media	
Email		Other	

8. *Any other comments are very welcome*

Please contact [agency volunteer coordinator email/phone] with any queries regarding the Introduction to Advance Care Planning session.

Thank You ACP Volunteer Ambassadors [host agency name]