Contemplating and communicating your future healthcare wishes

McCabe Centre for Law and Cancer

Cancer Council Victoria

Webinar 20 April 2015

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Cancer Council Victoria acknowledges the Traditional Owners of the land and waters throughout Victoria and pays respect to them, their culture and their Elders past, present and future.

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Welcome

- Outline:
  - Background, introductions and scene-setting
  - Advance care planning: what is the law, and how does it affect you?
  - Panel discussion
  - Q & A

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Introductions

- **Sondra Davoren**, Senior Legal Policy Advisor, McCabe Centre
- **Dr Deborah Lawson**, Legal Policy Advisor, McCabe Centre
- **Dr Jennifer Weil**, Palliative Medicine Physician St Vincent's Melbourne
- **Clem Byard**, Clinical Nurse Specialist (Research) – Cancer Council 13 11 20

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Practising cancer nurses: your link into all Cancer Council information and support services

9 am – 5 pm, Monday to Friday

Commonly discussed topics

- Preventing cancer
- Symptoms / early detection
- Diagnosis, treatment and management
- Practical issues
- Psychological / emotional support
- Support for carers, family and friends

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Some background

- What is the McCabe Centre for Law and Cancer?
- Why a webinar on advance care planning?

Legal Services BOARD

Funded through the Legal Services Board Grants Program

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Disclaimer

The content in this webinar is general information only. The information is not intended to be legal advice,

and should not be relied on as such.

The legal information in this webinar is Victoria-specific. Please contact your local State or Territory Cancer Council for information about the laws and processes in your own region.

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Contemplating and communicating your future healthcare wishes

Dr Deborah Lawson

Legal Policy Advisor

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What is advance care planning?

- Discussing and planning future health and personal care;
- To guide medical decisions made about you;
- If you become unable to communicate or make your own decisions.

Talking with loved ones and doctors about what might be ahead, and what your preferences are; what kinds of treatments and conditions you would or would not find acceptable in the future.

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The law and advance care planning

- Appointment of substitute decision-makers (an agent) to make decisions if you become unable to make your own;
- Advance care directives: documents that record your views, wishes or decisions about medical care.

These processes only kick in if you become unable to communicate or make your own decisions

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Why is advance care planning important?

- Opens up the discussion
- Make sure people know what you want
  - Increases likelihood your wishes will be respected
  - Reduces likelihood of family conflict

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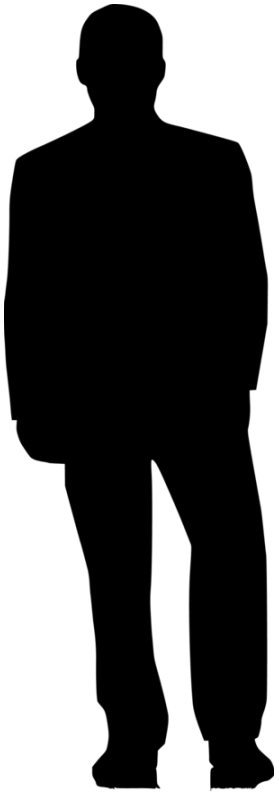
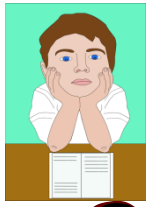
Meet William



- William: 65 years, diagnosed with bowel cancer
- Wife Sharon passed away seven years ago.
- Three adult children:
  - Robert (42, unemployed, Melbourne)
  - Laura (40, accountant, Perth, two small children)
  - Rebecca (36, lawyer), Melbourne)
- Family disagreement in Sharon's final days
- William is very independent
- Particularly strong views about not wanting to spend final days unconscious in hospital.



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What are my advance care planning options?

- Appoint an agent to make decisions for you
- Record your wishes in writing
- Do nothing
- It's up to you

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What are my advance care planning options?

Regardless of what actions you choose to take - talk to loved ones and doctors about your values, beliefs and preferences; tell them about what's important to you.

You can participate as much or as little as you want – there are no right or wrong choices, it's about knowing your options and what's right for you.

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When should I consider advance care planning?

- Whenever feels right for you
- Has value at any stage of life – particularly appointing an agent
- Recording wishes in writing valuable if currently unwell

Advance care planning must be done before you lose the ability to communicate or make your own decisions – you need 'legal capacity' to undertake these processes.

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Appointing an agent

Three different types of powers of attorney, which provide authority over different things:

- medical treatment
- guardianship – powers in relation to personal and lifestyle decisions; and
- financial – powers in relation to your financial and legal affairs.

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Rights and responsibilities of your agent

- Power to consent to medical treatment for you
- Power to refuse medical treatment for you limited to situations where:
  - Treatment would cause unreasonable distress;
  - Your agent reasonably believes that you would consider the treatment unwarranted.

No authority to refuse palliative care (pain relief, reasonable provision of food and water).

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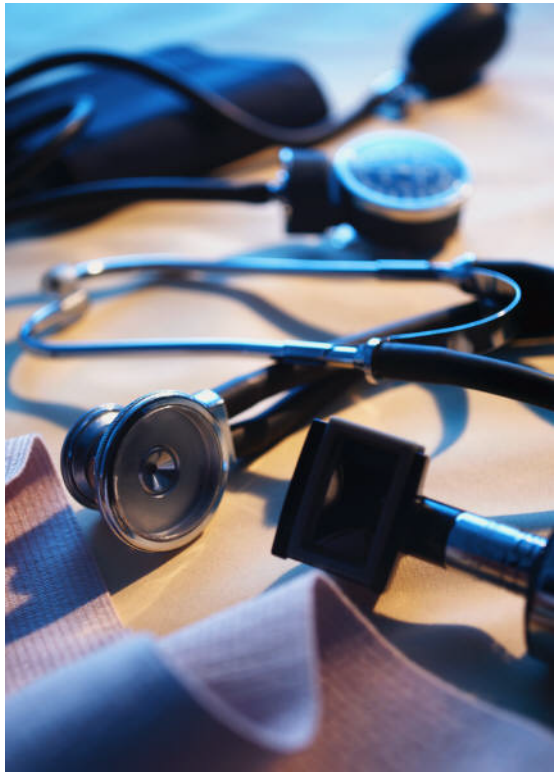
Rights and responsibilities of your agent

Responsibility:

- to act in your best interests; and
- to represent your healthcare preferences, with the aim of, wherever possible, making the same decision that you would have made.



- Your agent's decisions have the same legal force as if you had made them yourself.

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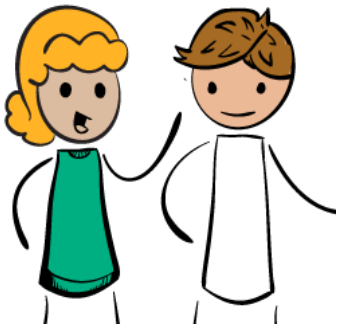

Talking to your agent

- Your medical condition and what may happen in the future
- Your values and beliefs
- Situations you find unacceptable or too distressing – procedures and/or outcomes of treatments
- Particular treatments you would/wouldn't want
- Other people that you might like involved.

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Who to appoint

- Doesn't have to be favourite family member!
- Available?
- Understand and act in accordance with your wishes?
- Trust?

- Office of the Public Advocate online resource: http://www.publicadvocate.vic.gov.au/you-decide-who-decides/
- You can only appoint one agent but you can appoint an alternative decision-maker

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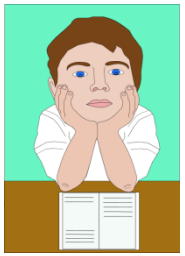
Back to William

- Which child to appoint?
- Who does he trust to communicate his wishes to his doctors and his other family members?
- Robert isn't great in a crisis, and insisted everything be done to prolong Sharon's life



- Laura might be best but lives in Perth
- Appoints Laura; Rebecca as alternate agent

How to appoint an agent

- It's easy –you don't need a lawyer!
- Forms can be downloaded from www.publicadvocate.vic.gov.au.
- Fill it out
- Have it witnessed by two people
  - One signatory must be a person who can sign statutory declarations
  - Your agent cannot be a witness!

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Let's take a look

- The Enduring Power of Attorney (Medical Treatment) form

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I've appointed an agent -what next?

- Keep the original safe and certified copies for everyday use.
- Tell people, particularly:
  - the agent
  - loved ones that you haven't appointed
  - Your medical team
- Give copies to your GP, oncologist, agent, solicitor, family members, friends.
- Have a copy placed on your medical record.
- Stick a copy on your fridge.

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What if I change my mind?

- You can cancel the appointment at any time – as long as you still have capacity.
- Tell the agent.
- Destroy the document and any copies.
- Complete a Revocation of Enduring Power of Attorney form and give a copy to your agent.
- If you appoint a new agent, the earlier appointment is automatically cancelled – let the original agent know!

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Appointing an agent - summary

- Right to consent to medical treatment and to refuse where treatment would cause unreasonable distress or believe you wouldn't want treatment.
- Can't refuse palliative care
- Appoint someone you trust
- Talk in detail about your values and preferences.
- Make sure you tell people you've appointed an agent
- Keep copies
- You can change your mind

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Options for recording your wishes

- Refusal of Treatment Certificate
- Advance care directives

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Refusal of Treatment Certificates

You can refuse future medical treatment for a **current** medical condition.

- Can only made about condition you already have – option if you currently have disease.
- Can't be used to refuse palliative care (reasonable pain relief, or food and water).
- Doctors cannot treat or to continue to treat you if they know there is a Certificate in force.

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How to complete a Refusal of Treatment Certificate

- Ask doctor for a form or download one
- Specify treatment refused – all or specific.

- To sign you must:
  - have been given sufficient information;
  - understand the information and what you are doing; and
  - be making the decision voluntarily.

- A doctor and one other person must witness and be satisfied requirements met.

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How to complete a Refusal of Treatment Certificate

- Your agent (or a VCAT-appointed guardian) can also refuse medical treatment for you.
- Same conditions must be met but the agent must also be convinced that either –
  - The treatment would cause you unreasonable distress; or
  - there are reasonable grounds for believing you would, after serious consideration, have considered the treatment unwarranted.

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What next?

Refusal of Treatment Certificate 'trumps' agent's decisions, so it's very important to tell people, particularly:

- any agent that you've appointed;
- other loved ones; and
- your medical team.

- Doctor must give copy to VCAT in 7 days.
- Make copies – to keep, give to your medical team and loved ones, stick on fridge and have placed on medical record.

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Can I change my mind?

- Yes, if you still have capacity.
- Can easily be cancelled at any time by signing a Notice of Cancellation form.

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Other forms of advance care directives

Valuable if:

- You don't have a current condition
- You want to provide more information

- Can be as simple or as detailed as you like.
- Discuss situations and outcomes that would acceptable or unacceptable to you
- Provides guidance on how a decision can be made that accords with your values

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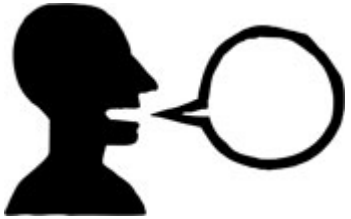

Completing an advance care directive

- Format not as strict as Refusal of Treatment Certificate.
- Can even just be a letter.
- Open and ongoing conversations with agent, loved ones and doctors can contribute to form and content.

- Different services offer different templates, based on the same general idea.

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What next?

Tell people that you've completed an advance care directive:

- any agent that you've appointed;
- other loved ones; and
- the doctors and nurses involved in your treatment.

- Keep a copy
- Copies to: GP, oncologist, agent, solicitor, family member, friend.
- Stick a copy on your fridge.
- Ask to have the plan placed on your medical record.

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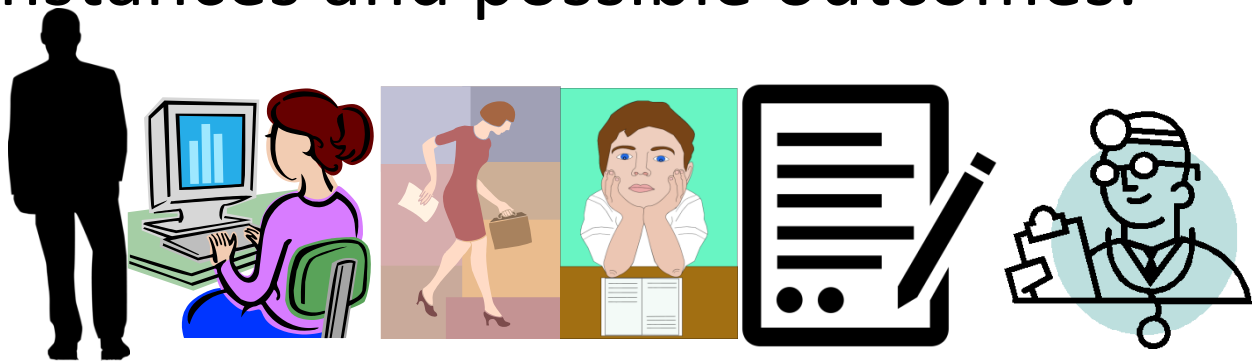
What's William up to?

- Completes a Refusal of Treatment Certificate refusing resuscitation
- Considers this will provide more protection if agent unavailable or feels pressured
- Also completes advance care plan, to provide more information and for a great variety of circumstances and possible outcomes.



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A journey, not a moment in time

- Advance care planning is an ongoing process as your medical condition and/or your values and wishes change.
- You can participate as little or as much as you like – it's up to you.
- Appointments and directives can be updated – just make sure that you let people know!

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Who decides for me otherwise?

Doctor can seek consent from a 'person responsible' - the first person in the following list:

- Your spouse or domestic partner
- Your primary carer;
- Your nearest relative over 18, in the following order: child; parent; sibling; grandparent; grandchild; uncle or aunt; nephew or niece.

None of these people – unless they're also your agent - can refuse life-saving treatment for you.

Appointing an agent is the only way to control who will make these kinds of decisions for you.

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If William doesn't undertake advance care planning

Robert would be the one to make William's medical decisions, should he lose the ability to make his own.

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In summary …

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Further information and assistance

- Cancer Council – 13 11 20
- Victorian Department of Health www.health.vic.gov.au/acp
- Office of the Public Advocate – 1300 309 337 www.publicadvocate.vic.gov.au
- Download *Take Control: a kit for making powers of attorney and guardianship* at: www.publicadvocate.vic.gov.au/publications/121/
- Advance Care Planning Australia http://advancecareplanning.org.au
- Ask at your treatment centre – some hospitals have Advance Care Planning Programs.

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Panel Discussion

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Q: Why is advance care planning important?

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Q: How do you raise the issue of Advance Care Planning with patients who have a cancer diagnosis?

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Q: Is advance care planning the same throughout Australia?

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Q. How up to date must an advance care directive be to be effective?

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Q. Are Advance Care Directives legally recognised in Victoria?

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THANK YOU

- Q & A to follow
- Webinar for health professionals later this year
- Please complete the exit survey.
- Thank you to our esteemed panelists and wonderful support team
- Thank you all for joining!

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Q&A session

Q: I loved the presentation, well done. Learnt lots in the comfort of my own home.

A: Thanks!!

Q: Will we be receiving a copy of this webinar? I was late in attending.

A: Thanks for your question. Yes we will be making a copy of the webinar available, with links to some of the resources. This will be available on the Cancer Council Victoria and McCabe Centre websites tomorrow. We'll email participants to let them know.

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Q&A session

Q: Thank you for a great presentation. I was just needing clarification in regards to Refusal of Treatment Certificates. If there is one in place, it cannot be over turned by the appointed agent unless you go through the VCAT process. Is this correct?

A: Hi. A refusal of Treatment Certificate does trump an agent's decision unless there is some reason to suspect that it is not valid. For example, the circumstances weren't anticipated by the person when they made the certificate, or there is a reason to think that the person changed their mind since making the decision. Just let me double-check whether a VCAT application is required and get back to you; I'll send you an email tomorrow with further information about overturning refusal of treatment certificate. I want to ensure that I can take the time to give you correct information.

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Q&A session

Q: What do I need to do to learn more about advanced directives with the aim of working in this area?

A: Hi, you could call Cancer Council 13 11 20 for more information or check out http://www.publicadvocate.vic.gov.au or http://advancecareplanning.org.au. The Office of the Public Advocate's website is a great place to start with. They may be able to direct you to specific learning resources for more information.

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Q&A session

Q: Can you suggest a good ACP Decision Aid specifically designed for patients about to have major cancer surgery?-

A: Hi, thanks for the question. I'm not aware of any decision aids that are designed for cancer surgery. You could call the Decision Assist Advance Care Planning Phone Advisory Service. It is open from 8am until 8pm seven days a week, 1300 668 908.

Q: Comment: The Decision Assist National Specialist Palliative Care and Advance Care Planning Advisory Line is available for health professionals working in residential aged care facilities for in the community. The line is open 24 hours for specialist care seven days a week and from 8am till 8pm for advance care planning.

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Q&A session

Q: Not sure if my question that I had sent in was addressed. Thank you I will wait for that and thank you. May I please be invited to the next webinar and how do I book that now?

A: Thank you for your question, we have you email address on file as part of this webinar and we will be sure to send you information on upcoming webinars.

Q: Who is the best person to see if there are no relatives?

A: Thanks for your question. An agent can be any person that you trust to make a decision on your behalf. It doesn't have to be relative. If you haven't appointed someone then a doctor can seek consent to treatment from a 'person responsible' a person responsible doesn't have to be a relative, and in fact, the first person on this list is a spouse or domestic partner, followed by a primary carer, and then a close relative.

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Q&A session

Q: Given that each hospital has their own ACP form, in relation to a person being treated in one hospital who then presents to another hospital for whatever reason, what is the status of the ACP directive in the second hospital that would not be familiar with the patient?

A: Thank you for your question. You're right that the forms are a little different from hospital to hospital, but the general principles are the same, and the wishes and treatment options that you express in one form should be honoured by doctors in other hospitals.

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