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WHAT THIS PRESENTATION IS ALL ABOUT

- ❑ Background to Dying with Dignity Victoria
- ❑ Understanding your legal rights (*including the new laws*)
- ❑ Advance Care Planning (*stipulating what treatments you will or will not accept at the end of life*)
- ❑ Medical Treatment Decision Maker (*appointing one or more people to see that your wishes are carried out if you lose competency*)
- ❑ Voluntary Assisted Dying (VAD) (*legal requirements and process*)



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DYING WITH DIGNITY VICTORIA

- Established in 1974 as the Voluntary Euthanasia Society of Victoria
- Heavily dependent on volunteers
- Played a crucial role in bringing about the Medical Treatment Act 1988
 - Refusal of treatment provisions
- Campaigned successfully for legislation to formally recognise Advance Care Directives – Medical Treatment Planning and Decisions Act 2016
- Campaigned Successfully for the Voluntary Assisted Dying Act 2017



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DYING WITH DIGNITY VICTORIA CURRENT ACTIVITIES

- ❖ Interaction with the Care Navigators (*who assist with the process of VAD*)
- ❖ Submissions to Committees of Inquiry
- ❖ Providing witnesses and contact people (when needed) for the final request for medication
- ❖ Information
- ❖ Support for other States (*several of which have succeeded in passing similar laws to Victoria*)
- ❖ Initiatives for improvement in the process, and legislation
- ❖ Provision of resources
- ❖ Counselling





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THE TWO LAWS

1. MEDICAL TREATMENT PLANNING AND DECISIONS ACT 2016

- In full effect – since March 2018
- Allows you to make clear what treatment you will accept at end of life via your:

- ❖ ADVANCE CARE DIRECTIVE
 - ❖ INSTRUCTIONAL DIRECTIVE
 - ❖ VALUES DIRECTIVE
- ❖ MEDICAL TREATMENT DECISION-MAKER



2. VOLUNTARY ASSISTED DYING ACT 2017 (VAD)

- Came into effect on 19 June 2019
- Legislation overview



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UNDERSTANDING YOUR LEGAL RIGHTS

YOU HAVE A RIGHT TO:

- **refuse/consent** to medical treatment
- document your future **medical-treatment wishes**
- **appoint someone** to act for you for when you no longer have decision-making capacity
- demand **maximum relief of pain**





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OLD POWER OF ATTORNEY DOCUMENTS ARE STILL VALID

- Documents completed **before March 2018** are still **valid today and don't need to be replaced**
 - Enduring Power of Attorney – Financial
 - Enduring Power of Attorney – Guardianship
- **But it is preferable to update the two medical documents (*The Enduring Power of Attorney Medical, The Refusal of Medical Treatment*) to the new forms which relate to the new law:**
 - **Medical Treatment Planning and Decisions Act 2016**

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ADVANCE CARE PLANNING

Create a plan while you have capacity, to be invoked only if and when you no longer have capacity

1. Write an Advance Care Directive (*instructions regarding your future care*)
2. Appoint a Medical Treatment Decision Maker (*who ensures your instructions are followed*)
3. Start the Conversations:
 - With your **family**
 - With your **friends**
 - With your **doctor**

*Let them know what you want and
Importantly what you do not want*





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ADVANCE CARE DIRECTIVE

BE PROACTIVE!

Your **Advance Care Directive** comes into effect only if you have **LOST** decision-making capacity

- **Instructional Directive**
- The first thing to do is determine when and under what circumstances you want the Treatment Directive to apply
 - Treatment Directives – general
 - (there is a separate form for Treatment Directives for Dementia)




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ADVANCE CARE DIRECTIVE INSTRUCTIONAL DIRECTIVE

- This Instructional Directive is **legally binding** and communicates your medical treatment decisions directly to your health practitioners
- *You may wish to consult a medical practitioner if choosing to complete this Instructional Directive*
 - Your Instructional Directive will only be used if you do not have capacity to make a medical-treatment decision
 - Your medical-treatment decisions in this Instructional Directive take effect as if you had consented to, or refused to, begin or continue medical treatment
 - If any of your statements are unclear or uncertain in particular circumstances, it will become a *Values Directive* (see slide 14)
- (In some limited circumstances set out in the Act, a health practitioner may not be required to comply with your Instructional Directive)


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ADVANCE CARE DIRECTIVE

This is the form you complete
FIRSTLY *YOU* decide under what circumstances you wish
this directive to be applied

Applying this Instructional Directive

This Instructional Directive must apply **unless**:

	<u>Agree</u>	<u>Disagree</u>
I am suffering only a transient (temporary) loss of competence, such as hypoglycaemia or TIA (transient ischaemic attack) or mild concussion	<input type="radio"/>	<input type="radio"/>
I am suffering from a severe illness but in the opinion of two independent medical practitioners (at least one a specialist), I am likely to recover to a state of independence and competence, without profound physical or psychological suffering.	<input type="radio"/>	<input type="radio"/>

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ADVANCE CARE DIRECTIVE

SECONDLY *YOU* decide what level and type of treatment you will accept

I declare that in respect of medical intervention or treatment aimed at prolonging or sustaining my life:

<u>Treatment</u>	<u>Refuse</u>	<u>Accept</u>
Artificial feeding (nutrition and / or hydration)	<input type="radio"/>	<input type="radio"/>
Antibiotics	<input type="radio"/>	<input type="radio"/>
Artificial respiration	<input type="radio"/>	<input type="radio"/>
Any surgical procedures	<input type="radio"/>	<input type="radio"/>
Circulatory support, including CPR	<input type="radio"/>	<input type="radio"/>
Corrections of abnormal levels of any toxic substance	<input type="radio"/>	<input type="radio"/>
Blood transfusion	<input type="radio"/>	<input type="radio"/>
Drug treatment of high / low blood sugar	<input type="radio"/>	<input type="radio"/>
Drug treatment of high / low blood pressure	<input type="radio"/>	<input type="radio"/>
Renal dialysis	<input type="radio"/>	<input type="radio"/>

Further, that any persistent distressing symptoms (pain, breathlessness, and those caused by lack of food and fluid) are to be **maximally palliated** by appropriate analgesic, sedative or other palliative treatment (including keeping lips, mouth and eyes moist), even though that palliative treatment may also have the additional consequence of shortening my life.

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ADVANCE CARE DIRECTIVE DEMENTIA

- ☐ First decide the conditions under which your Advance Care Directive regarding Dementia will operate
 - ☐ Only if you have been admitted to ongoing institutional care OR
 - ☐ Regardless of whether you are at home, in the community or an institution
- ☐ Then decide under what conditions you will refuse medical treatment intended to prolong life
- ☐ And finally make a decision about assisted (spoon) feeding
 - ☐ ***It is important to demonstrate mental competency as often and for as long as possible***
 - ☐ NOTE: Dementia is *not* currently considered a valid reason for application for VAD (Voluntary Assisted Dying)



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Dementia

If I have been diagnosed with dementia and am judged by a doctor as not competent to make decisions regarding my medical treatment, and

- ☐ Regardless of whether my primary care is in the home / community, or in an institution
- ☐ Only if I have been admitted to ongoing institutional care

then I **declare** that I refuse any medical treatment with the purpose or outcome of prolonging my life:

- ☐ Even if I appear to be content as judged by my Medical Treatment Decision Maker.
- ☐ Except if I appear to be content as judged by my Medical Treatment Decision Maker.

I also declare that:

- ☐ I refuse nutrition / hydration by assisted spoon feeding in any circumstances
- ☐ I accept spoon feeding but only if I appear to accept spoon feeding voluntarily and enjoy my food, as judged by my Medical Treatment Decision Maker.





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ADVANCE CARE DIRECTIVE

Now to YOUR wishes and values – what things are important to you


- Values Directive, **not** legally binding but provides guidance
 - Record your values and preferences
 - *DWDV provide some guidance for the Values Directive on the website*
- Organ Donation {record your wishes regarding donating organ(s)}
- Your Medical Treatment Decision Maker(s)
 - Record details of your appointed Medical Treatment Decision Maker(s)




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ADVANCE CARE DIRECTIVE

- Sample Forms from
 - DWDV <https://www.dwdv.org.au/resources>
 - Office of the public advocate <https://www.publicadvocate.vic.gov.au>
 - And other advice from Dept of Health <https://www2.health.vic.gov.au>
- Signing and witnessing
 - You sign
 - A registered Medical Practitioner witnesses and certifies
 - Another adult witnesses and certifies
- What to do with the copies
 - Upload to your My Health Record (if you have one set up)
 - Have **multiple copies** and distribute to your Medical Treatment Decision Maker, your GP or practice, your medical team, hospital, aged-care facility, etc







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PROTOCOL FOR VOLUNTARY REFUSAL OF FOOD AND FLUID (VRFF)

- ***It is within your rights to refuse food and fluid which may be an option you choose if you do not meet the strict requirements for Voluntary Assisted Dying***
- VRFF Results in death by dehydration, not starvation
- If you want to include VRFF in your Advance Care Directive, discuss in detail with your Medical Treatment Decision Maker


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THE IMPORTANCE OF APPOINTING A MEDICAL TREATMENT DECISION MAKER

- Choosing the right person.
- ***Your Medical Treatment Decision Maker's role is to see your wishes and instructions carried out. Only if something is unclear or ambiguous does she or he make a decision on your behalf, based on your wishes and their knowledge of you***
 - Appoint someone you trust
 - Someone who understands your wishes
 - Someone who has the ability to make medical-treatment decisions based on your wishes
 - Someone who is strong enough to insist on what you want

You may appoint more than one person, but only one can speak on your behalf at any time.

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ROLE OF YOUR MEDICAL TREATMENT DECISION MAKER

Situation	Role of Decision Maker
Advance Care Directive (ACD) with Instructional Directive	Advocate and ensure that the Directive is followed
ACD with Values Directive only	Instruct your medical team, based on your documented values
No Advance Care Directive (ACD)	Instruct your medical team, based on her/his knowledge of your values & preferences
For "Significant treatments" not covered by ACD Instructional Directive	Instruct your medical team, based on your ACD (Values and Instructional Directive).

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APPOINTING A MEDICAL TREATMENT DECISION MAKER

- Signing and witnessing: three people involved
 1. **You** sign
 2. Witnessed by **Medical Practitioner or someone able to witness affidavits**
 3. **Another adult person (any competent adult)**



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APPOINTING A MEDICAL TREATMENT DECISION MAKER

- Acceptance of the appointment
 - Each appointed Medical Treatment Decision Maker signs the acceptance form
 - Each acceptance is witnessed by an adult witness
- What do you do with the copies? (*As with the Advance Care Directive*)
 - Upload to your 'My Health Record' (if you have one)
 - Distribute copies to MTDM, medical team, hospitals, aged-care facility etc



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WHAT HAPPENS IF YOU DON'T APPOINT A MEDICAL TREATMENT DECISION MAKER?

- If you do not appoint a MTDM then it is the first person listed below who is in a close and continuing relationship with you (*and who is able and willing to act in the role*)
 1. Your spouse or domestic partner
 2. Your primary carer (not a paid service provider)
 3. Your adult child
 4. Your parent
 5. Your adult sibling





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VOLUNTARY ASSISTED DYING ACT

- Came into effect in Victoria on 19 June 2019
- Allows a person with
 - decision-making capacity,
 - a terminal illness and
 - intolerable suffering
 ... to make a request to a doctor for assistance to end their life by self-administration* of medication
- The request must be enduring and not made under duress
- This is a complex piece of legislation (68 safeguards, 143 clauses, 8 statutory forms)
- * *in some circumstances the medication may be Doctor administered*



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VOLUNTARY ASSISTED DYING ACT

- **THE PERSON MUST INITIATE THE REQUEST**
- A doctor **cannot initiate** the subject of Voluntary Assisted Dying, nor suggest it as a treatment option. Such a discussion must be initiated by the person
- A doctor **can respond to requests for information** about end-of-life options which could include:
 - Possible further treatments which have not been considered
 - Palliative care
 - Refusal of medical treatment
 - Voluntary refusal of food and fluids
 - Voluntary assisted dying





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VOLUNTARY ASSISTED DYING ACT DEFINITION OF 'TERMINAL ILLNESS'

- Defined in the Act as ***'an illness that is expected to cause death within weeks or months, but not exceeding 6 months (except in the case of neuro-degenerative illness – Motor Neurone Disease, MS, Parkinson's, where 12 months is the time period)***
- Must be associated with ***advanced, incurable and progressive illness...***
- ***...which is causing (intolerable) suffering*** that cannot be relieved in a manner that the person considers tolerable
- ***The person is the judge of 'intolerable' suffering, which can be suffering other than just physical pain.***

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VOLUNTARY ASSISTED DYING ACT – THE PROCESS

- Person makes three requests for VAD over no less than 10 days
 - a verbal request
 - a written request
 - signed before two witnesses (DWDV can help provide)
 - a second verbal request
- Two medical practitioners independently certify eligibility
 - both practitioners are to be fellows of a medical college
 - one of the practitioners must have experience and expertise in the disease of the person
- N.B **The person can opt out at any stage.**



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VOLUNTARY ASSISTED DYING ACT – THE PROCESS CONT..

- As each stage of the process the medical practitioners must complete relevant paperwork to submit to the VAD Review Board before progressing to next stage.
- After all stages of have been completed, medical practitioner seeks permission from the Health Department to prescribe the medication.
- Pharmacists at the Statewide Pharmacy, Alfred Hospital, receive script and 2 Pharmacists will deliver medication to the Person when requested, and explain process.
- Oral medication is left with person to ingest at chosen time
- A special provision can be made for those unable to ingest oral medication.

N.B. The person can opt out of process at any stage.



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VOLUNTARY ASSISTED DYING (VAD) STATEWIDE CARE NAVIGATORS

- ***“...key support role for ANYONE across Victoria seeking information about Voluntary Assisted Dying or assistance going through the process”***
- Respond to contacts made with them
- Provide access to Support Packages (e.g. \$ for travel)
- Provide education to Health Services
- Located at the Peter MacCallum Centre
 - vadcarenavigator@petermac.org
 - 03 8559 5823 0436 848 344





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PREPARE EARLY!

- ***As you can see, the process will take some time***
- If you are considering voluntary assisted dying, do your research and planning early
- Identify medical practitioners
 - who will assist you with voluntary assisted dying and
 - who have done the required training
- Discuss with family, friends, carers

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PREPARE EARLY!

Locate and gather documentary proof of demographic eligibility

- ***Age over 18 years - one of the following***
 - Medical records
 - Birth certificate
 - Victorian driver's licence
- ***Australian citizen or permanent resident – one of the following***
 - Australian birth certificate, if born before 20 August 1986
 - Passport establishing Australian citizenship
 - Permanent resident visa
 - Permanent resident Visa Grant Number
- ***Normally resident in Victoria for at least the last 12 months – one or more of the following***
 - Victorian driver's licence or vehicle registration
 - Registration on the Victorian electoral roll
 - Medical record (showing Victorian residential address)
 - Lease documents and utility bills



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FINDING A DOCTOR FOR VAD

- Not everyone will find the process of accessing the new legislation easy
- When next you see your GP, please ask **"If I were eligible under the Voluntary Assisted Dying Act, would you support me if I wanted to use the process?"**
 - If they answer Yes, then ask if they have done the required special training
 - If No, then you could contact the Statewide Voluntary Assisted Dying Care Navigators for assistance – see slide 28 for contact details
 - **Dr Rodney Syme (ret'd)** is offering personalised support and counselling for those who seek it
 - If you need to speak to **Dr Syme**, please email us at office@dwdv.org.au or call the office on 0491 718 632 or use the website Call-back request button



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FINDING A DOCTOR FOR VAD

- MORE DOCTORS ARE NEEDED AND DWDV NEEDS TO KNOW WHICH DOCTORS CURRENTLY SUPPORT VAD (Voluntary Assisted Dying)
- A highly confidential list of supportive (and trained) doctors is being compiled to be accessed only by Dr Rodney Syme
- Ask your GP (or Specialist) if (s)he supports VAD and if they have completed the training
- If the answers are 'Yes' ask your Doctor if they agree to having their name listed
- Then let DWDV know, are they supportive or not?
- PLEASE HELP US TO HELP YOU!!





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HOW'S IT GOING?

- It is going really well!
 - Reports from the supervisory VAD Review Board (VADRB) are consistently positive.
 - Former Supreme Court Judge Betty King, who chairs the Review Board says: *"I have not seen one example so far of anyone who has been pushed, coerced or inveigled in any way into taking the assisted dying medication"*
 - **Oncologist Cameron McLaren, who has been involved in dozens of VAD cases observed the following:**

"The atmosphere has been very peaceful. It's been a real moment of closure for the families to say goodbye"

"I'm still surprised by how I've never seen a person flinch about picking up or taking the drink. They are so committed to it"



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WHAT NEXT?

- Have conversations about your end-of-life choices
- Appoint your Medical Treatment Decision Maker
- Complete your Advance Care Directive
- Distribute copies of these documents to My Health Record, doctors, aged-care facility, MTDM, family, friends





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SUPPORT DYING WITH DIGNITY VICTORIA

- Almost entirely volunteers
- Join! Become a member
- Donate. (Donations are tax-deductible)
- Leave a bequest.
- Volunteer

There is still much to be done to ensure people can have a dignified death.

dwdv.org.au



Contact Dying With Dignity Victoria:

Address: PO Box 743, Kew, VIC, 3101, Australia

Phone: 0491 718 632

Email: dwdv@dwdv.org.au

Website: <https://www.dwdv.org.au>