



**SUBMISSION RE GUARDIANSHIP AND
ADMINISTRATION AMENDMENT
(ADVANCE CARE DIRECTIVES) BILL**

OCTOBER 2020

YOUR RIGHT TO CHOOSE

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Introduction

Dying with Dignity Tasmania Inc is an organisation concerned with all aspects of ensuring that the legislation supporting end of life planning is appropriate and that Tasmanians are fully informed of their options and properly supported in making timely decisions about their choices and recording those choices in a way that is immediately accessible in case of need.

Currently our major concern is with the legislation concerning voluntary assisted dying, but in recent years we have run a series of programs round Tasmania concerned with all aspects of end of life planning, in the course of which we have learned a great deal about the level of knowledge and the needs of Tasmanians if they are to achieve timely and complete end of life plans. A copy of the contents page of the manual developed for this program is attached as Attachment A. It should be noted that it covers Advance Care Directives (ACDs) and Enduring Guardianship which are the subject of this Bill, but also a range of other matters that are the subject of separate legislation.

We believe that all aspects of education and support for end of life planning should be treated as a coherent whole and supported as such through government and administrative support. We also believe that the final form for the Act should not be decided until careful consideration has been given to the Regulations that should be prescribed under Section 8 of the present Act in order to ensure that processes are developed to encourage and facilitate understanding and uptake of end of life planning by the general population.

This submission consists of the following sections:

1. Commentary directly concerning the Bill, with a particular focus on the new Section 35A, but also including some comments on other amendments;
2. Issues of concern that relate to the implications of the proposed move from the present system (ACDs available under common law and Enduring Guardianship available under Tasmanian statutory law) to the new system with implications for ACDs under common law that are not completely clear. This includes the issue of whether ACDs will continue to be free - as they are under common law - or will attract a fee for service;
3. Issues relating to ensuring that the people are made fully aware of the importance of end of life planning and are provided with encouragement and help to ensure that they think through and record their wishes in a timely way. This includes issues of the role of professionals and health institutions in supporting the preparation and recording of end of life plans. These do not directly concern the Bill as it stands but would become critically important matters of regulation and funding, presumably through the Board and Public Guardian, though this is not clear, if the Bill becomes law.

Section 1 Commentary directly concerning the Bill

1A Commentary on Parts 1 to 5 and 6 to the end

This appears to be simply concerned with tidying up the existing Act, with the exception of Sections 27A, 32(2) and 90 (2). Our comments on Section 27A are included with those on Part 5A (See Sec V). Our comments on Section 32(2) are included in Section 2 of this submission. Section 90(2) refers to the powers to prescribe or waive fees, and we have a major issue with fees under the proposed Act.

1B Commentary on Part 5A

Table of comments by Section

35 A to F and H	are essentially definitional and supported, apart from the fact that - the definition of an advance care directive form (Sec 35C (1)) appears to limit the form in which an advance care directive can be expressed - a matter taken up in Section 2 of this submission; - the meaning and implications of section 35D(2) are not clear to a layman.
35G	prohibits the making of an ACD on behalf of another person. It appears to mean that a family member can no longer do an ACD eg. for their parent with dementia, on the basis of how they knew them before the dementia set in. The only way they can put something in place to prevent some of the awful things that are now mandated for dementia patients, is to go through the lengthy and costly process of legally appointing a guardian. This is not supported. This whole area requires careful consideration. It appears to be written to avoid the risk of abuse - a matter of major concern - but may make it extremely difficult for people living remotely, in isolation or within an institution under lock down to make a valid ACD.
35I	Witnessing of an ACD is a matter of major concern that is taken up in Section 2 of this submission as it appears to be both unreasonably restrictive and at risk of being impractical in some circumstances in comparison with current witnessing requirements under common law. It and Section 35G need to be worked through together.
35J to K	Are supported
35L(3)	It is not clear what kinds of provisions that might be included in an Advance Care Directive might be non-binding provisions or how a non-binding provision is handled separately from a binding provision.
35M	Supported
35N	States that an ACD cannot be varied. This presumably means that a new ACD must be made, involving the whole process of witnessing and a fee if fees are to be charged. There should be a simpler process prescribed whereby the person making an ACD can vary it without charge on demonstrating that it is their free choice.
35O to R	Supported
35S(1)	It is not clear what, if any, alternative arrangements for provision of care must be made if the particular provider refuses to do so.
35S 3(a)	As expressed this carries a risk of a doctor following their own passion rather than a patient's wishes. It needs review and tightening.
35T and U	Supported
Sec 35V	It is not clear what, if any are the implications for a person who chooses not to register an ACD with the Board. Section 27A of the Bill provides some procedures for checking whether such a Directive exists but it is not clear how these Sections work together.
Sec 35W to 35ZJ	Basically supported, but these sections seem to be written on the presumption that non-professional parties to a dispute will understand how to proceed under them. See Section 3 of this submission. As editorial points: 35X(1) surely the word should be 'revoking' not 'giving' 35X(7) does this mean that a new ACD would be needed? 35ZA refers to 'varied ACD', when 35(N) says that an ACD cannot be varied.

It is not clear to the layman how Sec 32(2) and Sec 90(2) fit with Part 35A or their implications for validity of the common law versions of Advance Care Directives. This needs to be clarified.

Section 2 Issues of concern relating to the move from the present system

There is no specific reference in the Bill to the common law version of an Advance Care Directive. Many such ACDs will not comply with the requirements for registration (Section 35V(2)). Section 35V(3) makes it clear that that will in itself not render a common law version invalid, but there is no provision to make it easy to locate such Directives and there is no specific reference to any process for gathering and registering any Directives made before the amended Act comes into force, nor is there any reference in the proposed Part 5A to the treatment of Enduring Guardian instruments currently registered with the Guardianship and Administration Board. These points need clarification.

Similarly, it is not clear whether the statutory version of an Advance Care Directive can be prepared and registered free - as is the case with the common law version - or whether there would be a charge. We believe that, if there is a charge, it could seriously inhibit uptake of the statutory version.

The most critical concern with the Bill is Section 35I, concerning witnessing. The requirements for witnessing are much more restrictive than under the common law version and many people wishing to prepare an Advance Care Directive would find it impractical to meet them. These include people living in isolation with few contacts other than their immediate family, people in some aged care residences as well as others. If failure to witness in accordance with Section 35I is a barrier to registration it may make access to an Advance Care Directive difficult or impossible at a time of need. We believe that this Section needs careful review to ensure that the witnessing requirements are practical for everyone.

Section 3 Issues relating to implementation of the purpose of the Bill

Our experience has been that most people have given little thought to end of life planning with the exception of the Will and have little idea where to start with such planning. DWD Tas, COTA and some other bodies have done work in this field but there is a large job ahead and these bodies would need active support from a body such as the Guardianship and Administration Board.

Similarly, while General Practitioners, hospitals and other bodies are happy to accept and file Advance Care Directives, they have neither the time nor the expertise to assist their patients in preparing them and are unlikely to raise the for their patients to prepare them. Our experience has been that there is no consistent approach between health care professionals and health institutions and bodies as to handling Advance Care Directives and a consistent approach is unlikely to develop without specific support from a body such as the Guardianship and Administration Board.

We believe that it is essential that there is explicit provision within the legislation for organisational and financial promotion of good end of life planning as an important role of the managing body. This could be achieved through amendment to Section 8 of the existing Act (Functions of the Board) or through the administrative processes set out in that Section.

It needs to be recognised that unless these needs are provided for at this stage the objectives of the Act are unlikely to be achieved.

Attachment A
Contents page of Eol Planning Manual developed by DWD Tasmania

END OF LIFE PLANNING DOCUMENTATION
CONTENTS

Summary	1.
The Need	2.
Document storage and accessibility	3.
The Will and treatment of Superannuation Funds	3.
To Notify on my Death - Financial and related key documents	4.
Expressing your wishes about financial matters - (Enduring) Power of Attorney	4.
Expressing your wishes about health and lifestyle issues –	
Introductory Note	
Enduring Guardianship and Advance Care Directive	5.
Enduring Guardian (EG)	7.
Advance Care Directive (ACD)	8.
Medical Goals of Care (MGOC)	8.
Organ Donor	9.
Funeral arrangements and What to do following death of another	9.
Useful websites	9.

ATTACHMENTS

Attachment 1 – Form for listing key End-of-Life data	
Attachment 2 – Enduring Power of Attorney: Explanation and Forms	
Attachment 3 – Enduring Guardian: Infosheet and Form	
Attachment 4 – Advance Care Directive: Factsheet and Form	
Attachment 5	
5-1: Step by Step Guide to preparing an ACD or EG	
5-2: Guide to the Role of (Enduring Guardian) or Person Responsible	
5-3: Some Common questions and Answers	
Attachment 6 – Examples of Health Care Directions	
Attachment 7 – Table Comparing MGOC, ACD and EG	
Attachment 8 – What to Do Following a Death	

