

Guardianship and Administration Amendment (Advance Care Directives) Bill 2020

Comments on Proposed Legislation October 2020

The Anglican Church in Tasmania

Dr Helen Lord MB BS MPHCh FChPM

“Advance Care Directives are instructions about a person’s future decisions for medical treatment or health care made by a person when they have decision making ability in anticipation of a time when they do not have the ability to make those decisions due to injury or illness.”

The Anglican Church:

- Supports legislative measures that will improve advance care planning, including use of advance care directives to limit unnecessary or burdensome treatments in a manner that encourages discussion about end of life care and communication of terminal care preferences
- Supports legislative measures that will protect the rights of all vulnerable members of the community: the lonely, the homeless, the elderly, the young, the distressed, the disabled and other groups.

The amendments provided under the proposed Advance Care Directives Bill are welcome. They will help people to have confidence that they can avoid unnecessary or unwanted medical interventions, and to have an opportunity to express their preferences, values, and beliefs to inform decisions about care if they lose capacity.

Summary of suggested changes and additions to the Bill:

- I suggest there is a need for advance care plans or directives to be discussed with a trusted clinician, and so countersigned.
- There is a need for directives to be updated every 3-5 years and to be validated at the time of writing to see if the values and beliefs are congruent
- Directives need to be written by the person concerned, witnessed, dated and capacity assessed at the time of writing, otherwise they are not valid.
- For those who need enduring guardianship, such as the disabled, then there is a need to review this arrangement every 3-5 years to ensure the guardians have capacity.

- **New directives should replace older ones on the Register.**
- **There is a need for a Register that can be accessed by health professionals and people at times other than just during the working week.**
- **Advance Care Directives written under this new legislation may provide the certainty that Enduring Guardianship has provided until now.**
- **There is a need for paper based as well as online forms and for access to information and Registry by means other than online**
- **It is important that advance care directives are optional and any advance care planning is performed in a sensitive manner.**
- **It is important that cost should not be a barrier to completing an advance care directive.**
- **Consideration needs to be given to the role of the Guardianship Board when there is no person responsible**
- **There is a need to engage an independent interpreter before completing an advance care directive for those with English as a second language and this needs to be recorded on the Directive.**
- **A non-binding advance care directive could balance the different needs of parents and minors and mean that there is consultation on major decisions**

The Anglican Church in Tasmania

- Anglican Church members have an integral and ongoing interest in **promoting good care**, which includes advance care planning.
- In 2016 20.6% of all Tasmanians identified as Anglican
- Support and pastoral care are performed by individual Anglican parishes and members of churches at a community level. It is hard to quantify this **care within the community**, and it is likely to be considerable.
- The Anglican Church in Tasmania also provides chaplains and pastoral care workers in the Tasmanian Health Service Hospitals and clinics. It provides chaplaincy services that work in other environments (prison, university, church schools). It provides pastoral support for nursing homes around the State in collaboration with other Christian churches
- The core values of the Anglican Church of **caring, sharing and celebrating life** align well with the goals of many within the community. Demonstrating **compassion, demonstrating respect, and providing hope and justice** are at the centre of the Anglican Church's social policy.

Tasmanian Statistics

- Tasmania has an **aging** population in comparison with other Australian States
- Tasmania has higher rates of **disability** and mental health conditions; higher levels of **social disadvantage**; lower levels of **education**; lower levels of **health literacy**; and higher rates of **potentially reversible** hospital admissions in comparison with other Australian states
- Tasmania has the highest proportion of the population living in **outer regional areas**. These areas have more difficulty with access to medical services than those living in inner regional areas.

Observations on the preparation of Advance Care Directives and Reasons for Comments:

1. I have seen many advance care plans. The best plans have been written after consultation with family/the person (s) responsible and the person's doctor or palliative care nurses. They provide concise and relevant material, provide certainty for the person and clinicians.
I suggest there is a need for advance care plans or directives to be discussed with a trusted clinician, and so countersigned.
2. I have seen plans written many years ago which contain beliefs or ideas that the person no longer holds or have directives which are now out of keeping with their values and beliefs. I have only picked up these facts as I know the person.
There is a need for directives to be updated every 3-5 years and to be validated at the time of writing to see if the values and beliefs are congruent
3. I have seen plans on advance care directive templates written by others (family, carers) when the person has lost capacity. This is contrary to the purpose of making an Advance Care Directive
Directives need to be written by the person concerned, witnessed, dated and capacity assessed at the time of writing, otherwise they are not valid.
4. Married couples and friends often act as enduring guardians for each other. They often age together and lose capacity simultaneously. The cost and burden of reapplying to change the arrangement may prohibit this from occurring and action to provide care is difficult. Correctly completed advance care directives may help others in decision making in these situations and reduce the need to appoint enduring guardians.
For those who need enduring guardianship, such as the disabled, then there is a need to review this arrangement every 3-5 years to ensure the guardians have capacity.
5. **Advance Care Directives should not be costly to lodge and new directives should replace older ones.**
6. **There is a need for a Register that can be accessed by health professionals and people at times other than just during the working week.**
7. Many older Tasmanians do not have access to the internet or have the technical skills to complete online forms and are more familiar with paper-based forms.
There is a need for paper based as well as online forms and for access to information and Registry by means other than online.

Comments on the Protection and Care of Vulnerable Groups within the Community:

1. The homeless, victims of abuse and bullying may find advance care planning difficult
It is important that advance care directives are optional and any advance care planning is performed in a sensitive manner.
2. Those who are socially disadvantaged are less likely to complete advance care directives
It is important that cost should not be a barrier to completing an advance care directive.
3. Those who are socially isolated may have difficulty in naming a person responsible, even with the new Advance Care Directive legislation. **Consideration needs to be given**

to the role of the Guardianship Board when there is no person responsible, and the Board should be adequately resourced.

4. Those with English as a second language

There is a need to engage an independent interpreter before completing an advance care directive and this needs to be recorded on the Directive.

Minors and Advance Care Directives Background and Comments:

- 1) Life threatening illness in minors is distressing for everyone involved including the minor.
- 2) There is increasing recognition that minors with life threatening illness wish to express their views and preferences and there should be a means of enabling this to occur in a non-binding manner, with withdrawal of treatment and major decisions made with **consultation between parents, guardians, clinicians and the minor**, with the minor having more input as they mature.
- 3) There is a high likelihood of restorative treatments being available and beneficial for minors, in the event of life-threatening illness or injury, hence the need for medical consultation.
- 4) The Gillick principle which guides treatment in usual circumstances in adolescents, states: "The authority of a parent decreases as the child becomes increasingly competent. A child under the age of 16 is able to consent to treatment if the child is capable of fully understanding the medical treatment proposed and gives consent"
This principle does not normally apply to the withdrawal of treatment.
- 5) There is a wide range of decision-making ability in adolescents, so age alone cannot guide these decisions
- 6) The impact of the death of a child on the rest of the family is considerable, so it important to address the needs of all involved.

A non-binding advance care directive could balance the different needs of parents and minors and mean that there is consultation on major decisions

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Background

Advance Care Planning (ACP) Current Situation

ACP is a process of communication between patients, relatives and professional caregivers about patients' values and care preferences for the end of life.

- ACP occurs already in Tasmania
- ACP has been actively promoted by Palliative Care Tasmania for many years and is used in many care settings within Tasmania
- ACP has been actively promoted by the Royal Australian College of General practitioners and the Royal Australian College of Physicians and the Australian Government Health Department
- ACP raises awareness of the need to anticipate a possible future deterioration of health.
- ACP are known to increase the potential to improve current and future healthcare decision-making, provide patients with a sense of control, and improve their quality of life.
- ACP in the elderly has been associated with improved health (less anxiety and depression, better quality of life) and better bereavement outcomes for relatives
- A rigid approach to ACP has been associated with poorer outcomes and difficulties in seeking medical assistance for some within the community: this group requires a more nuanced approach to advance care planning. Formal Advance Care Directives may be counterproductive. This group includes those who are cynical, hostile, pessimistic, extremely anxious, resentful, are unable to trust and be supported and will include many who have been victims of abuse and bullying within the state. These are the more vulnerable within the community and need an approach which fosters trust and support
- In the age care setting, many older people wish their doctor to initiate the conversation, even though they might have long held views on the matter
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Advanced Care Directive (ACD) Current situation

An ACD is an individual's (Person Concerned's) own written wishes regarding health care preferences and directions if lacking capacity at some future time. It is a formal Advanced Care Plan.

- It is meant to provide guidance to family, friends, carers, or enduring guardians in the event of incapacity as to a person's wishes on health care
- In Tasmania, an ACD is respected, though has no legal standing
- An ACD is considered in completing Medical Goals of Care forms (Appendix 1) used within Tasmanian Health Service Hospitals to aid decisions. The Medical Goal of Care Form is used as a basis of discussion on admission to Tasmanian State Hospitals hospital for incorporating a person's wishes or ACD. Non-government hospitals have similar forms which are to guide major care decisions and can be varied as people's conditions change, decision-making capacity is restored or lost. So, it is common practice within Tasmanian hospitals for ACDs to be incorporated into care plans.
- The Medical Goals of Care Forms (Appendix 1) are respected by Ambulance Tasmania, and I have seen this give great comfort for palliative care patients going home, that they can be reassured that if an ambulance is called they will not receive unwanted treatment (cardiopulmonary resuscitation, intubation, intensive care or intravenous or nasogastric treatments) and that these can be specified or it left to medical staff to determine if there is an easily corrected condition that have caused any sudden decline. People vary in their wishes on these matters and it is important to document on a form that can be transferable between institutions, wards and home.
- Each State has different legislation around ACDs and their legal standing, which can be a cause of confusion amongst care providers and patients newly arrived in the State.
- In Tasmania there is no standardised ACD form: there is one representative form on the DHHS website, which many already use.

- In Tasmania this can be filled in by someone other than the Person Concerned: caution needs to be used in interpreting this, however. I have seen this completed by a disgruntled relative or by a staff member at a care home with a particular bias. It has only come to light after admission, so there is a need for care interpreting ACDs
- There is no check on decision making capacity at the time of writing: capacity is assumed. Caution needs to be used when interpreting ACDs when they do not appear to fit with the values or preferences of the Person Concerned. There is value in having a medical professional or some other independent person who knows the person well to endorse the form at the time of writing: capacity can be assessed at that time.
- Preferences for care are stable over time for about 70 % of people: they are more stable if written when seriously ill, engaged in the process or written by those who are better educated. It is notable however that for some 30% of people their preferences for care will change over time. So, it is important for Plans and Directives to be reviewed.
- The Australian Advanced Care Planning website suggests reviewing ACPs and ACDs with new medical diagnosis, changes in social circumstances and at regular intervals.

Matters pertaining to Advance Care Directives

Default position on resuscitation:

The default should be that resuscitation be carried out unless deemed medically futile or a readily available advanced directive stating this limitation is in place.

1. Capacity for Medical Decision Making

“Capacity is an adult’s ability to make a decision for themselves.”

- A person has capacity to make a decision when they are able to:
 - Understand the facts and choices involved
 - Weigh up the consequences
 - Communicate the decision
- Capacity is decision specific: limitation of future treatment requires a person to be able to envisage future health needs and the types of treatments available
- Capacity can be affected by illness, cognitive factors, the decision, the type of information provided, stress, mental health (anxiety, depression, psychosis) , and circumstances (which may change)
- Theos with disability and learning difficulties have specific cognitive impairments which make capacity assessment difficult and, in some cases, impossible (hence the need for an Enduring Guardian)
- Capacity can be affected by coercion and undue influence
- Capacity can be regained with improvement in health, mental state and cognition.

2. Enduring Guardianship

- Is currently governed by the Guardianship and Administration Act 1995, which also covers guardianship of those with disabilities
- a Person Concerned can appoint a Person Responsible by completing an Enduring Guardianship form, gaining the written consent of the Person Responsible (they can also appoint joint or substitute

Guardians, who also need to give consent). This form has to be witnessed by two witnesses not related to the Person Concerned or Guardians and be lodged with the Guardianship Board with the payment of a fee. The Board keeps the records. There is no formal means of assessing capacity at the time of lodgement. Should there be any dispute this is overseen by the Guardianship Board.

- The Enduring Guardian becomes active in making decisions about health care if the Person Concerned loses capacity for the task.
- “Guardianship is invested in a person not a form”
- Currently provides certainty especially for those with disabilities
- Currently provides some certainty for those who register and pay the fee
- The cost and effort required to lodge the forms may be difficult for the rural and disadvantaged populations
- If the guardians need to be changed then the process needs to be repeated and another fee paid
- Access to information lodged with the Guardianship board is difficult to access after-hours (122 hours of the week) for those working in emergency situations
- There is often confusion around the appointment of the Guardian, especially if the Guardian was appointed a long time ago. The Guardian may have lost capacity for their own decisions so cannot be expected to make good decisions for others. The Guardian may have died and no replacement made. Joint guardians may disagree. A review date of 3-5 years to review these circumstances is suggested.
- In practice an Enduring Guardianship is suggested if there are high levels of family dysfunction, the main carer lacks capacity or where there is likely to be dispute over care planning amongst carers and families
- It can only be written by a person with capacity (again capacity is assumed: there is no formal test) This can be difficult to verify at times.

3. Person responsible hierarchy

This has been determined under the Guardianship and Administration Act 1995, and from first to last in descending order of authority is:

- a **guardian** (including an Enduring Guardian) who has the power to consent to health care, which includes the power to refuse or withdraw consent to treatment)
- a **spouse** - including a de-facto spouse
- an **unpaid carer** who is now providing domestic services or support to the patient, or who provided these services and support before the patient entered a residential facility
- a **relative or friend** who has both a close personal relationship and a personal interest in the patient's welfare.

If there is no Person Responsible then the responsibility rests with the Guardianship Board

4. Vulnerable communities and use of ACDs

It is known that the use of Advance Care Directives is higher in those who are better educated, and that there are vulnerable groups in the community who are anxious about completing such forms and those who lack the resources to complete forms.

i. Homeless:

Little is known about the situation on advance care planning in Tasmania. Work among the homeless in Canada on Advance Care Planning demonstrates that most want full resuscitation in the event of a medical emergency and that 61% were able to name a substitute decision maker. This work on advance care planning was able to complete documentation for 50% of the population with a concerted effort and cooperation by a number of agencies. There was suspicion and distrust around efforts for documentation and it is yet to be seen how the completion of documentation will benefit the health of this group (whether their wishes were respected).

The homeless as a group have a large chronic health burden, early mortality, low use of primary care services and high use of hospital emergency service. I would suggest that from my experience these observations and findings would be similar to the situation in Tasmania.

It is suggested that ACP be approached sensitively and if there is an ACD for full resuscitation then this will need to be respected. Full resuscitation and Medical Goals of Care (A) (see appendix 1) should continue to be the default position.

ii. Lower socioeconomic status:

Those with lower levels of education are less likely to have completed an ACD. It is known that those with higher educational levels are more likely to complete ACDs. Higher educational attainment is associated with increased use of private insurance and hence access to the option of a private hospital bed for end-of-life care. It is known that health professionals are concerned about initiating end-of-life discussions with patients where there are insufficient resources to support patient choices about end-of-life care as often occurs in the State Hospital System, hence another factor for reduced ACD use in this group. This group is therefore likely to have less choice with their end-of-life care.

There may also be reluctance in those with lower socioeconomic status to complete ACDs due to fear that any documentation will automatically lead to curtailment of services or withdrawal of restorative services too early and so lead to early demise. They may not have the resources to complete one without aid. Hence there should be no requirement for one to be completed and no penalty (reverse discrimination) for those not completing one. The discussion over ACD as part of any hospital admission needs to be undertaken in a sensitive manner and using good communication skills. Palliative care providers are in the best position to do this if there is advanced illness.

In the UK two thirds of lower socioeconomic status cancer patients wish to die at home. Improving palliative care services so there was better access to palliative care services has been found to increase the percentage able to die at home, and was associated with greater patient and carer satisfaction.

The needs of those of lower socioeconomic status are best met with ensuring there is adequate and timely access to hospice beds and for preparation of an ACP to be approached sensitively, as for the homeless.

iii. Social Isolation:

Those who are isolated through illness or choice may have difficulty in naming a Person Responsible or nominating a Guardian. In Glenorchy 30% of households have a single occupant, which is high by Australian standards. Figures for other parts of Tasmania on social isolation are not available. Many older widowed or divorced men fall into this category of social isolation as do older gay men whose partners have died. The current system that provides the most certainty for this group involves making an Enduring Guardianship application. If they do not have a relationship with someone who is able to act as a Person Responsible this avenue is denied them.

Consideration needs to be given to lodgement of an ACD with the Guardianship Board. The same limitations to ACDs need to be made: the importance of timing: too early and the Person Concerned's expectations may be unrealistic: too late and the Person Concerned may lack capacity. A three-five yearly review would ensure some validity of the process. Encouraging discussion as a part of medical consultations may facilitate earlier uptake at the most appropriate time.

For those who are socially isolated it is suggested that if they wish to make an ACD then they should be encouraged to find someone they can trust as a guardian and if not, they should be able to lodge their directive with preferences with the Guardianship Board: this would mean extending the functions and powers of the Board and would require adequate resources.

iv: The elderly and those in nursing homes

Many elderly in the community wish to discuss their preferences for end-of-life care. It is known that the elderly can be swayed in their preferences by those facilitating the conversation. It is essential that the conversations are conducted without coercion: hence the need for safeguards on ensuring the ACD is discussed with family, carers, general practitioners and clinicians and for the Person Concerned and Person Responsible to both sign any ACD.

Many patients entering a nursing home have thought about their preferences for treatment. The evidence is that many will not initiate discussion on this and prefer for others to initiate the conversation

Some Tasmanian nursing homes have a discussion on “patient wishes” on admission and document this conversation, with a plan to review every year or if a change in condition occurs.

There is a need for more palliative care services for this area. The Tasmanian Health Palliative Care Service has not traditionally provided services in nursing homes as these are Australian (as opposed to State) Government funded.

It is a different matter for those with dementia or other neurodegenerative conditions who are likely to have lost capacity, hence the suggestion that conversations on patient preferences occur early on in neurodegenerative disease trajectories. GP involvement is crucial in this situation.

v: Those with mental illness

It is important that those who are mentally ill receive appropriate treatment and this includes treatment appropriate for any other illnesses. Hence the importance of maintaining the default position of restorative treatment, and for any decisions be made in accordance with the Mental Health Act.

vi: Those with disability

Those with disability are vulnerable and are often fearful of being denied access to services. It is important that the default position of restorative treatment continue. The Guardianship Board arrangements in place for those with disabilities should continue.

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Appendix 1

Information on the Medical Goals of Care forms

The Tasmanian Health Service Hospitals currently use a Medical Goals of Care form for all hospital admissions, except day surgery. This sits in the front of the hospital written notes or electronic record. After discussion between clinicians and the patient or person responsible places the patient in one of 4 categories:

- A. restorative and curative care: full resuscitation
- B. restoration with limitations that are stated: (may be chronic illness who has an ACD saying no CPR in the event of serious illness or injury with no prospect of recovery)
- C. palliative: usually last months-year. some limitations on resuscitation after discussion with patient
- D. terminal, usually last days: no resuscitation or IV fluids recommended

The default position, if the form is not completed is GOC A. full resuscitation

The form is completed by senior medical staff and is a means of communication within the hospital

The form can be used for hospital transfers by ambulance and provides a means of discussion what the patient wants and discussion about expectations.

The Medical GOC Form on the next 2 pages

This form has improved conversations within hospital over end-of-life care and communication within the hospital over the goals of Care and appropriate treatment.

Tasmanian Health service Medical Goals of Care.

http://www.dhhs.tas.gov.au/_data/assets/pdf_file/0010/100612/41799THOS_GoalsOfCare97748.pdf

Information on the development of the Medical Goals of Care:

Thomas R et al., Goals of Care: a clinical framework for limitation of medical treatment. MJA. 2014 201(8): 452-455 Accessed 11/6/16³⁷



MEDICAL GOALS OF CARE (GOC) PLAN

TASMANIAN HEALTH ORGANISATION
 North North West South

PT ID																			
FAMILY NAME: _____ D.O.B. _____																			
OTHER NAMES: _____ SEX _____																			
ADDRESS: _____ MARITAL STATUS _____																			
REL _____																			



This form is to communicate the medical decision for appropriate treatment goals of care for this patient. Chose A, B, C or D. If changes are made, this form must be crossed through, marked void and a new form completed.

DIAGNOSIS:		
NO LIMITATION OF TREATMENT:		
A. The goal of care is CURATIVE or RESTORATIVE. Treatment aim is PROLONGING LIFE <input type="checkbox"/> For CPR and all appropriate life-sustaining treatments →		
	Hospital CODE BLUE	Community For full resuscitation
LIMITATION OF MEDICAL TREATMENT:		
<input type="checkbox"/> Patient has an advanced care directive and / or has requested the following treatment limitations: Please specify: _____		
B. The goal of care is CURATIVE or RESTORATIVE with limitations: <input type="checkbox"/> NOT FOR CPR but is for all respiratory support measures → <input type="checkbox"/> NOT FOR CPR or INTUBATION but is for other active management → Specific notes: _____		
	For CODE BLUE and MET calls	For treatment and transfer to hospital
	For MET calls NOT for CODE BLUE	
C. The goal of care is PALLIATIVE. Treatment aim is quality of life <input type="checkbox"/> NOT FOR CPR OR INTUBATION → Specific notes: _____		
	MET call <input type="checkbox"/> YES	Contact GP for planning
	MET call <input type="checkbox"/> NO	
D. The goal of care is COMFORT DURING THE DYING PROCESS <input type="checkbox"/> NOT FOR CPR or INTUBATION →		
For terminal care NOT for CODE BLUE NOT for MET		
Reason for limitation of medical treatment:		<input type="checkbox"/> medical grounds <input type="checkbox"/> patient wishes
Discussed with:		<input type="checkbox"/> patient <input type="checkbox"/> person responsible
PRINT DOCTOR'S NAME:		DESIGNATION:
SIGNATURE:		DATE: DD / MM / YYYY
GP / consultant responsible: PRINT NAME		GP / consultant informed: <input type="checkbox"/> YES <input type="checkbox"/> NO
This form is endorsed for ambulance transfer, and for the home or care facility.		
Abbreviation key:	CPR = cardio-pulmonary resuscitation	GP = general practitioner MET = medical emergency team

GOALS OF CARE PLAN

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PROCEDURE FOR COMPLETING A GOALS OF CARE (GOC) FORM

MEDICAL ASSESSMENT

A clinical evaluation of the patient's situation to one of the three goals of care categories: curative / restorative, palliative or dying (terminal). The following may be helpful to ask, especially if limitations are being considered (after MJA 2005; 183:230-1):

1. Is the diagnosis correct?
2. Does the patient have capacity and not wish to have certain or all treatments, or if lacking capacity, has an advance directive or person responsible stating this?
3. Is medical treatment likely to prolong life or improve quality of life? Does the treatment carry a far greater risk of complications than possible benefits?
4. Has sufficient time elapsed to be reasonably confident that there is no reasonable prospect of substantial improvement or recovery?
5. Should another medical opinion be obtained?
6. Has the patient or the person responsible been advised of the above? Have they had a chance to express their opinions?
7. Has the patient's general practitioner been involved?

IMPLEMENTATION

1. Tick the box on the form that best describes the goals of care for the patient at this time.
 - A. **CURATIVE or RESTORATIVE** – if no treatment limitations are required tick box A. Refusal of a single treatment, such as blood products, in the context of otherwise full active treatment should be documented in the first line under limitations of medical treatment.
 - B. **CURATIVE or RESTORATIVE with limitations** – If in hospital, limitations to code blue or MET calls can be further documented. If in the community, the patient is for active treatment and transfer to a hospital if appropriate.
 - C. **PALLIATIVE** – The treatment aim is quality of life. If in hospital limitations to MET calls can be further documented. If in the community the GP can be contacted for further direction in management.
 - D. **DYING** – The treatment aim is comfort while the patient is dying. The prognosis is hours to days.
2. The details of the GOC discussions should be clearly documented in the patient's current progress notes.
3. The ultimate responsibility for treatment decisions including cessation of life-prolonging medical treatment and deployment of palliative and terminal care is a medical one and not the responsibility of the patient or person responsible.
4. The GOC form should not be completed by an intern.
5. The completed GOC form is filed in the current admission record, in the alerts section.
6. If the GOC change, the old form should be crossed out, marked VOID and a new form signed.
7. On discharge, a copy of the form can be sent with the patient or to the GP with the discharge summary if appropriate.
8. On discharge, the GOC form is scanned into the alerts section of the Digital Medical Record.
9. The Tasmanian Ambulance Service will recognise and act in accordance to the GOC form.
10. General practitioners or specialists may complete a GOC plan for ongoing care in the community and this form can be sent with the patient to the hospital if required.
11. Day patients who are low risk are not required to have a GOC form completed.