

Inquiry into Palliative Care

**Quality Palliative Care: enhancing communication,
protecting the vulnerable, providing a good death.**

Submission by the Anglican Church in Tasmania

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*Terms of Reference for the Standing Committee on Community Development's
Inquiry into Palliative Care:*

*To inquire into and report upon the matter of care of palliative patients generally,
specifically the matters of:*

- (i) advance care directives;*
- (ii) administration of medical treatments to minors;*
- (iii) the administration of emergency medical treatment;*
- (iv) other matters incidental thereto.*

Preamble

This submission, in congruence with the core values of the Anglican Church:

- supports the work of palliative care providers and integrated palliative care services
- supports legislative measures that will improve advance care planning 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.
- supports measures that will enhance spiritual care
and, in the face of existential distress, provide a good death.

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Palliative Care: a background

Palliative Care is defined by the World Health Organization as “an approach that improves the quality of life for patients and their families facing problem(s) associated with life threatening illness”. The full definition is in appendix 1.

Good palliative care has the potential to provide dividends for the health of the community, not just in the present but also into the future, as good palliative care associated with a “good” death is associated with better bereavement outcomes.²

A “good” death can mean different things to different people. The most important things that researchers have found on interviewing patients facing terminal illness are:

- good pain and symptom management
- being able to participate in decisions about medical treatment and care
- having a knowledge of what to expect during the course of the illness and the opportunity to plan for the events that would follow death
- the opportunity to attend to religious or spiritual beliefs, review one’s life, resolve conflicts, spend time with family and friends, and say goodbye
- being able to contribute to the wellbeing of others
- receiving empathic care which affirms the patient as a unique and whole person.³

Specialist Palliative Care involves good pain and symptom control, excellent communication, using prognostication and holistic patient centred care (biopsychosocial and spiritual care) and work as part of a multidisciplinary team.

The Anglican Church in Tasmania

The Anglican Church has an integral and ongoing interest in promoting good palliative care.

In the 2011 Australian Census 27% of the Tasmanian population identified as Anglican; 58% of the population identified as being Christian⁴.

The Anglican Church in Tasmania 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 church consists of forty-five parishes throughout the State and its islands. Support and pastoral care is performed by individual Anglican parishes at a community level by both clergy and parishioners.

The core values of the Anglican Church of caring, sharing and celebrating life⁵ align well with the palliative care goals of patients, carers and families as noted above, and continue to align, after the death of the patient, with the need for ongoing pastoral support for families and carers.

Demonstrating compassion, demonstrating respect, and providing hope and justice are at the centre of the Anglican Church’s social policy.⁶

The Anglican Church in Tasmania is integral to palliative care provision in Tasmania.

Tasmanian Statistics

- Tasmania has an aging population in comparison with other Australian States⁷.
- 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 states⁷.
- 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 areas⁷.
- Older Tasmanians are more likely to have a Christian religious affiliation⁸.

Matters pertaining to Advance Care Directives

Recommendations pertaining to Advance Care Directives (ACDs)

Discussions about end-of-life issues with family, carers and clinicians are to be encouraged. Such discussions are appropriately documented as an ACD as they seek to respect a patient's dignity, provide avenues for care and provide hope for a good death.

1. An ACD should be written after discussion with:
 - Family and carers
 - Person Responsible, if different from family and carers
 - General practitioner or medical specialist
2. The ACD should include:
 - Preferences for care (place, type of care)
 - Any limitation of treatment and guidance on the circumstances in which the limitation of treatment should apply, and be guided by information from discussion with a clinician
 - The reasoning or values behind the directive
3. The ACD should be signed by both the patient (Person Concerned) and the Person Responsible
4. An ACD may include preferences for treatment: however, treatment may not be demanded. This reduces the stress on carers and on the patient when expectations may not be able to be met.
5. An ACD may not include requests for euthanasia or physician assisted suicide
6. Capacity should be assessed and an ACD should be countersigned by a general practitioner or medical specialist to be valid
7. An ACD should be voluntary and not mandatory
8. An ACD should be reviewed if there is a significant change in diagnosis or treatment
9. An ACD should be reviewed 5-10 years
10. An ACD can only become operative if the person concerned loses capacity

11. Place of storage of an ACD needs to be with the Person Responsible and the Person Concerned
12. Consideration needs to be given to an electronic state-wide system that would enable emergency, primary care and other medical services access to an ACD

One form of wording of an ACD that may be recommended is “I wish that treatment aimed at prolonging life be stopped or withheld and palliative care be provided, if at some time in the future it is the opinion of the treating team responsible for my medical care that recovery is unlikely and the outcome of such treatments would be a permanent coma”.

Recommendations regarding Enduring Guardianship and the Guardianship Board and Advanced Care Directives:

- 1) In the event of any family-carer conflict, recommend appointing an Enduring Guardian to ensure a just process
- 2) In the event of a family-carer dispute suggest referral to the Guardianship Board
- 3) If a person concerned is unable to nominate a Person Responsible (due to social isolation) suggest referral to the Guardianship board and have ACD lodged with the Guardianship Board: this will require a new process. This is the suggested way to provide some peace of mind to the socially isolated.
- 4) Remove the current lodgement fee for placing an Enduring Guardianship with the Guardianship Board, as this is a barrier for many groups in the community.
- 5) Ensure that access to Guardianship Board records by treating medical staff is available twenty-four hours a day.

Background Information, summary of research and discussion

1. Advance Care Planning (ACP)

- ACP is a process of communication between patients, relatives and professional caregivers about patients’ values and care preferences.
- ACP occurs during most palliative care consultations in Tasmania
- ACP raises awareness of the need to anticipate a possible future deterioration of health.
- ACP has the potential to improve current and future healthcare decision-making, provide patients with a sense of control, and improve their quality of life.⁹
- ACP in the elderly has been associated with improved health (less anxiety and depression, better quality of life) and better bereavement outcomes for relatives¹⁰
- For some personality types advanced care planning has been associated with poorer outcomes and difficulties in seeking medical assistance, this group requires more assistance with advance care planning¹¹
- 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 matter¹²
- 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 educated¹³. It is notable however that for some 30% of people their preferences for care will change over time.

2. Advanced Care Directive (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 not a demand for a particular treatment or preference such as euthanasia to occur: refer to Australian Framework for the use of Advance Care Directives¹⁴.
- It is meant to provide guidance to family, friends, carers, or enduring guardians in the event of incapacity
- In Tasmania the ACD is respected, though has no legal standing
- An ACD is taken into account in completing Medical Goals of Care forms used within Tasmanian Health Service Hospitals (see appendix 2)¹⁵.
- 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 form: there is one representative form on the DHHS website¹⁶.
- In Tasmania this can be filled in by someone other than the Person Concerned: caution needs to be used in interpreting this, however.
- There is no check on 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 who knows the patient endorse the form at the time of writing: capacity can be assessed at that time.

3. Capacity for Medical Decision Making

"Capacity is an adult's ability to make a decision for themselves."¹⁷

- 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

Under the law everyone is assumed to have capacity, unless otherwise determined

- Capacity is decision specific
- Capacity can be affected by the decision, the type of information provided, stress, mental health, and circumstances (which may change)
- Capacity can be regained
- The definitions of capacity and understanding of capacity are Australia-wide¹⁷.

4. Enduring Guardianship

- Is governed by the Guardianship and Administration Act 1995, which also covers guardianship of those with disabilities¹⁸.
- 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”¹⁸.
- 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 may be 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. A review date of every 5-10 years is suggested.
- In practice it is suggested to use an Enduring Guardianship 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.

5. 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 Board¹⁸.

6. Specific problems with the use of Advance Care Directives

Whilst it may seem simple to complete an Advance Care Directive there are some potential problems:

- those with poor health literacy are more likely to have difficulty with accessing and completing forms (Tasmania has high levels of health illiteracy)¹⁹.
- it is known that what is written can be affected by those aiding filling in the forms, and the questions that may be asked to ascertain a patients preferences²⁰.
- it is known that people writing an advance care directive before experiencing an illness may have unrealistic expectations of what can be attained by treatment²¹
- new medical treatments may become available such that if the person concerned knew of these they would change the ACD (this is only a problem if the patient loses capacity)²²
- some fear completing forms for limitation of treatment as they are worried beneficial treatments will be terminated too soon or beneficial treatment not be considered if they become unwell²³
- some forms are completed in such a way that a person's preferences for treatment/withholding treatment is not clear when the need arises²²
- some unreasonable patient preferences “I never wish to go to.....Hospital again” are not able to be fulfilled due to circumstances beyond anyone's control: this can lead to family, carer or patient distress and may lead to delay in seeking medical help for correctable medical problems or treatment

for pain. An informed discussion prior to the writing of an ACD on the likely medical needs could have avoided this distress.

- An ACD may not be accessible when needed (in emergency situations)²²
- Currently ACDs written elsewhere in Australia have no validity in Tasmania and vice-versa²².
- Increased use of ACDs elsewhere has led to increased need for palliative care services⁹.

7. Vulnerable communities and use of ACDs

It is known that the use of Advance Care Directives is higher in those who are better educated^{10,20,21,23,24}, 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). Canada has new legislation around euthanasia and physician assisted suicide which has just been enacted²⁴.

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 services²⁵. 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)¹⁵ (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 ACDs¹⁰. 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 group²³. 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 demise²³. 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.

Education alone will not address this fear of being denied access to and use of health services.

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 satisfaction²⁶.

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 standards²⁷. 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 died²³. 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 capacity²¹. A five-ten 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 conversation²³. 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 treatment¹². The evidence is that many will not initiate discussion on this and prefer for others to initiate the conversation¹².

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 does not provide 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 Act²⁸.

vi: Those with disability

Those with disability are vulnerable and are often fearful of being denied access to services, in a similar way to those of lower socioeconomic status. It is important that the default position of restorative treatment continue. The Guardianship Board usually has formal arrangements in place for those with disabilities.

Matters arising from the administration of medical treatments to minors

Recommendations :

- Treatment decisions for minors (those aged under 18 years) are best served by facilitating discussion and communication between parents or guardians, the minor, and their treating clinicians as to what is in the best interest of the child, recognising that there is a range of capacity amongst minors (the Gillick principle) to consent to treatment.
- In the emergency situation the authority to consent or refuse treatment should in general rest with parents or guardians, in the interests of justice and protection of the vulnerable.
- If no parent or guardian is available then the default position, as at present, should be to provide emergency treatment in order to preserve life.

Background Information:

- Permission to consent or withdraw treatment for minors is normally at the discretion of parents or guardians.
- Currently the age of competency for minors is covered by common law based on the Gillick principle:
“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”²⁹.
- The Gillick principle does not extend to refusing life-saving treatment: under the age of 18 any refusal of treatment can only be undertaken with parental consent: the default position would be to provide life-saving treatment unless there is parental or guardian refusal of treatment²⁹.
- If there is conflict over treatment choices for minors, or doubt as to the capacity of parents or guardians, then urgent referral to the Guardianship Board is required.

Matters pertaining to emergency medical treatment

Recommendations:

In the event of an unexpected medical emergency the provision of emergency medical treatment should always be the default position in order to respect life.

- Anglican values respect the dignity of all human life, and so imply that the provision of emergency medical treatment should be the default position.

Compassion dictates that in situations of medical futility, the terminal phase of illness, or where there is a very poor prospect of recovery, then there may need to be a decision made to withdraw emergency treatment when any of these situations is recognised.

- Justice dictates that there needs to be a clear medical diagnosis, a consensus of opinion among clinicians and a consultation with family and carers before such a decision is made.

Discussion- Guidelines for treatment in a situation other than an unexpected emergency:

Current medical practice already has comprehensive guidelines to assist medical staff in deciding what form of care to provide. It is increasingly recognised that palliative type care may be more appropriate than interventional care, depending on a patient's particular situation.

Emergency medical treatment should be provided in the event of an emergency unless:

- The patient has capacity and refuses treatment. If there is doubt about capacity then referral is made to the Guardianship Board OR to Mental Health Act Guidelines
OR
- There is a well established diagnosis of dying (Goals of Care D)¹⁵ – see appendix 2
OR
- There is a well-established palliative diagnosis (Goals of Care C) – see appendix 2- and the patient has a “valid and applicable” ACD declining treatment in this situation OR the situation has been discussed with the patient, or Person Responsible, or Enduring Guardian, and refusal of treatment is agreed upon
OR
- There is a reasonable ACD covering the situation OR discussion with patient, Person Responsible, or Enduring Guardian, is in agreement AND medical opinion is that the treatment is futile and chance of recovery is poor.

This is a good balance between respecting life and patient's preferences, compassionate care and justice for those who lack capacity.

Other matters arising:

1) Persons expressing a wish to die in the advanced illness setting

Patients may be at variance with their families in their wishes:

Many patients with advanced illness say that they have had feelings of wishing to die, but would not act on it and that the desire has passed¹². From personal experience it is very rare for these wishes to be expressed by a patient themselves. It is much more common for family members to be expressing this about their relatives. However, this is usually found to be at variance with the particular patient's views and wishes when these are elicited. It may be that family members are more sensitised to and upset by seeing their family member cope with an advanced illness and so remember conversations expressing despair. It may be that when time is actually limited, time is perceived differently. It is known that good open communication on end-of-life matters can ease patient anxiety³⁰. It is essential that this is considered as a symptom in a setting of existential distress. Listening to the patient's wishes, and respecting these wishes, is pre-eminent in this situation.

Legalising euthanasia will reverse the function of an ACD:

If euthanasia were to be enacted in Tasmania as in the Netherlands, where the default is now for "medically assisted dying" or euthanasia for everyone, then there would need to be a change in the way that end-of-life care is approached. Instead of limitation of treatment being discussed, with the default position of restorative care, as at present, the default position changes to facilitated dying and ACDs would be required for those who do not wish to have euthanasia. There has been difficulty with interpreting advanced care planning in the Netherlands where patients may want some limitation of treatment (allow for natural death), but however do not want euthanasia and have to put down that they wish for "life sustaining treatment" to allow preferences to be expressed and avoid euthanasia³¹. Euthanasia is responsible for 4% of deaths in the Netherlands and at least 7% of euthanasia cases occur without patient consent (based on Dutch figures from 2012)³².

If Euthanasia were to become legal, then equity of access to an ACD would become a critical issue to address.

2) Existential Distress and Suffering in Palliative Care

Issues for patients:

The relief of existential distress and suffering are important issues in palliative care. These are often managed exclusively by palliative care providers. Hope and compassion are needed to manage these situations and many patients value the input of a spiritual adviser or pastoral supporter.

The following have been recognised as elements of both existential distress and suffering: fear of loss of control; loss of meaning; loss of identity; relationship distress; fear of loss of dignity; hopelessness³²

Various modalities have been tried to address existential distress and suffering. Spiritual well-being, finding meaning and hope can be impacted in a positive and significant manner by a number of modalities. Modalities used with benefit have included psychological strategies, dignity therapy, forgiveness therapy, music therapy, art therapy, and pastoral care³³.

There is a need to ensure that all these approaches are integrated into palliative care services.

Issues for palliative care staff:

Palliative care is delivered in Tasmania in a high pressure environment (many referrals, time and distance pressures, complexities in working across a number of other specialties, cutbacks to services, uncertainty in employment contracts, and the psycho-spiritual pressures of the work). Palliative care professionals have rates of post-traumatic stress that are estimated to be four times the average for similar health professional groups³⁴. Health professionals with psycho-spiritual training and good social networks are less prone to burnout³². There is a need to incorporate support for staff into palliative care services.

3) Relationship between spirituality and religion in palliative care

Spirituality is recognised as being a core domain of palliative care training³⁵.

Spirituality means different things to different people, and may or may not be equivalent to religion. People when asked about spirituality talk about relationships, meaning, connectedness, identity, affirmation of personhood and, in the palliative care setting, preparation for death³⁶.

Provision of spiritual care is essential to good palliative care and to a good death.

Summary

The Anglican Church in Tasmania encompasses a significant proportion of the Tasmanian population. Members have an integral and ongoing interest in promoting good palliative care.

The core values of the Anglican Church of caring, sharing and celebrating life⁵ align well with the palliative care goals of patients, carers and families. Demonstrating compassion, demonstrating respect, and providing hope and justice are at the centre of the Anglican Church's social policy.⁶

Matters pertaining to Advanced Care Directives (ACDs)

Discussions about end-of-life issues with family, carers and clinicians are to be encouraged. Such discussions are appropriately documented in an ACD as they seek to respect a patient's dignity, provide avenues for care and provide hope for a good death.

Advance Care Directives have the potential to lessen anxiety and enable family and carers to provide dignified, respectful end of life care.

Advance Care Directives should be voluntary. Patients should not be denied treatment at a health facility if they do not have an ACD in place.

Guidelines are required to ensure that ACDs accurately reflect a person's wishes, that they are reasonable, and that safeguards are built in to the development and recording of the wishes being expressed. Discussion with family and carers in the preparation of an ACD is recommended.

ACDs by their nature are directive rather than mandatory, giving guidance to carers and families when decision making is required.

The Guardianship Board and the creation of an Enduring Guardianship should retain a role in circumstances of potential carer/family dispute, incapacity or inability of a person to make an ACD.

An Enduring Guardianship agreement should be reviewed every five to ten years, should be available without cost to those at social disadvantage, and should be accessible by medical carers at all times.

Issues around treatment of minors

Treatment decisions for minors (those aged under 18 years) are best served by facilitating discussion and communication between parents or guardians, the minor and their clinicians as to what is in the best interest of the child, recognising that there is a range of capacity amongst minors (the Gillick principle) for consent to treatment.

In an emergency situation the authority to consent to or refuse treatment should in general rest with parents or guardians, in the interests of justice and protection of the vulnerable.

If no parent or guardian is available then the default position, as at present, should be to provide emergency treatment in order to preserve life.

Issues around administration of emergency medical treatment

In the event of an unexpected medical emergency, Anglican values respecting the dignity of all human life imply that the provision of emergency medical treatment should be the default position.

Compassion dictates that in situations of medical futility, the terminal phase of illness, or where there is a very poor prospect of recovery, then there may need to be a decision made to withdraw emergency treatment when any of these situations is recognised.

Justice dictates that there needs to be a clear medical diagnosis, a consensus of opinion among clinicians and a consultation with family and carers before such a decision is made.

Other related matters

1: Persons expressing a wish to die in the advanced illness setting

Patients may be at variance with their families in their wishes for terminal medical care. Listening to the patient's wishes, and respecting these wishes, is pre-eminent in this situation.

Legalising euthanasia will reverse the function of an ACD. Instead of limitation of treatment being discussed, with the default position of restorative care as at present, the default position changes to facilitated dying and ACDs would be required for those who do not wish to have euthanasia. Equity of access to an ACD would then become a critical issue to address.

2: Existential Distress and Suffering in Palliative Care

Issues for patients: The relief of existential distress and suffering are important issues in palliative care. These are often managed exclusively by palliative care providers. Hope and compassion are needed to manage these situations and many patients value the input of a spiritual adviser or pastoral supporter. There is a need to ensure that these approaches are integrated into palliative care services.

Issues for palliative care staff: Palliative care is delivered in Tasmania in a high pressure environment. Palliative care workers have high rates of post-traumatic stress. There is a need to incorporate support for staff into palliative care services.

3: Relationship between spirituality and religion in palliative care

Spirituality means different things to different people, and may or may not be equivalent to religion. People when asked about spirituality talk about relationships, meaning, connectedness, identity, affirmation of personhood and, in the palliative care setting, preparation for death³⁶.

Provision of spiritual care is essential to good palliative care and to a good death.

Biography:

Dr Helen Lord MB BS MPHc FACHPM

Dr Helen Lord was born in Hobart and studied at the University of Tasmania Medical School. She is a general practitioner and palliative care specialist. She has worked in palliative medicine in Tasmania since 1988 and in general practice at Blackmans Bay since 1990. She teaches at the University of Tasmania in palliative medicine and is an active member of Wellspring Anglican Church, Sandy Bay Tasmania.



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<https://www.mja.com.au/journal/2014/201/8/goals-care-clinical-framework-limitation-medical-treatment>

Appendix 1

WHO Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

<http://www.who.int/cancer/palliative/definition/en/>

Appendix 2

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. Accessed 13/6/16

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 is detailed in Reference 37:

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:	Hospital	Community
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 →	CODE BLUE	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 MET calls NOT for CODE BLUE	For treatment and transfer to hospital
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 MET call <input type="checkbox"/> NO	Contact GP for planning
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

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.