

DYING WITH DIGNITY

Guidelines on the Care and Management of People who are Dying



Tasmania

DEPARTMENT of
COMMUNITY and
HEALTH SERVICES

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These guidelines update the Dying with Dignity guidelines originally published in January 1996. This revised edition takes into account the experience gained and feedback received concerning the application of the 1996 guidelines, together with the provisions of the Guardianship and Administration Act 1995. The 1996 guidelines were based on New South Wales guidelines. The Tasmanian Dying with Dignity Working Group again gratefully acknowledges permission from New South Wales Health to draw on its guidelines.

DYING WITH DIGNITY
Guidelines On Management

	Page
1. Background	2
2. Aims	2
3. Principles	2
a) Respect for persons	
b) Autonomy	
c) Access and equity	
d) Quality	
4. Procedures - Development of a Care Plan	2
a) Discussion with patient	
b) Consultation	
c) Documentation of discussion	
d) Decision making	
e) Withholding or withdrawing life supporting treatment	
f) Documentation of decision made	
g) Implementation of plan for care	
h) Palliative care	
5. Related Issues	4
a) Cardiopulmonary resuscitation status	
b) Admission and discharge policy for specialist units	
c) Drugs which ameliorate symptoms but present a risk of shortening life	
d) Identification of responsible attending medical officer	
e) Advance directives	
f) Differing opinions regarding treatment plan	
g) Support services for family and friends	
6. Glossary	5
7. References	5

1. BACKGROUND

In recent years the development of sophisticated technologies has allowed the prolongation of life of a patient where this would previously not have occurred. In certain instances this may raise problems related to patient autonomy and the right to die with dignity.

Great changes have been seen in community attitudes relating to a person's right to play a role in his or her own medical decision making, to be fully informed of his/her condition and to die with dignity. The Tasmanian Department of Community and Health Services acknowledges this and, by a process of consultation, has developed these guidelines in conjunction with medical and community groups, for the management of the dying patient.

These guidelines, for use throughout Tasmania, indicate factors which should be taken into account in the management of a dying person. The procedures detailed are not prescriptive and these guidelines should be applied on a case by case basis.

In many circumstances, after consultation with the patient or advocate and the family, palliative care may be more appropriate than further life prolonging treatment.

Where a terminally ill patient requests this option, some health professionals may be concerned about their legal responsibility. The response of health professionals to such a request in certain circumstances may be compromised by the fear of criminal prosecution or civil liability.

Health professionals who apply these guidelines, in conjunction with the accepted clinical standard of their peers, and armed with accurate information and adequate consultation, should feel confident to make the decision to withhold or withdraw, futile or overly burdensome treatment. However, the guidelines do not in themselves have the force of law.

Patients and, unless the patient has requested otherwise, their families, should be assured that they will receive relevant information about the patient's condition, will be informed of progress and should feel confident that they can trust their doctor to take into account their wishes.

A patient's wishes may be communicated directly by the patient or through an advocate or by means of advance directive. The limitations of advance directives in predicting a wide variety of situations should be acknowledged by all involved. However, in circumstances where an advance directive does contain a clear wish of a patient relevant to the current circumstances, that wish should be respected and should guide the decision making process.

The *Guardianship and Administration Act 1995* (Tas), which came into force in 1997, contains references to advance directives and to those persons who have legal authority to make decisions for incompetent patients. In addition to issuing an advance directive, a patient may formally appoint a person as his/her enduring guardian with specific instructions as to how the powers of the guardian are to be applied. Such an appointment must be lodged with the Guardianship and Administration Board and confers on the enduring guardian the authority to consent to treatment of the patient, or refusal of treatment, when the patient is incapable of making decisions. The powers of the enduring guardian cannot be used to approve special treatment as defined in the *Guardianship and Administration Act* and decisions of advocates or agents can only be made in the best interests of the patient. The Act sets out the matters which should be taken into account by the guardian in making decisions on behalf of the patient.

The glossary (Section 6) provides definitions of terms used in these guidelines.

2. AIMS

These guidelines should:

- provide assistance in making appropriate decisions relating to the care of people who are dying

- increase community awareness of the rights of people who are dying
- stimulate wide discussion.

If the guidelines are to succeed in these aims they must be accepted by the community. Consistency throughout the system in the application and administration of these guidelines is a fundamental requirement for the success of the guidelines.

3. PRINCIPLES

In the Tasmanian community there is a diversity of cultural, religious, ethical and political perspectives, making consensus difficult. However, we share common needs regarding health care and can go beyond cultural and religious differences to agree upon fundamental values, based upon the inherent dignity of the person.

Four overriding broad principles are recognised by these guidelines. Decisions should be made in the light of these principles.

a) Respect for persons

Our society respects each individual and recognises the inherent dignity of the person. All people have equal and inalienable rights regardless of their social situation. A fundamental part of life is death, and a respect for persons entails assisting people to live fully while they are dying.

b) Autonomy

People have a right to discuss and make decisions about all aspects of their treatment, including the forgoing of treatment. Health care workers must respect the rights of all people to make decisions regarding their care and they should routinely become acquainted with the personal values and wishes of their patients and respect the right of all people to have these wishes documented in the medical history. Consultation with patients and their families is an important part of promoting autonomy.

The principle of autonomy raises particular issues in respect of incompetent patients - in general terms the need to take into account the patient's wishes and preferences in so far as they are known and in more specific terms the application of advance directives and the use of an enduring guardian. These matters are dealt with more fully in the relevant sections of these guidelines.

c) Access and equity

All people should have access to a level of health care which is consistent with social justice and clinical need. While budgetary constraints may limit the availability of some treatments to those with the greatest need and for whom they offer the most effective outcomes, no person should be denied access to basic and competent care. All people who are dying should have access to well conducted and competent palliative care.

d) Quality

Medical practitioners and other health care workers should act in accordance with the accepted ethical and professional standards of their disciplines, in promoting high quality health care.

4. PROCEDURES - DEVELOPMENT OF A CARE PLAN

a) Discussion with patient

Medical practitioners must ensure that information regarding prognosis and treatment options, including life prolonging procedures and palliative care, is clearly conveyed to the patient, the patient's advocate and to other persons who have the legally recognised authority to make decisions in relation to the patient's care. The educational and language standards of

the patient, the advocate and those other persons must be considered. Measures to facilitate discussions, for example the provision of interpreters, must be instituted.

Patients need to be informed of any reasonable alternatives to proposed management and as far as possible make a choice themselves. When treatment options exist, this should be acknowledged in discussion, and a recommendation of the preferred treatment should be made by the attending medical officer.

A second opinion should be offered if:

- the patient/advocate has doubts about an offered treatment plan
- the patient/advocate prefers an option not recommended by the attending medical officer
- there is disagreement amongst family and/or health professionals, all of whom have been close to the patient, regarding the proposed management plan.

The attending medical officer should seek and clarify the patient's wishes. There may be some occasions where a patient's wish to die may indicate an underlying depression or lack of understanding of the likely outcome of treatment. If the attending medical officer considers this to be the case, the medical officer should make this clear to the patient and offer counselling and referral to other health professionals. A patient may wish to have an advocate present during discussions about his/her wishes.

Discussion about these issues can occur at any time, but is best initiated at an early stage of a life threatening illness. At this stage a patient is more likely to have the time and energy to think through the alternatives and discuss them with family members.

A dying patient and his/her family must be reassured that they have received all relevant medical information, will continue to be informed of their progress, will have their views respected and can feel confident that a decision to forgo life supporting treatment will be matched by a commitment to continued palliative care.

In the case of children, although the responsibility for decisions regarding treatment rests with the parents or guardians, acting in the child's best interests, it is important for older children and adolescents to be informed and consulted and for their wishes to be considered in any decisions made.

b) Consultation

Wherever possible, consultation involving the patient and/or the patient's advocate or other representative should be carried out prior to the commencement of any new stage of treatment.

Consultation must ensure that:

- patient autonomy is observed
- medical consensus is achieved where possible prior to recommending the forgoing of treatment
- the families and guardians of, or persons responsible for, incompetent patients are given the opportunity to participate fully in discussions regarding the forgoing of treatment
- differences of opinion are adequately discussed
- sufficient time and support are given to all participating persons.

It should be understood that the only legal authority which a family member or friend of an incompetent patient can exercise in relation to the patient is a power given whilst the patient was competent by appointment as an 'enduring guardian' under the *Guardianship and Administration Act 1995*, or if the person comes within the meaning of a 'person responsible' under that Act, or by order of the Guardianship and Administration Board.

c) Documentation of discussion

The attending medical officer should document his/her discussions with the patient or the advocate or the enduring guardian regarding the patient's management. The patient's wishes regarding life supporting treatment, nomination of an advocate and details of any advance directive should be fully documented as a clear indication that procedures outlined in these guidelines have been followed. If a patient is admitted to a health care facility or transferred, all relevant documentation should accompany the patient. Where possible, any discussion which is documented pursuant to these guidelines should be acknowledged by the patient's (or advocate's or guardian's) signature.

d) Decision making

Having proceeded through the above steps, a management plan should be developed detailing the:

- goals of treatment
- treatment to be used
- duration of the treatment to be employed
- circumstances under which treatment should be forgone.

All members of the caring team should be involved in developing a treatment plan, although ultimate responsibility for the plan rests with the attending medical officer subject to the patient's (or advocate's or enduring guardian's) acceptance of the plan. This plan should be fully discussed with the patient/advocate/guardian and the family as it is being developed, if the patient has consented to their involvement or is incompetent.

The patient has the right to refuse any treatment. If the patient's condition precludes involvement in decision making the advocate or enduring guardian should be involved. The contents of an advance directive, where made, must also be taken into account in the light of growing case law authority supporting the validity of advance directives at common law. Where there is a request for continuation of medically futile or overly burdensome treatment, the attending medical officer should consider the request in the context of the overall management plan and the best interests of the patient at that time.

The *Guardianship and Administration Act 1995* has made provision for substituted decision making on behalf of a patient where the patient is unable because of physical or mental capacity to make informed decisions, in the absence of prior appointment of an enduring guardian.

Under the Act decisions on the provision of continuation of treatment may be made by the person's guardian, spouse, carer, close friend or relative (known collectively as the 'person responsible'). In addition to the person responsible (as defined in detail in the Act) the Guardianship and Administration Board may also make orders which relate to the treatment of the patient if the person responsible or other interested person seeks the views of the Board. In some cases it may be appropriate or necessary to apply to the Board for appointment of a guardian who can make appropriate decisions and give approval for suggested treatments. This may be essential when there is conflict within the family as to which family member should be making the decisions on behalf of the patient and the patient has not appointed an enduring guardian.

Where the patient is not capable of involvement, no enduring guardian has been appointed, and no advocate or advance directive has been arranged, any views that the patient was known to hold should be taken into consideration. These may be known by a health care professional or by a family or other representative.

If the patient's views are not known to anyone, then decisions should be made by the attending medical officer in the patient's best interest after a process of consultation with the patient's family. In some circumstances, there may be disagreement as

to the appropriate course of action. The views of all family members should be considered by the attending medical officer and the ultimate decision made on the basis of the best interests of the patient.

e) Withholding or withdrawing life supporting treatment

At some point in the patient's illness when death is approaching, a request may be made for consideration of withdrawal of life supporting treatment. This may come from the patient, family, advocate, enduring guardian or health professional.

In relation to an incompetent patient, the withholding or withdrawing of life supporting treatment should proceed on the basis of the discussion in the forgoing section on decision making, relating to the provisions of the *Guardianship and Administration Act* and the role of the Board.

f) Documentation of decision made

Discussion regarding termination of life supporting treatment should be documented regardless of the decision taken. Full details of the decision making process and the care plan must be detailed clearly and unambiguously.

g) Implementation of plan for care

Where possible, all staff involved in the treatment of the patient should attempt to be familiar and in sympathy with the management plan.

The attending medical officer is responsible for ensuring that the approach described in these guidelines has been followed. If followed, it should be reasonable to withdraw or withhold intensive monitoring or therapies which are considered to be futile or too burdensome for the patient. Treatment should not be withdrawn with the intention of bringing about the death of the patient, but because the treatment itself is futile or burdensome.

Support should be offered to the patient's family and friends.

h) Palliative care

The provision of palliative care for patients who are dying should continue throughout the final stages of illness. This should encompass controlling pain, relieving other symptoms of disease, and providing emotional and psychological support. If the patient wishes to see a minister of religion, counsellor, social worker, etc this should be facilitated. A palliative care order should be documented in the notes.

5. RELATED ISSUES

a) Cardiopulmonary resuscitation status

Cardiopulmonary resuscitation should not be instituted if it is contrary to the patient's wishes or expectations, or is overly burdensome or is clearly medically futile.

The issue of whether cardiopulmonary resuscitation should be instituted should be discussed with the patient/advocate and/or family as part of the management plan, in most circumstances.

Documentation should:

- be detailed and unambiguous
- include what treatment is to be commenced or continued
- include what treatment is to be withheld or withdrawn
- detail the discussions that have occurred with the patient/advocate, and the reasoning.

Suggested wording of the patient's status, depending on the decision made, may be:

'For active cardiopulmonary resuscitation'

OR

'In the event of a cardiac arrest, cardiopulmonary resuscitation is inappropriate but in the meantime palliative care should be administered'.

b) Admission and discharge policy for specialist units

Patients should only be admitted to a specialist unit, other than a specialist palliative care unit, if it promises to improve outcome. Ordinarily the patient should be discharged or transferred elsewhere when this no longer applies. However, if death is imminent and space permits, it may be more appropriate for the patient to remain in the specialist unit.

c) Drugs which ameliorate symptoms but present a risk of shortening life

In general, when correctly prescribed, drugs which ameliorate symptoms should not present a risk of shortening life. In rare instances there may be circumstances where large doses of drugs are required to provide adequate sedation for terminal agitation, pain relief or other severe uncontrollable symptoms.

The following general principles should apply when an attending medical officer prescribes drugs such as benzodiazepines, major tranquillisers or opioids, which ameliorate symptoms but present a risk of shortening life. The attending medical officer and the patient/advocate must have:

- considered the full range of foreseeable effects
- knowingly accepted whatever risk of death is entailed
- found the risk to be justified in light of the symptoms being experienced by the patient.

Drugs should not be prescribed with the intention of shortening life.

d) Identification of the responsible attending medical officer

When more than one attending medical officer is involved in the care of a patient, it should always be clear to the patient, the family and all those involved in caring for the patient, which attending medical officer has the final responsibility for decisions made concerning the care of terminally ill patients.

e) Advance directives

Whilst the limitations of advance directives must be acknowledged, particularly as they cannot take into account every clinical eventuality, they can in some circumstances provide useful guidance as to the patient's wishes. Advance directives should therefore be:

- suggested as an option to the patient as a means of indicating to the attending medical officer the patient's wishes
- prepared by the patient, signed and witnessed
- respected by health care professionals where they are satisfied that the wish expressed covers the present situation
- periodically reviewed and updated.

Advance directives should not be followed where the clear purpose would be to shorten life.

f) Differing opinions regarding management plan

When care providers have legitimate differences of opinion, those involved should first meet to resolve their differences, so they can present the patient or advocate with a consensus view of the recommended treatment/choice.

The consensus view nevertheless needs to include information to the patient of the uncertainties that have arisen which have resulted in differing opinions.

g) Support services for family and friends

All people, including patients, advocates, family members and friends should be informed about and have access to clergy, pastoral care, grief counselling and support services such as social workers. Follow up and debriefing with families should be an essential part of the treatment plan, and the attending medical officer should ensure that access to this is facilitated.

6. GLOSSARY

Advance directives

A written or properly documented oral request made when the patient had legal capacity, was well informed about treatment alternatives, and had considered potential future situations. An advance directive should be regularly reviewed by the patient.

Advocate

A responsible person, whether family or friend, whom the patient, when competent, has nominated to speak for him/her, and who is familiar with the patient's views and philosophies.

Attending medical officer

A senior medical practitioner or medical practitioner involved in the patient's admission and ongoing care. If there is more than one attending medical officer, refer to 5. Related Issues, Section (d).

Burdensome treatment

Treatment may be considered burdensome where the negative impact of that treatment significantly outweighs the likely benefits, given due regard to the circumstances and wishes of the patient.

Enduring guardian

A person formally appointed by a competent adult in accordance with the requirements of the *Guardianship and Administration Act 1995* to represent the patient's interests and make a range of health and lifestyle decisions (including those in relation to medical treatment) on behalf of the patient at times when the patient is unable by reason of disability to make reasonable judgements on his/her own behalf.

Family member

For the purposes of this document, a person whom the patient when conscious, expressed a desire to involve in the discussion and decision making process. This may be a family member, partner or friend.

Futile treatment

Investigations and treatment which according to professional judgement are therapeutically useless, that is, have no reasonable possibility of improving the patient's state of health.

Life supporting treatment

Treatment given to a sick patient with the aim of maintaining life. It may include, but is not limited to, cardiopulmonary resuscitation, ventilation, surgery, chemotherapy, radiation therapy, administration of medications, physiotherapy, and renal dialysis. It does not include the provision of reasonable nutrition or hydration or appropriate palliative measures.

Palliative care

(WHO Technical Report Series 804, 1990)

The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anticancer treatment. Palliative care:

- affirms life and regards dying as a normal process
- neither hastens nor postpones death
- provides relief from pain and other distressing symptoms
- 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 patient's illness and in their own bereavement.

Person responsible

The *Guardianship and Administration Act* provides that substituted decision making in respect of a person unable to make informed decisions may be made by the 'person responsible'. That person in order of priority is the person's guardian (whether appointed by the person under an enduring guardianship arrangement or appointed by the Guardianship and Administration Board), the person's spouse, the person's carer or a close friend or relative. Regard should be had to S4 of the *Guardianship and Administration Act* which clarifies who may or may not be regarded as the person responsible.

Special treatment

The *Guardianship and Administration Act* constrains the person responsible from consenting to certain procedures defined as 'special treatment' under that Act. This includes termination of pregnancy, removal of non-regenerative tissue, sterilisation and other prescribed procedures (not yet Gazetted).

Substituted decisions

Decisions made by the person responsible are to have regard for the wishes of the patient so far as they can be ascertained. These views could be covered in an advance directive (above) or be contained in the instrument of appointment of an enduring guardian or otherwise ascertained from the patient's prior expressed wishes and views.

7. REFERENCES

- Stanley, JM, "The Appleton Consensus. Suggested International Guidelines for Decisions to Forgo Medical Treatment", *Journal of the Danish Medical Association* 1989:303-311.
- The Hastings Centre, "Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying", NY: Briarcliff Manor, 1987.
- Dying with Dignity Interim Guidelines on Management, NSW Department of Health, March 1993.