

Guidelines for end-of-life care and decision-making



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Purpose

1

NSW Health places a high priority on health professionals working collaboratively with each other, and with patients and their families throughout all phases of end-of-life care. Such care is dependant on open and early communication in an environment of trust. These guidelines set out a process for reaching end-of-life decisions. This process promotes such communication, compassionate and appropriate treatment decisions, fairness, and seeks to safeguard both patients and health professionals.

Ideally, patients are able to determine their own decisions for end-of-life care. Some aspects of the guidelines apply to these patients. Often, however, patients lose decision-making capacity before their wishes for the use of life sustaining treatment have been determined. In those situations, the treating

team and family together need to plan care that considers the patient's best interests: reflecting the patient's wishes and values as much as possible and avoiding both inappropriate over- and under-treatment. These guidelines are particularly relevant to such situations where a consensus building approach is recommended.

Dying patients are cared for in many settings including intensive care units, hospital wards, hospice facilities, aged care facilities and the home. These guidelines provide useful advice for health professionals about a process for negotiating end of life decisions wherever that care is delivered.

These guidelines replace the *Dying with Dignity: interim guidelines on management (1993)*.

2 Principles

A large part of this document focuses on building consensus, in particular where patients do not have the capacity to decide on life-sustaining treatment for themselves. Consensus building is the most inclusive process for determining what is the best treatment for that individual, at that time, and in that place. A consensus view about best treatment is ethically based when it is in accordance with the following guiding principles.

Respect for life and care in dying

A primary goal of medical care is preservation of life, however when life cannot be preserved, the task is to provide comfort and dignity to the dying person, and to support others in doing so.

The right to know and to choose

All persons receiving healthcare have a right to be informed about their condition and their treatment options. They have a right to receive or refuse life-prolonging treatment. Caregivers have an ethical and legal obligation to acknowledge and honour these stated choices and preferences in accordance with these guidelines.

Appropriate withholding and withdrawal of life-sustaining treatment

Appropriate end-of-life care should intend to provide the best possible treatment for an individual at that time. It recognises that if the goals of care shift to primarily accommodate comfort and dignity, then withholding or withdrawal of life-sustaining medical interventions may be permissible in the best interests of the dying patient.

A collaborative approach to care

Families and healthcare professionals have an obligation to work together to make compassionate decisions for patients who lack decision-making capacity, taking account of previously expressed patient wishes where known. Many health professionals in the treating team play a role in end-of-life care and a collaborative approach should be fostered.

Transparency and accountability

In order to preserve the trust of those receiving health care, and to ensure that decisions are fairly made, the decision-making process and its outcomes should be clear to the participants and accurately recorded.

Non-discriminatory care

Treatment decisions at the end of life should be non-discriminatory and should be dependent only on factors that are relevant to the patient's medical condition, values and wishes.

Rights and obligations of healthcare professionals

Health professionals are under no obligation to provide treatments that, in the circumstances, are unreasonable, in particular, those that offer negligible prospect of benefit to the patient. Patients have a right to receive care, and health professionals have a responsibility to practice, in accordance with community and professional norms and legal standards.

Continuous improvement

Health professionals have an obligation to strive for ongoing improvement in standards of end-of-life care. This situation requires education and support for those health professionals managing dying patients and their families.

Planning in advance

3

Decision-making capacity is often lost as serious illness or death approaches. Therefore timely and appropriate decision-making about end-of-life care is more likely where those close to the patient understand the patient's wishes in advance.

With discussion and planning, the patient's preferences and values can inform decision-making as priorities change during the time leading to the patient's death. Currently in NSW, people can plan in advance for end-of-life care by:

- developing an advance care plan in conjunction with their healthcare professionals while being treated in a care setting
- discussing their preferences for life-sustaining treatment with their family before they are acutely ill
- formally appointing and informing an enduring guardian
- writing an advance care directive.

The critical element for effective advance care planning by any of the above approaches is discussion between the patient and those close to him or her while the patient still has decision-making capacity.

NSW Health has developed best practice guidelines for health professionals on advance care planning for end-of-life care titled *Using Advance Care Directives (NSW)*. Those guidelines should be read in conjunction with this document in order to assist advance care planning where possible and at the earliest appropriate stage. The guidelines are available at www.health.nsw.gov.au (see also paragraph 7.6 of these guidelines).

4 Foundations of sound decision-making

The following section discusses a number of factors that support a sound process for end-of-life decision-making. The process itself is discussed in more detail in section 5. These factors include:

- the changing context of treatment limitation decisions at the end of life
- the relationship between the treating team and the patient with decision-making capacity
- the collaborative nature of the treating team
- the consensus building model where the patient has no decision-making capacity
- accountability
- the importance of palliative care.

4.1 The changing context of treatment limitation decisions at the end of life

Because planning for end-of-life care usually takes place in the context of ever-changing circumstances, it is useful to follow the cyclic feedback process for end-of-life decision-making set out in section 5 (see 5.1). One reason for this constant change is the difficulty in predicting, with certainty, an individual's response to particular treatment. Often life-sustaining treatment will be commenced while further investigations are carried out or information sought in order to make a more accurate prognosis. When all available information has been collected, the appropriateness of continuing the treatment is reviewed with the treating team, patient and/or their family. Furthermore, patients' wishes may change as they develop an appreciation of their clinical condition. This process of review, decision-making and treatment trial may be repeated a number of times as the patient's condition improves or deteriorates. These decisions are often based on probabilities, rather than certainties.

4.2 The relationship between the treating team and the patient with decision-making capacity

People are said to have decision-making capacity if they are able to comprehend, retain and weigh up relevant information and then make a choice. A person's decision-making capacity may be adversely affected by a number of chronic or acute illnesses. As a result, decision-making capacity may vary over time and therefore necessitate re-assessment periodically.

An adult patient with decision-making capacity may accept or refuse life-sustaining treatment, even where that decision may lead to serious deterioration in health or death. It is crucial that the patient is properly informed of the consequences of refusing such treatment. A patient may make choices about treatment consistent with his or her own values, even where these values differ from those of the treating team.

A patient with decision-making capacity does not share decision-making authority with treating health professionals. Rather the treating team acts in an advisory capacity to the patient enabling him or her to make choices regarding reasonable treatment options. Such patients may choose to make decisions without reference to family or others close to them. It is essential that health professionals continue to keep patients informed about their medical condition as they improve or deteriorate, and as the patient's decision-making capacity fluctuates. Patients should be given the opportunity to participate in treatment decisions consistent with their level of decision-making capacity.

The general principles regarding consent for medical treatment apply in relation to the treatment of dying patients as they do for other patients. Healthcare professionals must be familiar with the Department's policy on consent (Circular 2004/84).

4.3 The collaborative nature of the treating team

The treating team involved in end-of-life care, either through direct decision-making or in supportive roles, may variously include medical specialists, surgeons, general practitioners, nurses and allied health workers such as social workers, patient advocates, chaplains or pastoral care workers. Individual members of the treating team may have closer or prolonged involvement with the patient and may be aware of the patient's values and wishes. Other team members may be more involved in how the patient is psychologically or spiritually coping with illness. Each member may bring valuable perspectives and information to the process of planning care and their collaborative involvement should be actively pursued. Junior nurses and doctors should not be excluded where end-of-life decisions are considered, although they should be supervised in any discussions about end-of-life decisions with patients or their families. Reaching agreement within the treating team about appropriate care is an important initial step in a collaborative approach, particularly where the patient no longer has decision-making capacity. It can help reduce subjectivity or bias, particularly in cases of uncertainty.

Nurses and doctors have independent ethical duties towards patients, and the particular burdens that treatment limitation decisions place on nurses should be recognised. Nurses play a significant role in providing clinical and social information about or to the patient and family; in the potential initiation of treatment limitation discussions; and as managers of the dying process. Nurses must be part of the collaborative process whereby the treating team develops a management plan with patients and/or their families.

4.4 A consensus-building model when the patient lacks decision-making capacity

A consensus building approach to end-of-life decision-making that considers the patient's best interests as paramount is recommended where the patient lacks the capacity to determine his or her own care. This collaborative process aims to draw on the family and treating team's knowledge and understanding of the patient's personal values and medical condition. A consensus is sought within the treating team, and between the treating team and family about a plan of care that is as consistent with the patient's wishes and values as possible, and which also supports the family in the degree of involvement it wishes to have.

The approach of shared decision-making is recommended as sole decision-making by any one party, either the senior treating clinician or the family, may fail to achieve the best possible treatment decision. A consensus approach with appropriate involvement from both treating team and family:

- avoids placing a senior treating clinician in a position of guessing at a patient's wishes concerning end-of-life treatment without the participation of others, or precipitously withholding or withdrawing treatment
- is consistent with a desire by many patients for their family to be involved in end-of-life decisions when they are not able
- avoids imposing possibly additional stress on a family who may perceive that they carry the burden of decision-making and which may later contribute to feelings of guilt
- minimises inappropriate input to decisions where concerns arise about conflict of interest within a family or a family's inability to understand medical aspects of care.

Foundations of sound decision-making

The treating team, and senior treating clinician in particular, should therefore not merely outline treatment options then delegate decision-making responsibility to families, but rather they should make recommendations for management based on their understanding of the patient's medical condition and prognosis, allow time for discussion and reflection, while continuing to work with, and support, a family and reach a consensus decision.

Families should be provided with a contact point for appropriate members of the treating team, hospital or community-based staff after the patient's death to discuss unanswered questions, as this may be beneficial in allaying guilt or uncertainties.

Elements that are critical to the success of this approach and options for resolving disagreements are discussed in section 5.

4.5 Accountability

The senior treating clinician is accountable, as leader of the treating team, to the patient, the family, the employing health authority, and ultimately the courts for the process whereby a consensus about end-of-life decisions is sought, and the reasonableness of the planned course of action. Following the process set out in these guidelines and adequate documentation of that process will ensure that the senior treating clinician and the treating team meet the obligations required for accountability in end-of-life treatment decisions.

4.6 Importance of palliative care

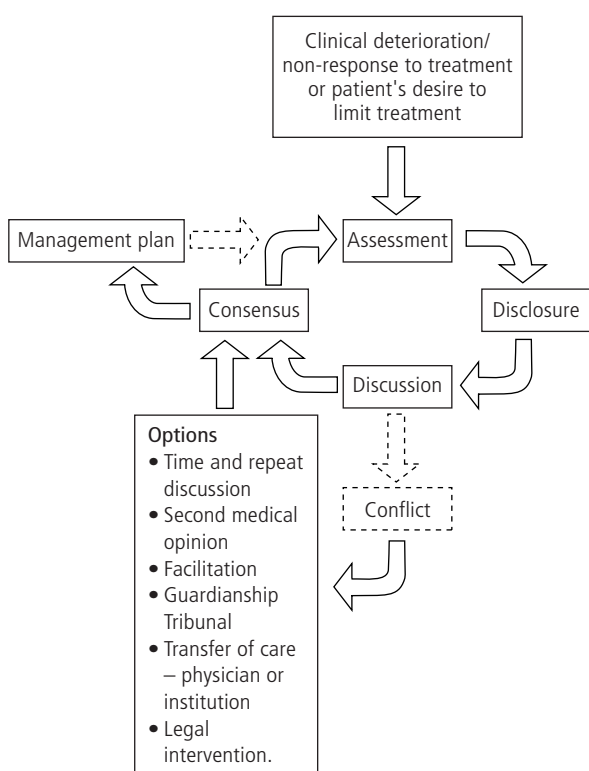
The provision of palliative care for patients should continue throughout all phases of terminal illness, and especially during the dying phase. This care should encompass controlling pain, relieving other systems of disease and providing emotional and psychological support in preparation for death. Other issues such as relief of psychological suffering, spiritual care and addressing any unresolved issues for the patient may be raised during discussions about end-of-life care. The specific details of palliative care should be documented. See 7.3

Developing a management plan

5

Planning end-of-life care is an iterative or cyclic process based on **assessment, disclosure, discussion** and **consensus building** with the patient and/or their family and the treatment team. This process can take place over a short period, such as hours, where the patient suddenly or unexpectedly deteriorates, but it can also extend over weeks or months. The key points in each step of this process (section 5.1) are discussed in the following sections.

5.1 Process of end-of-life decision-making



5.2 Assessment

A sudden or unexpected deterioration, or uncertainty about prognosis, usually requires efforts to stabilise the patient so that a complete assessment can be undertaken and potential reversibility of the condition be established. The treating team should undertake this assessment at the earliest appropriate time. Life-sustaining treatment already commenced may be subsequently withdrawn if deemed appropriate upon assessment of the patient's wishes or clinical condition.

Where there is reasonable doubt about the medical assessment in the treating team, advice should be sought from other senior clinicians with experience in the condition if possible. Second opinions should be documented.

Assessment should also include evidence of the patient's preferences and values where available from the patient, or his or her family if the patient has no capacity to express those wishes. Patients' preferences for life sustaining treatment are not static over time and should be regularly reviewed by the treating team.

A patient's desire regarding direct communication and information must be respected. The patient also has a choice to nominate someone to receive information on his or her behalf, or to exclude family members from discussions and decision-making processes.

The desire for autonomous-style decision-making or the preference for a collective or delegated approach to end-of-life decisions may vary among patients from different cultural or religious backgrounds. This aspect should be explored on an individual basis to avoid inappropriate clinical decisions and poor interaction with patients and families. The informal use of untrained interpreters such as other family members should be avoided where possible to prevent role confusion and misinterpretation of clinical information.

Failure to demonstrate any improvement in clinical condition over an extended period appropriately generates questions about further initiation or continuation of treatment. The patient, the treating team or the family may initiate such discussions.

5.3 Disclosure

Honest information in non-technical language should be provided to patients and their families for them to participate meaningfully in decisions about end-of-life care. Uncertainty about prognosis or likely response to treatment should be communicated to patients and their families. Prognostic information is ideally given by a health professional who is respected as an expert.

Patients and families may be caught off guard when conversations about the goals of care and possible treatment cessation occur suddenly, very late, without preparation, or when they have not received a balanced picture of the patient's prognosis. Patients and their families should be engaged in open communication about possible outcomes early in treatment, especially where the patient is seriously or critically ill, in order to prevent unrealistic expectations about what can be achieved with treatment. Early, honest and regular communication can also help create the trust needed for shared decision-making and to defuse tension.

5.4 Discussion

Discussions with patients and their families about treatment limitation should ideally occur in stages over a period of time, preferably while the patient can determine the appropriateness of treatment or its cessation. The presence of nursing staff, or other key members of the treating team, at these discussions is recommended to support and facilitate communication between the treating team and the family.

Strategic opportunities for the treating team to initiate or revisit discussion about end-of-life care may include recent hospitalisation with severe, progressive illness or repeated recent admissions, inquiries from the patient or family about palliative or hospice care or an expression by the patient of a wish to die.

Having the same person/s communicate with the patient or family on behalf of the treating team throughout this process can be useful, as minor differences in explanation of the patient's condition or progress can seem to patients and families like major disagreements or discord in the team. Ideally, this health professional should be experienced in conducting such discussions, have earned trust before treatment limitation is discussed, and be able to discuss prognostic information.

The phrases 'do everything' or 'do nothing' are unproductive and should be avoided: neither term is ever strictly enacted and such terminology is a barrier to informed discussion regarding the benefits and burdens of certain courses of action. The ongoing care with the goal of providing comfort to the dying patient should be emphasised with the patient and his or her family where limitation of life-sustaining treatment is planned.

5.5 Documenting a consensus decision

The agreed management plan for end-of-life care, and decisions about the use of life-sustaining treatment within that plan, should be documented and conveyed to all members of the treating team. Such communication may be difficult where many staff care for the patient but adequate documentation may assist in this regard. The senior treating clinician is responsible for summarising discussions held with the patient, family and treating team in the patient notes. These notes must clearly state:

- medical facts leading to the decision, including prognosis
- persons involved in the discussion
- statement of the patient's wishes, where known
- goals of treatment
- details about medical treatments to be provided, timeframe before review, or details about treatments to be withdrawn/withheld.

Management plans may cover a shorter or longer period of time, depending on the clinical situation of the patient. Decisions that involve withholding treatment such as CPR should be regularly reviewed in accordance with fluctuations in the patient's condition. A change in the appropriateness of withholding treatment such as CPR needs to be re-documented. (See also 7.5).

Other appropriate treating team members should continue to document other aspects of care that will be maintained or enhanced, such as comfort measures.

Thorough documentation of decision-making processes and subsequent care enables greater transparency and accountability in the care provided and ensures that all health professionals fulfil their professional and legal obligations.

Resolving disagreements

6

In most situations where a patient is dying, the patient, family and treating team readily come to an agreement on appropriate medical management. However, disagreements can arise regarding treatment limitation decisions, or about other aspects of end-of-life care. Most disagreements between the treating team, the patient or the family can be prevented by early, sensitive and proactive communication that clarifies goals of treatment, possible outcomes and the patient's values and wishes.

6.1 Disagreement in the healthcare team

In circumstances where one team member is in disagreement with the others, the team as a whole should consider the basis for disagreement and seek the opinions of professionals from the same discipline as the disagreeing member. In the event that support for this position cannot be found, it may be appropriate for the dissenting member not to continue being involved in the treating team. As in other areas of clinical practice, a health professional may exercise conscientious objection and not participate in a particular practice which is contrary to his or her moral beliefs.

Counselling or other psychological support may be appropriate where disagreement occurs about the appropriateness of treatment limitation, particularly for nurses who, in some settings and by their more intimate involvement in the care of dying patients, may be more acutely aware of the patient's distress.

6.2 When a patient's family disagrees with a patient's decision

The wishes of the adult patient with decision-making capacity are paramount. If the patient's expressed wishes regarding active treatment or refusal of treatment prior to loss of decision-making capacity are known, then these wishes prevail over the wishes of the family. Disagreements between the patient and his or her family

may arise if the family is not properly informed by the treating team about the directions given by the patient, and every effort should be made to communicate this information to the family.

6.3 Inappropriate requests for continuing treatment

At times a family or a patient requests a test or intervention that appears unreasonable or inappropriate to the treating team. Such a request may appear inappropriate in the following scenarios:

- where the patient's condition continues to deteriorate even with optimal therapeutic interventions
- where the treatment would not be successful in producing the clinical effect for which it is ordinarily used
- where the treatment might successfully produce a clinical effect, but still fail to serve important patient goals such as independence from life-support devices, survival in order to leave hospital, or improvement from permanent unconsciousness.

A focus should be kept on the patient. All requests for continuing treatment should be given due consideration before decisions about the appropriateness of treatments are made. Any request should lead to a review of the diagnosis and prognosis and the margins of certainty in each aspect. Health professionals should initially endeavour to explain to the patient or family why they think the desired test or treatment is inappropriate.

Families of patients without decision-making capacity who demand continued treatment in such situations might have unrealistic expectations about what can be achieved. More often though, a family will ask for 'everything to be done' if they are not ready to accept the patient's inevitable death. This situation may be exacerbated when the family are not engaged early in treatment planning prior to the onset of the dying process (see 5.2) or where guilt may be associated with fractured or distant relationships within the family.

Resolving disagreements

The efforts of nursing and medical staff, pastoral care workers, social workers or other counsellors should be directed to supporting family members and assisting them to resolve their difficulties in accepting the reality of the patient's impending death. In such circumstances, it is preferable to continue treatment until conflict with relatives is resolved; however time critical situations pose extremely difficult choices and challenges (see 6.5).

6.4 Potentially inappropriate requests for cessation of treatment by the patient

Unrelieved pain, suffering or depression may influence a patient's request for treatment cessation. Under such circumstances, it is appropriate to explore the patient's feelings, possibly with the assistance of a qualified professional, and to address any issues that may be resolvable.

It may be appropriate to negotiate with the patient an agreed plan of continuing treatment and further discussion in the near future, while acknowledging that sustained wishes for treatment refusal in the competent patient are ultimately paramount.

6.5 Options for resolving disagreement

The following approaches are possible avenues for resolving disagreements in the end-of-life care setting. Not all options will be available in all clinical contexts. However, the simple approaches should be taken first.

Time and repeat discussion

Unless decisions about life-sustaining treatment need to be made urgently, giving families time to come to terms with the impending death of the patient, and to seek further discussion with family or others providing support may be sufficient to resolve outstanding issues.

Second medical opinion

A request for a second medical opinion may be raised with, or directed to, any member of the treating team. Offering a second opinion may also be appropriate if the family are displaying anxieties or uncertainties regarding diagnosis or prognosis. It is the responsibility of the senior treating clinician to facilitate any second medical

opinion. This opinion should be from a health professional with relevant expertise in the patient's condition and who is demonstrably independent from the treating team.

Time limited treatment trial

Such a course of action may be undertaken to clarify prognostic uncertainty or resolve disagreement about prognosis, provided the trial is in the best interests of the patient. It may be advisable to clarify with the treating team and family what treatments are being commenced or continued, the criteria for assessment and the timeframe for review before possible continuation or withdrawal.

Facilitation

Involvement of a third party may assist in clarifying and addressing the concerns of the patient and/or family members, or in finding agreement where an impasse has occurred between the family and the treating team. The third party may be a senior member of the hospital administration, a senior health professional, or another person agreed upon by those involved. The person should have sufficient seniority, be respected by all parties, and be demonstrably independent of the treating team.

Patient transfer

When the above steps have not resolved the situation, the practicality of transferring the care of the patient to another institution or another suitable treating clinician within the same institution should be investigated with those involved.

Guardianship Tribunal

The Guardianship Tribunal may provide advice in relation to end-of-life care for patients lacking decision-making capacity. Advice may include whether it is appropriate for the Tribunal to deal with an application for consent to a proposed treatment on behalf of such a patient.

As palliative care is medical treatment under Part 5 of the *Guardianship Act*, consent may be sought for it to be provided to replace more active treatment. The application must set out the proposed treatment, and any alternative treatments, and the nature and degree of any significant risks associated with either the proposed treatment or the alternatives to it.

Legal intervention

The NSW Supreme Court, or the Family Court of Australia in respect of children and young people under 18 years old, has jurisdiction to hear matters relating to treatment limitation decisions. Senior treating clinicians or their delegates may consider initiating a Court action when they are unsure of whether the proposed treatment or treatment limitation is in accordance with their duties as medical practitioners, and when all of the above steps have failed to resolve their concerns.

Before initiating a Court action, the senior treating clinician should usually have:

- obtained a second specialist medical opinion in writing
- received senior institutional advice

- discussed this course of action with the family
- sought advice from the Guardianship Tribunal if the patient does not have decision-making capacity
- informed the hospital executive of the proposed approach.

Where this option is taken, continued consultation should take place with family members to assist in clarifying the issues and to determine whether a legally acceptable solution that is in the best interests of the patient can be reached. Family members or 'persons responsible' may decide to independently initiate a Court action if they have concerns regarding end-of-life decisions where the patient lacks decision-making capacity. Family members or person responsible should be specifically informed that they have this option, where appropriate.

7 Specific issues

7.1 Distinction between euthanasia, assisted suicide and lawful treatment limitation decisions

Euthanasia and assisted suicide both involve deliberate acts or omissions that are undertaken with the intention of ending a person's life and are inconsistent with the duties of a medical practitioner.

Euthanasia and assisted suicide are different from withholding or withdrawing life-sustaining treatment in accordance with good medical practice by a medical practitioner. When treatment is withheld or withdrawn in these circumstances, and a patient subsequently dies, the law classifies the cause of death as the patient's underlying condition and not the actions of others (see 7.3). Care of terminally ill patients that is lawful never involves an intention to end a patient's life.

Both euthanasia and assisted suicide are crimes under the *Crimes Act 1900 (NSW)* and are not endorsed in this document, or by the NSW Department of Health.

7.2 Children and young people

End-of-life decisions in children pose particular difficulties. This difficulty is in part because, unlike adults, children are often unable to understand or fully understand choices concerning life-sustaining treatments or functional states, and the implications for decision-making. Children are also less likely to have expressed values that would, in adults, be known by the family and inform treatment decisions. Parents and the treating team may nevertheless consider that continued treatment is not appropriate where the child's condition is intolerable to the child or where the child is dying.

Older or mature minors (that is, between 14 and 18 years) may not make treatment limitation decisions solely by themselves, even where their capacity to make other medical decisions is not in doubt. However, older minors should be involved in discussions with their parents and the treating team regarding their prognosis and treatment, as appropriate to their level of understanding, emotional maturity and in accordance with their best

interests. Multidisciplinary support, as described below, may be necessary where a child's expressed wishes about end-of-life treatment are contrary to those of his or her parents.

Where the treating clinician and parents differ in their assessment of what is in the best interests of the child, or where the parents disagree with each other, the following strategies (additional to those discussed in 6.5) may be useful:

- The understandable anxieties of parents in relation to treatment limitation decisions may be complicated by potential feelings of guilt and responsibility for the child's subsequent death. Appropriate multidisciplinary support for parents should be provided at this time. This assistance may ultimately involve working with parents to refocus their hopes and goals.
- Assessment of the family dynamics and possible genesis of disagreement within that family by an appropriately qualified mental health or social work professional and family counsellor.
- Appointment of an appropriately qualified professional, such as a counsellor, in the treating team to advocate independently for the interests of the child.

The consensus-building approach to treatment limitation decisions outlined elsewhere in these guidelines is also applicable in this setting. Where the process fails to bring a consensus about the appropriateness of treatment limitation, resolution will require application to the Court.

In situations where the child is subject to a care order conferring parental responsibility on the Minister for Community Services generally or specifically for medical decisions, the law treats the Minister as the child's parent. The treating clinician should consult with the Minister about the appropriateness of life-sustaining medical treatment by contacting the Department of Community Services. Treatment should continue to be provided, time permitting, while consultation takes place. Disagreements between the treatment team and the Minister or Minister's delegate about the appropriate course of action should be resolved by the same processes as apply to other parents as outlined in these Guidelines.

7.3 Appropriate use of analgesia and sedation

Analgesia and sedation should be provided by whatever route is necessary for relief, in proportion with clinical need, and with the primary goal of relieving pain or other unwanted symptoms. Such administration will not be unlawful provided the intention of the medical practitioner is the relief of symptoms, even if the medical practitioner is aware that the administration of the drug might also hasten death.

7.4 Artificial hydration and nutrition

Use of artificial hydration and nutrition is an intervention with its own possible burdens and discomforts, for example, those related to having tubes in situ or regularly replaced. Withdrawal of artificial hydration and nutrition, like the withdrawal of other medical interventions, can be seen as a treatment limitation decision that may be made in accordance with these guidelines. It is recognised that the provision of artificial hydration and nutrition may be a particularly sensitive matter for some in the community who believe that it must be continued, unless specifically refused by the patient. The offering of food and fluids by ordinary, non-medical means should be part of the care of dying patients as appropriate to their clinical condition or wishes.

7.5 No CPR orders

The term No Cardiopulmonary Resuscitation (No CPR) order is preferred as less ambiguous than Do Not Resuscitate (DNR) or Not For Resuscitation (NFR) orders and the interventions to which they apply.

The principles for withholding CPR are consistent with those for withdrawing life-sustaining treatment as outlined in these guidelines. Decisions relating to withholding CPR should be made on an individual basis, not involving blanket decisions or policies, for example, related to age or disability. (See also section 3 Planning end-of-life care in advance).

A No CPR order may be compatible with providing the patient with maximum therapeutic care, short of CPR. The treating clinician and treating team should reassure the patient, or his or her family, that all comfort and other appropriate care will be provided.

No CPR orders should be clearly written in the patient's medical notes as with other treatment decisions. Use of covert symbols on charts, medical notes or wristbands is not appropriate. Where the decision to apply a No CPR order has not been discussed with the patient because he or she lacks decision-making capacity, that fact should be documented.

Where no explicit decision has been made about the appropriateness, or otherwise, of attempting resuscitation of the hospitalised patient, then resuscitation should be commenced until a senior doctor is available who should determine, based on likely prognosis, whether CPR should continue and then direct the team accordingly.

Where paramedics have been called to a patient whose condition has deteriorated and cardiac arrest occurs, there is a presumption that emergency medical care is appropriate.

7.6 Advance care directives

A number of conditions, outlined below, should be met before the treatment decisions in an advance care directive (see Glossary) are followed:

- the directive is intended to apply to the clinical circumstances that have arisen
- the directive must be sufficiently clear and specific to guide clinical care
- there must not be any evidence to suggest that the directive does not reflect the current intentions of the patient, or was made as a result of undue influence
- the directive should be made by the patient him or herself and should reflect his or her wishes, rather than the wishes of another person.

Specific issues

In addition, it is best practice, but not legally necessary, that:

- the patient should periodically review the directive, for example, once a year, after an illness, or with a change in health status
- the directive should be available at the time decisions need to be made, for example, by ensuring the likely person responsible and primary healthcare provider have a copy of the directive and any of its revisions
- the directive should be signed and witnessed
- a medical practitioner should be involved in discussions with the patient to assist with the development of the directive.

See also section 3 of these guidelines. For more detailed information about advance care directives and advance care planning, see *Using Advance Care Directives (NSW)*, NSW Health, 2004.

7.7 Persistent vegetative state (post-coma unresponsiveness)

Treatment limitation for a severely brain-injured patient is a decision that should be made in accordance with these guidelines. Diagnosis of persistent vegetative state is difficult and usually protracted, often taking months to confirm. The National Health and Medical Research Council has released advice on this matter titled *Post-coma unresponsiveness (vegetative state): a clinical framework for diagnosis*. It is available on www.nhmrc.gov.au.

7.8 Emergency treatment

In some circumstances, for example where a patient's condition suddenly deteriorates and his or her wishes or likelihood of recovery are unknown, a treating clinician or health professional may provide medical treatment without consent (from either the patient or the person responsible) if the treatment is necessary as a matter of urgency. Such situations might be to:

- save the patient's life
- prevent serious damage to the patient's health; or, except in cases of special medical treatment,
- alleviate significant pain or distress.

This treatment should be no more than is reasonably required in the best interests of the patient.

This does not apply, however, if the patient, when competent, has unequivocally refused the provision of such treatment in the applicable circumstances and the clinician is satisfied on the available evidence that such a direction has been made.

Developing local policy

8

These guidelines should form the basis of local policy on end-of-life decision-making, considering local conditions and resources. Local policy development is recommended for the following situations:

- No CPR orders
- minimum standards for documentation of decisions about withholding, or withdrawal of, treatment
- dispute resolution for patients, families and staff.

Local policy may expand on these guidelines by, for example, identifying relevant persons or contacts within the hospital/Area Health Service who may serve certain roles.

Quality improvement activities for end-of-life care that incorporate self-audit, with other sources of performance feedback, such as complaints and commendations, should be developed to guide future practice.

Area Health Services or individual hospitals should identify an appropriate implementation group to undertake local policy development using these guidelines.

Glossary

Advance care directives

An advance care directive contains instructions that consent to, or refuse, the future use of specified medical treatments. It becomes effective in situations where the patient no longer has the capacity to make treatment decisions.

Family

For the purposes of this document and recognising the collaborative nature of end-of-life care, the term 'family' is used to refer to a person or persons who have a close, ongoing, personal relationship with the patient, whom the patient may have expressed a desire to be involved in treatment decisions, and who have themselves indicated a preparedness to be involved in such decisions. This person or persons may or may not include the immediate biological family. However, it may include other relatives, partner (including same sex and de facto partners), friend, or 'person responsible' according to any expressed wishes of the patient.

Life-sustaining treatment

Life-sustaining treatment is any medical intervention, technology, procedure or medication that is administered to forestall the moment of death, whether or not the treatment is intended to affect life-threatening diseases or biological processes. These treatments may include, but are not limited to, mechanical ventilation, artificial hydration and nutrition, cardiopulmonary resuscitation or certain medications (including antibiotics).

Palliative care

Palliative care is competent and compassionate care which provides coordinated medical, nursing and allied health services for people who are terminally ill, delivered where possible in the environment of the patient's choice. It provides relief from pain and other distressing symptoms, integrates psychological and spiritual aspects of care, focuses on supporting patients to live as actively as possible until death, and includes grief and bereavement support for the patient, family and other carers during the life of the patient, and continues after the death of the patient.

Patient

For the purposes of this document, the patient describes the person receiving end-of-life care in an institution such as an intensive care unit, hospital ward, hospice facility, aged-care facility and the home.

Person responsible

The *Guardianship Act 1987 (NSW)* establishes who can give valid consent for medical treatment to an incompetent patient aged 16 years and over. Consent of the person responsible is required in relation to provision of minor and major medical treatment. The Act establishes a hierarchy for determining who is the person responsible as follows:

- The patient's lawfully appointed guardian (including an enduring guardian) but only if the order or instrument appointing the guardian extends to medical treatment.
- If there is no guardian, a spouse including a de facto spouse and same sex partner with whom the person has a close continuing relationship.
- If there is no such person, a person who has the care of the patient (otherwise than for fee and reward).
- If there is no such person, a close friend or relative.

See the Department's consent policy (circular 2004/84) for further information on substitute consent and persons responsible.

Treatment limitation decisions

Decisions that involve the reduction, withdrawal or withholding of life-sustaining treatment.

Treating team

The multidisciplinary team of health professionals involved in the patient's management and care, including medical, nursing, allied health, social workers and counsellors, carers and spiritual advisors.

Resources and contacts

NSW Department of Health

1. Information on requirements for organ donation and autopsy:
Circular 2004/1 – Use and retention of human tissue including organ donation, post-mortem examination and coronial matters
2. Information on informed consent requirements:
Circular 2004/84 – Patient information and consent to medical treatment (2004)

These Circulars, further copies of these Guidelines and Using Advance Care Directives (NSW) can be downloaded through NSW Health websites:

Health website (internet)

www.health.nsw.gov.au/pubs

Healthnet (intranet)

<http://internal.health.nsw.gov.au/pubs>

Hard copies of these guidelines can also be obtained through:

Better Health Centre
Locked Mail Bag 5003
Gladesville NSW 2111
Tel. (02) 9816 0452
Fax. (02) 9816 0492

Other websites

3. Information on palliative care standards and guidelines:
www.pallcare.org.au/publications/index
4. Information on substitute consent and the role of the Office of the Public Guardian
www.lawlink.nsw.gov.au/opg.nsf.pages/substituteindex
5. Information on enduring guardianship and the role of the Guardianship Tribunal
www.gt.nsw.gov.au/publications
6. Information on organ donation and brain death
www.health.gov.au/nhmrc/issues/humanethics.htm

Other resources

Video – *Substitute consent: when the patient can't give a valid consent,*

Guardianship Tribunal, Locked Bag 9, Balmain NSW

Tel. (02) 9555 8500 or Fax. (02) 9555 9049

Guide – *Enduring Guardianship: Your Way to Plan Ahead,*
Office of the Public Guardian,

PO Box A231 Sydney South NSW

Tel. (02) 9265 3184 or Fax. (02) 9265 2645

NSW Health General Bereavement Support Training
Program (information booklet and CD ROM) April 2003
www.health.nsw.gov.au

