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ADVANCE PLANNING

'In this world nothing is certain but taxes and death.' Benjamin Franklin

Despite this certainty, many people live their lives without really considering their own mortality. However, the diagnosis of a life-limiting illness, and particularly the awareness of physical deterioration as the illness progresses, will prompt the patient (and those close to them) to face their impending death. This is generally psychologically and spiritually demanding, and the extent to which a person is able to do this, and discuss it with others, varies.

Certain coping styles (e.g. 'Must think positive' or 'Must put on a brave face') can impede communication and reflection. It is a challenging area for health professionals, and it is easier to re-inforce the positive thinking ('Perhaps the next cycle of chemotherapy will help') rather than help the patient plan for all eventualities ('Hope for the best, but plan for the worst').

Patients may come to terms with the fact that their life is drawing to a close but see no need to make specific arrangements. However, pro-active 'Advance Care Planning' is now recommended.^{1,2} In the UK, national guidelines provide advice about how, when, and where to discuss this with patients.³

A health professional should introduce the topic sensitively when they consider it likely to benefit the care of the patient. This should be done before the terminal phase, such as at the time of:

- diagnosis of a life-limiting illness
- disease progression, leading to multiple hospital admissions
- increased risk of cardiorespiratory arrest
- admission to a care home.

However, it can be done at any time by anyone, e.g. a well person prompted to do so by the death of a relative or friend. It is a voluntary process and there should be no pressure to take part. The choice not to confront future issues should be respected.

Advance care planning involves discussion between health professionals and the patient, and (if the patient wishes) relatives/informal carers, in order to identify:

- their concerns
- their understanding of their illness and prognosis
- important values or personal goals for care
- preferences for the types of care or treatment that may be beneficial in the future and the availability of these.

The discussion should be:

- documented
- regularly reviewed
- communicated to key persons involved in their care.

Possible outcomes arising from such a discussion include completion of:

- an informal statement of wishes and preferences (Box 13.A)
- a formal Advance Decision to Refuse Treatment (ADRT, see p.409)
- a Lasting Power of Attorney, to appoint a welfare attorney who would take decisions on a person's behalf should they subsequently lose capacity.

An example of advance care planning is the Preferred Place of Care (PPC) Plan, a nationally recommended tool to support high quality terminal care.^{4,5} This comprises a patient-held record documenting the patient's wishes, the socio-economic circumstances of the family, the services being accessed, reasons for change in the care, and a needs assessment which documents care on an ongoing basis. It aims to facilitate:

- greater choice for patients in where they wish to live and die
- fewer emergency admissions of patients who wish to die at home
- fewer older people being transferred from a care home to hospital in the last week of life.

Box 13.A Statement of wishes and preferences⁶

This is a statement recorded in the patient's clinical notes to convey their:

- wishes and preferences about future treatment and care, e.g.:
 - ▷ personal preferences
 - ▷ who they want involved in future decision-making
 - ▷ types of medical treatment which may or may not be wanted
 - ▷ place of care
- beliefs or values that govern how they make decisions in order to guide future decision-making.

Acts which are illegal cannot be included, e.g. assisted suicide.

They are not legally binding.

When a person lacks mental capacity, a professional carer formulating a decision about care or treatment must take any statement of wishes and preferences into account when trying to determine the patient's best interests.

If not documented in the clinical notes, relatives or other carers should be contacted to determine whether any statement of wishes or preferences exists, or for help in determining the patient's probable wishes.

Advance Decision to Refuse Treatment

An Advance Decision to Refuse Treatment (ADRT) is a set of instructions that a person aged over 18 years with mental capacity can make to refuse treatment should they lose capacity in the future. It is covered by statute law in England and Wales (Mental Capacity Act 2005), and by common law in Scotland and Northern Ireland. A valid and applicable ADRT is as legally binding as a contemporary refusal of treatment made by a person with capacity (Box 13.B).

Box 13.B The law and an Advance Decision to Refuse Treatment (ADRT)⁷

Legal requirements for an ADRT which refuses life-sustaining treatment are:

- it must be in writing (this includes being recorded in the clinical notes or being written on behalf of the patient)
- it must contain a specific statement that the person wishes the ADRT to apply even though treatment refusal may result in earlier death
- it must be signed by the person (or on their behalf in their presence) and by a witness.

An ADRT is valid if:

- the person had mental capacity when they made the ADRT (Box 13.C)
- the ADRT was made voluntarily, i.e. the person was not put under undue pressure or coerced into making it
- the person was informed as to the broad nature and purpose of the treatment they are refusing.

An ADRT is applicable if:

- there is a refusal of a specific treatment, e.g. CPR, chemotherapy
- the treatment in question is that specified by the ADRT
- the circumstances in which the refusal is to apply are specified and exist at the time the decision needs to be made.

An ADRT may not be valid or applicable if:

- there have been changes in circumstances which give reasonable grounds for believing these would have affected the person's refusal, e.g. a new treatment has been discovered for the person's illness
- since making the ADRT, the person has done anything clearly inconsistent with the ADRT remaining their fixed decision
- since making the ADRT, the person has subsequently withdrawn their decision (verbally or in writing)
- the person has subsequently conferred power to make that decision on an attorney.⁸

On the other hand, a *request for treatment* is *not* legally binding, although it will provide the clinical team with insight into the person's wishes and preferences. A person may not make a request for their life to be ended. A person with a Living Will or Advance Directive written before October 2007 needs to ensure that it complies with the standards for an ADRT, particularly if they wish to refuse life-sustaining treatment. Life-sustaining treatment is defined as a treatment which the healthcare provider regards as necessary to sustain life.

Box 13.C Mental capacity⁷

Persons over the age of 16 years are presumed to have mental capacity until shown otherwise.

Any evaluation of capacity has to be made in relation to a particular decision (e.g. choice of treatment) at a particular time.

An evaluation of capacity will normally involve discussion with the person's family, friends or carers, or an Independent Mental Capacity Advocate (IMCA) if one has been appointed.

An individual's capacity can vary over time, so health and social care professionals should identify the time and manner most suitable to the patient to discuss treatment options. It may be necessary to call upon expert evaluation of the person's capacity, e.g. psychiatrist, clinical psychologist.

Loss of capacity may be temporary, e.g. due to a reversible concurrent illness or complication. If the patient who lacks capacity may regain it soon, e.g. after receiving medical treatment, defer decision making until then, if possible.

The two stage test of capacity

1 *Diagnostic*: does the patient have an impairment of the mind or brain, which means that they are unable to make the decision for themselves?

2 *Functional*: the patient is unable to:

- understand the information relevant to the decision, including the likely consequences of making or not making the decision
- retain that information for as long as is necessary to make and communicate the decision
- use that information as part of the process of making the decision
- communicate the decision by some means.

All evaluations of a person's capacity should be documented in the patient's clinical notes. Determining capacity should be conducted using a multi-professional approach. However, the final responsibility remains with the senior professional involved.

A person may refuse any treatment but can never refuse basic care, e.g. shelter, warmth, hygiene measures, the offer of oral food and fluids. Artificial nutrition and hydration are regarded as treatment and may thus be refused. It is essential this is pointed out to people at the time the ADRT is created.

An ADRT may be verbal or written. However, if a person wishes to refuse life-sustaining treatment, this part of the ADRT must be written and follow a specific format (Box 13.B). Although it is recommended that people talk to their GP, consultant or solicitor before formulating an ADRT, this is not a legal requirement. If a person gives a verbal ADRT, it should if possible be documented in the clinical notes and signed by the person. However, people should be encouraged to produce a formal written ADRT.

There is no official format for a written ADRT, unless life-sustaining treatment is refused (Box 13.B). There is no set review period for an ADRT. Decisions made a long time in advance are not automatically invalid or inapplicable, but a regularly reviewed ADRT is more likely to be valid and applicable to current circumstances.

An ADRT may be withdrawn in full or in part either in writing or verbally at any time while the person has capacity. If a verbal withdrawal is made, it should be documented in the clinical notes.

Health professionals must take practical and reasonable steps to determine whether a patient has made an ADRT. It is good practice for the clinical team to ask the patient, family member or GP if an ADRT exists. However, the onus is on the patient to ensure that clinical teams involved in their care know about the ADRT. Patients should be advised to provide a copy of the ADRT for their GP, clinical notes, solicitor and family members.

An ADRT only comes into effect if a person loses mental capacity. All patients are assumed to have mental capacity unless they fail the test for capacity (Box 13.C). Once the clinical team has been given an ADRT belonging to a patient who has lost mental capacity, they must establish if it is valid and applicable (Box 13.B). If it is found to be so, the ADRT must be complied with or they could be liable to criminal or civil proceedings.

If an ADRT is not valid or applicable to current circumstances, it may still provide the clinical team with insight into the person's wishes and preferences. A retrospective evaluation of the validity of an ADRT may be difficult to make. If a health professional or family member has reasonable doubts or there are disagreements over the validity or applicability of an ADRT, the senior clinician in charge of the patient should consult with all parties involved in the patient's care to seek evidence concerning the validity and scope of the ADRT (not to try to overrule it). Details of these discussions should be recorded in the patient's clinical notes. If the senior clinician comes to the view that the ADRT is valid and applicable, it must be complied with.⁸

If serious doubt or disagreement persist, apply to the Court of Protection for a ruling. The court can rule if the ADRT exists, is valid and is applicable, but cannot overturn a valid and applicable ADRT.

While court proceedings are being undertaken, or in an emergency where there may not be sufficient time to evaluate the validity and applicability of an ADRT, health professionals may provide life-sustaining treatment, or any treatment necessary to prevent a serious deterioration in the patient's condition.

If a health professional has a conscientious objection to complying with an ADRT, this should be discussed with the multiprofessional team. If necessary, care of the patient should be transferred to another health professional who is able to comply with the ADRT. This must be done without affecting the patient's care.

An ADRT for a mental disorder may not apply if the person is, or is liable, to be detained under the Mental Health Act 1983. If necessary, clarification should be sought from a psychiatrist.⁸

Lasting Power of Attorney (LPA)

Different statutes cover proxy decision-making in England and Wales, and Scotland.

England and Wales

LPA is covered by statute law in England and Wales (Mental Capacity Act 2005). A person aged over 18 years who has capacity may make an LPA to appoint one or more persons as attorney(s) to take decisions on their behalf if they subsequently lose capacity. An LPA can cover decisions relating to healthcare and/or personal welfare (a personal welfare attorney), and/or property and financial affairs (a property and financial affairs attorney). A personal welfare attorney can refuse treatment on behalf

of an incapacitated person, but can only refuse life-sustaining treatment if the LPA specifies this. A personal welfare attorney cannot demand inappropriate medical treatment. The LPA replaces the previous role of Enduring Power of Attorney.

An ADRT overrules a personal welfare attorney, unless the LPA was made after the ADRT and specifies that the personal welfare attorney has authority to make decisions about the same treatment. Before relying on the authority of a personal welfare attorney, the clinical team must be satisfied that:

- the patient lacks capacity to make the decision
- the LPA has been registered with the Office of the Public Guardian
- a statement has been included in the LPA specifically authorizing the welfare attorney to make decisions relevant to the current situation
- the decision being made by the attorney is in the patient's best interests.

Scotland

A different statute covers the appointment of welfare attorneys in Scotland (Adults with Incapacity (Scotland) Act 2000).⁹ In Scotland, a person aged over 16 years may appoint one person as welfare attorney to take decisions on their behalf if they subsequently lose capacity. The Sheriff may appoint a welfare guardian with similar powers. As in England and Wales, the welfare attorney or guardian cannot demand inappropriate medical treatment. Before relying on the authority of a welfare attorney, the clinical team must be satisfied that:

- the patient lacks capacity to make the decision
- the welfare attorney or guardian has specific power to consent to treatment
- the decision being made by the attorney would benefit the patient
- the attorney has taken account of the patient's past and present wishes as far as they can be ascertained.

Where there is disagreement between the healthcare team and welfare attorney or guardian (e.g. the healthcare team believe it would benefit the patient to attempt CPR in the event of cardiorespiratory arrest but the welfare attorney disagrees), the clinical team should apply to the Mental Welfare Commission of Scotland to appoint a 'nominated medical practitioner' to give an opinion. This opinion is final unless appealed by either party to the Court of Sessions.

Northern Ireland

In Northern Ireland, there is currently no provision for the appointment of proxy decision-makers for patients who lack capacity. However, those close to the patient should be consulted by the clinical team when determining the patient's best interests.

Independent Mental Capacity Advocate (IMCA)

Most adults who lack capacity, and who have not written an ADRT or appointed a welfare attorney, will have family, friends or carers who can and should be consulted about their views if a decision needs to be made on their behalf. In England and Wales, statute law stipulates that if there is no-one appropriate to consult, an IMCA should be appointed for the person when decisions have to be made about:¹⁰

- serious medical treatment e.g. chemotherapy, major surgery, withholding or withdrawing artificial nutrition and hydration:
 - ▷ when the likely benefits and possible burdens are finely balanced
 - ▷ when a decision between choice of treatment is finely balanced
 - ▷ when what is proposed is likely to have serious consequences, e.g. potentially shortening the person's life, serious and prolonged pain or other major distress

- moving the person into long-term care (> 4 weeks in a hospital or 8 weeks in a care home)
- a long-term move (≥ 8 weeks) to a different hospital or care home
- adult protection (in England).

The role of the IMCA is to support the person for whom the decision is being made by obtaining as much information as possible from that person and other sources about their wishes, feelings, beliefs and values. The IMCA will then prepare a written report for the healthcare team. The IMCA will not be the final decision-maker, but the decision-maker must take into account the information provided by the IMCA.

If a patient is known to be 'friendless', i.e. there is no one who could be consulted about their wishes should they lose capacity, they should be encouraged to partake in some form of advanced care planning, e.g. write an ADRT or appoint a welfare attorney.

Best interests

In England and Wales, decisions which are made on behalf of mentally incapacitated persons by health professionals or welfare attorneys must be in their best interests. Best interests are not limited to medical ones but encompass all of a person's interests, including psychological and social ones (Box 13.D). In Scotland, decisions made on behalf of mentally incapacitated persons by health professionals or welfare attorneys must be made for their benefit, taking into account their past and present wishes, as far as they can be ascertained.

Box 13.D Checklist for determining best interests⁷

Involve the person as much as possible in making the decision.

Find out the person's views, including past and present wishes and feelings that have been expressed verbally, in writing (i.e. a statement of wishes and preferences; see Box 13.A, p.408), through behaviour or habits; any religious, cultural or moral beliefs or values which might be likely to influence the decision.

Identify all relevant circumstances which the person who lacks capacity would take into account if they were making the decision themselves.

Avoid discrimination, e.g. age, appearance, condition or behaviour.

Consult and take into account the views of any welfare attorney, IMCA or court-appointed deputy, and as far as possible and where appropriate, anyone previously named by the person, e.g. carers, close family and friends.

If the decision concerns life-sustaining treatment, it must not be motivated by a desire to bring about the person's death.

When everyone appropriate has been consulted, create a 'balance sheet', listing the advantages and disadvantages of the various options, before making a final decision.

Any concerns or disputes regarding ADRTs, LPAs, decisions made by welfare attorneys, IMCAs or determination of best interests should be discussed with a senior colleague or reviewed in a case conference. If necessary, an application can be made to the Court of Protection (England and Wales) for a ruling. In certain circumstances, the

Court of Protection can appoint a deputy to undertake the role of welfare attorney, for example, where a person has ongoing lack of capacity, is undergoing complex medical treatment and is subject to dispute between family members.

CARDIOPULMONARY RESUSCITATION

General principles

National guidelines outline the general principles and provide a decision-making framework (Figure 13.1) on which local cardiopulmonary resuscitation (CPR) policies should be based. Written information about CPR policies should be readily available to patients and those close to them.¹¹

DNAR, Do Not Attempt Cardiopulmonary Resuscitation

When making decisions about CPR:¹¹

- it must be tailored to the patient's individual circumstances
- patients should be given opportunities to talk about CPR, but should not be forced to discuss the subject if they do not want to
- the responsibility rests with the senior clinician involved in the patient's care; this is generally a doctor, but can be a senior nurse in nurse-led services, or can be delegated to another competent person
- if possible, the decision should be agreed with the whole clinical team
- if there is doubt or disagreement about whether CPR would be appropriate, a further senior clinical opinion should be sought.

Elucidating the balance of the likely burdens, risks and benefits of CPR for an individual patient is important (Box 13.E). It must not be assumed that the same decision will be appropriate for all patients with a particular condition. The guidance highlights that a blanket policy which denies CPR to groups of patients, e.g. to all patients in a hospice, is unethical and probably unlawful.

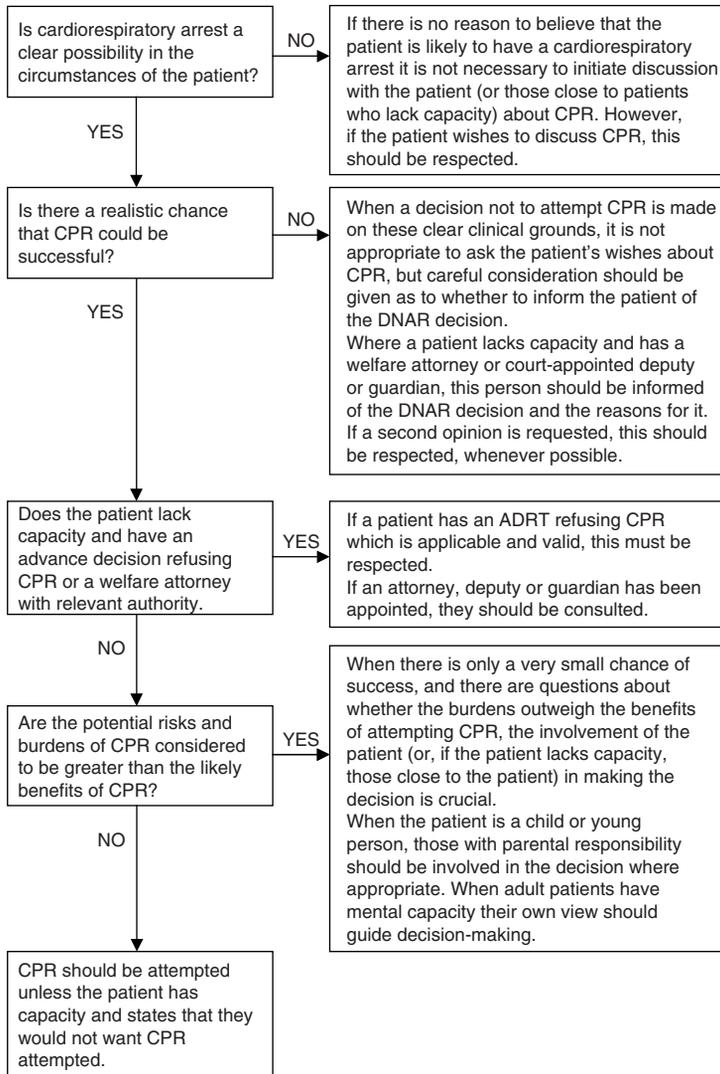
Clinicians should familiarize themselves with their local guidelines. The following points in the BMA guidelines contain information of particular relevance to palliative care.¹¹ Subtle differences exist between England and Wales and other areas of the UK.

Presumption in favour of CPR when there is no DNAR decision

Although the presumption is that health professionals will attempt CPR in the event of cardiorespiratory arrest, the guidelines state that this is clearly inappropriate in patients in the final stages of a terminal illness where death is imminent and unavoidable and CPR would not be successful. Thus, clinicians can make a considered decision not to commence CPR in such circumstances even when no formal DNAR decision has been made.¹¹

Clinical decisions not to attempt CPR

If the clinical team believes that CPR will not restart the heart and maintain breathing, it should not be offered or attempted, and a DNAR decision documented in the clinical notes. CPR is unlikely to be successful in patients with a life-limiting illness in their terminal phase.¹¹



Decisions about CPR are sensitive and complex, and should be undertaken by experienced clinicians and documented carefully. Decisions should be reviewed regularly, at a frequency determined by the clinician in charge, appropriate to the patient's condition and particularly when circumstances change. The patient should be informed of any changes to a previously discussed decision. When there is doubt, advice should be obtained.

Figure 13.1 Decision-making framework in CPR, adapted from BMA guidelines.¹¹

Box 13.E Background information on CPR

CPR is undertaken in an attempt to restore breathing (sometimes with assisted ventilation) and spontaneous circulation in the patient after cardiorespiratory arrest. The benefits of possibly prolonging life must be weighed against the possible burdens.

It is an invasive medical intervention and generally includes chest compressions, attempted defibrillation with electric shocks, injection of drugs and ventilation of the lungs. In some cases spontaneous cardiac function may be restored with prompt use of an electric shock alone.

In hospital, the survival rate after cardiorespiratory arrest and CPR is low. The chances of surviving to discharge are at best 15–20%, and half that outside hospital.

The probability of success depends on factors including the cause of the arrest, how soon after the arrest CPR is started, and the equipment and staff available.

Undesirable effects of CPR include rib or sternal fractures, hepatic or splenic rupture, and possible treatment subsequently in a coronary care or intensive care unit. This may include artificial ventilation and other life support measures.

There is a risk of brain damage and resulting disability, particularly if there is delay between the arrest and the initiation of CPR.

A decision to attempt CPR does not automatically mean that all other intensive treatments and procedures will also be appropriate. Even if the heart has been restarted, prolonged support for multi-organ failure with artificial ventilation or renal dialysis in an intensive care unit may be clinically inappropriate if the patient already had a very poor prognosis.

CPR may be seen as ‘traumatic’, with death occurring in a manner which the patient, family and friends would not have wished.

However, even for patients with a DNAR decision, it could still be appropriate to provide CPR for situations that are easily reversible, e.g. choking, blocked tracheostomy tube. If the patient is at high risk of such events, their management should be discussed with the patient and their wishes ascertained.

Prolonging life is not always beneficial. Even when there is a slight chance that CPR may be successful, it is lawful to withhold CPR on the basis that it would not be in the patient’s best interests, because the burdens outweigh the benefits. This should be done only after discussion with the patient, or those close to patients who lack capacity, and careful consideration of relevant factors including:

- the likely clinical outcome, including the likelihood of successfully restarting the patient’s heart and breathing for a sustained period, and the level of recovery that can realistically be expected after successful CPR
- the patient’s known or likely wishes, based on previously expressed views
- feelings, beliefs and values
- the patient’s human rights, including the right to life and the right to be free from degrading treatment
- the likelihood of the patient experiencing severe unmanageable pain or suffering
- the level of awareness the patient has of their existence and surroundings.

Communicating DNAR decisions to patients

When a DNAR decision has been made because CPR will not be successful, it is not necessary or appropriate to initiate discussion with the patient to explore their wishes regarding CPR, unless the patient expresses a wish to discuss CPR.

The guidelines add that for patients approaching the end of their life, information about interventions which would not be clinically successful is unnecessarily burdensome and of little or no value. In other situations, it is necessary to decide how much information the patient wants to know (or, if the patient lacks capacity, those close to them). If it is decided not to inform the patient, the reason for this should be written in the medical records.

When a patient is informed of a DNAR decision, clinicians should:

- offer as much information as they want in a manner and format which they can understand
- answer questions as honestly as possible
- explain the aims of treatment
- assure them that a DNAR decision applies only to CPR and that all other appropriate treatment and care will continue.

To avoid confusion, it is recommended that DNAR decisions should specify 'do not attempt *cardiopulmonary* resuscitation'.

If a patient without capacity has a welfare attorney whose authority extends to making these clinical decisions, or if there is a court-appointed deputy or guardian with similar authority, this person should be informed of the decision and the reason for it. If a second opinion is requested, this should be arranged, if possible.

Requests for CPR in situations where it would not be successful

Patients, those close to them, a welfare attorney or court-appointed deputy cannot demand a treatment which is clinically inappropriate. The reasons for a DNAR decision should be sensitively explained by a senior clinician. If the decision is still not accepted, a second opinion should be offered. If this fails to resolve a disagreement between the clinical team and a welfare attorney or court-appointed guardian, the Court of Protection can be asked to make a declaration.

Decisions about CPR based on benefits and burdens

When CPR may be successful in restarting the patient's heart and maintaining breathing for a sustained period, the benefits of prolonging life must be weighed against the potential burdens to the patient. This must involve consideration of the patient's broader best interests, including their known or likely wishes. In these circumstances, discussion with the patient about whether CPR should be attempted is an essential part of the decision-making process.

A patient should be informed sensitively of the facts, including the risks and possible undesirable effects, to enable them to make an informed decision (see Box 13.E, p.416). When the patient lacks capacity, the clinical team and those close to the patient must decide what are the patient's best interests (see Box 13.D, p.413). If feasible, it should be explained to the patient that they are informing the decision-making process but that they have no legal authority to make the final decision, which rests with the senior clinician. If the patient has nobody to speak on their behalf, an IMCA should be consulted.

Refusal of CPR

A patient with capacity has the right to refuse any medical treatment, even if that refusal will result in their death. The decision must be respected, but it is necessary to ensure that the patient's decision is based on accurate information and not on any misunderstanding.

Communicating the decision

The clinician making the decision must document it clearly in the medical records. They (or a designated deputy) must also communicate the decision to other relevant health professionals in both primary and secondary care, particularly when the patient is transferred within or between establishments. National guidance to ambulance crews advise that CPR should be attempted, unless:

- there is a formal DNAR decision, or a valid and applicable ADRT
- the patient is known to be terminally ill and is being transferred to a palliative care facility (unless specific instructions to attempt CPR have been received).

Ambulance transfers will thus require the provision of appropriate information/documentation.

Allow Natural Death

It has been suggested that, in palliative care, the DNAR status should be substituted by 'Allow Natural Death' (AND) because:^{12,13}

- it is a positive rather than a negative statement
- there is a clear acknowledgement by all concerned that the patient is imminently dying
- it implies that everything being done for the patient is solely with the aim of making dying as comfortable as possible, but not prolonging it
- it means that artificial nutrition is likely to be discontinued, IV hydration scaled down (or not started), antibacterials strictly limited to symptom relief, and ventilators not considered.

One way of achieving this is to introduce the Liverpool Pathway for Care of the Dying (see p.424).

CONTINUITY OF CARE

Although a health professional may feel powerless in the face of rapidly approaching death, patients are generally more realistic. They know you cannot perform a miracle and time is limited. However, once the patient is faced with the fact that death is inevitable and imminent, support and companionship are of paramount importance.¹⁴ Thus, despite possibly having nothing new to offer, it is important to:

- continue to visit
- quietly indicate that 'At this stage the important thing is to keep you as comfortable as possible'
- simplify medication: 'Now that your husband is not so well, he can probably manage without some of his tablets'
- anticipate a time when the patient will not be able to swallow, and supply drug formulations which can be given SL, PR or SC

- continue to inform the family of the changing situation:
 - ▷ 'He's very weak now, but could still live for several days'
 - ▷ 'Although he seems better today, he's still very weak. He could quickly deteriorate and die within a few days'
- control agitation even if it results in sedation
- listen to the nurses.

Remember: existing symptoms may worsen or new symptoms arise (see p.424). These will necessitate further changes in management, including new measures to ensure the comfort of the patient. Given professional diligence, a peaceful death is generally possible.¹⁵

WITHHOLDING AND WITHDRAWING LIFE-PROLONGING MEDICAL TREATMENT

In addition to CPR (see p.414), other medical interventions prolong life and, in some circumstances, allow time for recovery when organ or system failure would otherwise result in death, e.g. renal dialysis, artificial nutrition, hydration and ventilation. However, none can reverse a chronic progressive disease process.

In the UK, guidance is available from professional organizations on how to reach a decision about withholding or withdrawing a life-prolonging treatment.^{16,17} Guidance from the GMC is currently being revised and updated. As with CPR, similar principles and factors must be taken into account when making a decision.

Those of particular relevance to palliative care include:

- the primary goal of medical treatment is to benefit the patient by restoring or maintaining the patient's health as far as is possible, maximizing benefit and minimizing harm; in the dying patient symptom management and comfort are paramount
- there is no obligation to provide a treatment that cannot achieve this goal and the treatment should, ethically and legally, be withheld or withdrawn
- good quality care and relief of symptoms should continue
- an act where the doctor's intention is to bring about a patient's death is unlawful.

Effective and sensitive communication with all concerned is vital to ensure understanding that:

- it is the underlying disease which is bringing about the death of the patient, not the withholding or withdrawing of a particular treatment
- all care which will enhance the comfort of the patient will continue.

ARTIFICIAL NUTRITION AND HYDRATION

The provision of artificial nutrition or hydration is regarded as a medical treatment and is not part of basic care.^{18,19} In the terminal stage, food and fluid intake generally diminish. It is at this time that a relative may ask about the possibility of nutrition or hydration by artificial means.¹⁸

Artificial nutrition has known risks, and there is no evidence of net benefit to dying patients.²⁰ This should be explained sensitively to those concerned. Generally, in

UK palliative care practice, this view also extends to artificial hydration. Further, fluid depletion in the dying patient may be beneficial as a result of:

- reduced pulmonary, salivary and GI secretions with a consequent reduction in cough, 'death rattle', and vomiting, and less need for interventions such as oropharyngeal suctioning
- reduced urinary output, and thus less incontinence and less need for an indwelling urinary catheter
- less oedema and ascites with fewer associated symptoms.

Several studies suggest that thirst correlates poorly with fluid intake,^{21–25} and dry mouth can generally be relieved by conscientious mouth care and small amounts of fluid, e.g. 1–2mL of water delivered by pipette or syringe into the dependent side of the mouth every 30–60min. Small ice chips can also be used.²⁶

IV hydration may have negative psychosocial effects in that the infusion acts as a barrier between the patient and the family. It is more difficult to embrace a spouse who is attached to a plastic tube, and doctors and nurses tend to become diverted from the more human aspects of care to the control of fluid balance and electrolytes.²⁷

Opinions differ about fluid administration.^{28–33} This reflects the heterogeneity of attitudes of clinicians, ethicists, patients, those close to them and local practice. Proponents of fluid therapy argue hydration decreases the risk of symptoms such as:

- delirium, or opioid toxicity, especially if renal failure develops
- sedation and myoclonus
- constipation, pressure sores and dry mouth.^{34–37}

However, in two RCTs, hydration did not reduce the incidence of delirium.^{22,36} Further, dry mouth is a common problem in cancer patients, and is related to several factors other than dehydration, e.g. drugs, oxygen therapy, and mouth breathing.^{25,38–40} In most patients, artificial hydration alone is unlikely to resolve dry mouth.²³

A systematic review of the literature on fluid status in the dying concluded that there was insufficient evidence to draw firm conclusions about either the beneficial or harmful effects of fluid administration in dying patients.⁴¹ Such conflicting data emphasize the need for individual evaluation and review in keeping with professional guidance. When there is uncertainty about the potential benefit of artificial hydration, a time-limited trial with specific goals could be undertaken, for example, give parenteral fluid for 48h, and see if the patient's delirium improves.^{11,17}

VOLUNTARY REFUSAL OF FOOD AND FLUID

Most patients with advanced life-limiting disease sooner or later become anorexic (see p.77). Food intake becomes less, often the result of cachexia, or simply associated with extreme weakness and disinterest. Particularly when a patient is deteriorating on a daily basis, it is important to prevent 'forced feeding' by the family or other carers.

However, sometimes a patient voluntarily and deliberately stops taking both food and fluid with the primary intention of hastening death.^{42–44} Generally, patients pursue this option for one or more of the following closely-related reasons:

- feel ready to die
- consider continued existence pointless
- quality of life poor
- a desire to be in control.

It is necessary to explore with a patient the reasons for their decision. Occasionally it is because of misunderstandings which, if resolved, results in a change of mind. However, if a patient with capacity confirms their intention, it is a legal obligation to respect this decision.⁴⁵

Discussion between both doctor and nurse on the one hand and the family on the other is clearly also important. If not already discussed between themselves, the family is likely to need time to work through their immediate distressed reaction before they are willing to ‘come on side’. Thus, for example, suggest that everybody thinks about it for 2 days and then discusses the matter again. This may prevent a lot of distress within the family and reduce the possibility of the family putting pressure on the patient not to go ahead.

In one report of >100 patients who stuck with their decision to refuse food and fluid, 85% died within 2 weeks. Almost all died peacefully (60% had cancer; the rest mainly neurological or cardiorespiratory disease).⁴⁴

The patient should be ‘given permission’ to change their mind at any time, and to start taking fluid and/or food again without loss of face. In practice, only a few do this. Reasons for a change of mind include:

- family pressure
- hunger discomfort
- lifting of depression
- alleviation of concerns.⁴⁴

‘GIVE DEATH A CHANCE’

In patients who are close to death it is often appropriate to ‘give death a chance’. All patients must die eventually; ultimately nature will take its course. In this respect, the skill is to decide when the burdens of any life-sustaining treatments are likely to outweigh any benefits, and thus when to allow death to occur without further impediment. Treatments which provide comfort and symptom relief should be continued.

For example, antibacterials are generally appropriate for the patient with advanced cancer who develops a chest infection while still relatively active and independent. However, in those who have become bedbound as a result of general progressive deterioration, and seem close to death, pneumonia should still be allowed to be ‘the old person’s friend’. In such circumstances it is generally appropriate *not* to prescribe antibacterials (see p.4).

If it is difficult to make a decision, the ‘2-day rule’ should be invoked, namely, if after 2–3 days of straightforward symptom management the patient is clearly holding his own, prescribe an antibacterial but, if the patient is clearly much worse, do not.

If feasible, such decisions should be taken with the patient. If the patient lacks capacity, seek the patient's views from an ADRT, welfare attorney with appropriate powers, or those close to the patient.

On the other hand, not all terminally ill patients who develop a chest infection die from it. Some patients progress only to a 'grumbling pneumonia' but no further. A continuing wet cough may cause much distress and, possibly, loss of sleep. In circumstances when the patient is neither better nor worse after 3–4 days, an antibacterial may well be indicated for symptom relief.

DYING AT HOME

Dying in comfort at home is possible, but generally requires:

- family or community support for the patient
- someone to be present to care for the patient
- empowerment of the family or community member, e.g. by providing information, support and access to help
- ready availability of professional support, e.g. visits from the primary healthcare or palliative care team, telephone advice
- access to appropriate medications
- access to appropriate practical aids, e.g. wheelchair, commode, pressure relieving mattress
- access to inpatient care if needed, e.g. for a period of time to manage symptoms.

Advance planning is vital. In the UK the Gold Standards Framework is a nationally recommended tool to support high quality palliative and terminal care in primary care.^{46–48} This facilitates:

- identification of patients approaching the end of life in need of palliative care
- evaluation of their care needs and preferences
- planning of their care
- communication across all relevant agencies throughout.

The Framework focuses on optimizing continuity of care, teamwork, advanced planning (including 'out of hours'), symptom management and patient carer and staff support. It can be used for any life-limiting disease and in care homes.

Planning for the last days will require an understanding by the patient and the family of what might happen and of available resources. Open and honest communication and regular support are vital. Ideally, this will include routine home visits from the primary health ± palliative care teams as well as being available for any emergency. If possible, indicate when the next home visit will be:

'I'll call in again next Wednesday, possibly between 12noon and 3pm. If I can't, I'll phone and let you know.'

Generally, the patient and family will feel better supported by this approach compared with one where the professional offers a visit at any time 'if you have any problems'.

Most situations are manageable in the home, although even carefully made plans may turn out to be inadequate. Particularly towards the end, the situation can change rapidly. Common problems, notably delirium (see p.207) and death rattle (see p.427), should be discussed with the relatives so as to prepare them psychologically and practically.

Generally, a point is reached when the patient will no longer be able to swallow reliably. The continuing administration of essential medicines needs to be anticipated and alternatives put in place. These include:

- intermittent SC bolus or by CSCI (this is the norm in the UK)
- sublingual or buccal administration, e.g. depositing a liquid concentrate into the dependent cheek of the moribund patient
- the rectal route, in patients not troubled by diarrhoea.

Ideally, a supply of drugs in injectable or suppository form should be prescribed and made available in the home in case they are needed, either for terminal symptoms or in the event of an emergency such as a seizure or massive haemorrhage.⁴⁹ Some services/associations promote the use of kits containing small quantities of a range of drugs for emergency use, e.g. 'just in case' kit, MND 'breathing space kit'.^{50,51} Care of the dying pathways, e.g. Liverpool Care Pathway (LCP), also prompt anticipatory prescribing.⁵²

Despite earlier expressing a wish to be cared for at home, many patients and families change their minds as the disease progresses. In a group of patients receiving palliative care at home in the UK, preference for home care eventually fell to about 1/2.⁵³ Ultimately:

- about 1/3 died at home
- about 1/3 were admitted 1–3 days before death
- about 1/3 were inpatients for longer periods.

It remains to be seen if advance care plans, e.g. Preferred Place of Care, will successfully focus professional efforts and resources to allow more patients to die at home.

DIAGNOSING IMMINENT DEATH

Estimating prognosis is difficult, even when death may be fairly imminent.^{54–57} A number of variables have been associated with decreased survival in patients with cancer (Box 13.F).^{56,58–60}

Box 13.F Factors associated with decreased survival in cancer patients⁵⁸

Clinical features	Biological factors	Other
Anorexia	Anaemia	Co-morbidity
Ascites	Raised CRP	Single status
Breathlessness	Hypo-albuminaemia	Older age
Delirium	Raised LDH	Poor performance status
Dry mouth	Leucocytosis	Metastatic disease
Dysphagia	Lymphocytopenia	Primary site of cancer, e.g.
Fever	Proteinuria	SCLC, ovary, pancreas,
Nausea	Hypercalcaemia	glioblastoma
Oedema	Hyponatraemia	
Pain		
Tachycardia		
Tiredness		
Weight loss		

Using such variables, attempts have been made to produce a reliable prognostic index. However, even the best of the currently available scales, the PaP score, provides only general guidance based on probability. Thus, patients are categorized as having a probability of >70%, 30–70% or <30% of surviving 30 days.⁵⁸

Fortunately, in practice, the following ‘rule’ is generally an accurate enough guide to prognosis in advanced cancer. If a patient is deteriorating (without an obvious reversible cause):

- month by month, they probably have several months to live
- week by week, they probably have only weeks to live
- day by day, they probably have only days to live.

Further, in the absence of a reversible cause for the deterioration, the following features collectively indicate that a patient almost certainly has only days to live:

- physically wasted and profoundly weak → bedbound
- drowsy for much of the day → coma
- very limited attention span → disoriented (→ delirium)
- unable to take tablets or has great difficulty swallowing them
- little or no oral intake of food and fluid.^{23,61}

LIVERPOOL CARE PATHWAY FOR THE DYING PATIENT

The Liverpool Care Pathway (LCP) for the dying patient is a nationally recommended tool to support high-quality terminal care.⁴⁶ Although initially for patients dying from cancer in hospital, it is increasingly used in other settings, and for patients dying from other life-limiting diseases.⁵²

At the most basic level, the LCP is a way of acknowledging that death is almost certainly imminent, and that it is now necessary and appropriate to focus primarily (but not necessarily exclusively) on comfort measures.^{62–64} A standard protocol is used, which becomes a part of the patient’s clinical records. This includes a checklist of things to be considered, e.g.:

- *simplifying medication*: particularly stopping long-term prophylactic medication, e.g. statins, warfarin, antihypertensives, oral hypoglycaemics
- *anticipatory prescribing*: using the guidelines supplied to prescribe p.r.n. medication should the patient develop symptoms such as pain, breathlessness, vomiting, delirium, and ensuring that generally drugs are prescribed both PO and SC/IV
- *IV hydration*: is it still appropriate? Can it be stopped?
- *communication*: discuss the changing situation with the patient’s family.

Similar care pathways have been used elsewhere, e.g. in the USA.^{65–67}

SYMPTOM RELIEF

Symptom relief in the last days of a patient’s life is generally a continuation of what is already being done. However, previously well-managed symptoms can recur or new symptoms develop.^{15,68–71} The same principles of management apply as before (see p.6). However, because time is short, there is a greater need for urgency on the part of the caring team.

General considerations

When death is close, medication should be simplified. Those providing no symptomatic benefit can be discontinued. In the last few days it is often appropriate to discontinue laxatives and antidepressants.

In patients with insulin-dependent diabetes mellitus, the dose of insulin should be reduced as oral intake diminishes and the regimen simplified. However, a decision to stop insulin completely should normally be taken only after discussion with the patient (if still has capacity) and the family. It is generally appropriate to stop insulin injections completely when the patient has become irreversibly unconscious as part of the dying process, and not because of hypoglycaemia or diabetic keto-acidosis, and when all other life-prolonging treatments have been stopped.⁷²

If it is felt strongly that the insulin should be continued, a simple regimen of once daily long-acting, or b.d. intermediate-acting insulin can be used, with the minimum of routine monitoring, i.e. once daily.⁷³

Similarly, in the last days, some nursing procedures which are normally regarded as essential may be discontinued. For example, care of pressure areas may cause a moribund patient to become distressed. If so, such care should be reduced or stopped.

Incontinence and retention of urine

In patients close to death, incontinence is generally best managed by an indwelling urinary catheter.⁷⁴ This provides maximum comfort with minimum ongoing disturbance.

A loaded rectum may well be the cause of retention in dying patients. This may necessitate treatment with a laxative suppository, an enema, or digital evacuation of the rectum.

Stopping dexamethasone in patients with intracranial malignancy

See p.285.

Pain

Also see Chapter 2.

About 90% of patients dying from cancer require a strong opioid. Data from several specialist palliative care centres, expressed in oral morphine equivalents, indicate that:

- the median dose in the last 24h of life is 50–150mg
- individual dose requirements vary widely, e.g. 20mg–2g/24h.^{75–77}

At one centre, over the course of an admission until death, the dose was increased in about 2/3, decreased in about 1/3 and unchanged in a few. The overall median increase in daily dose was about 20mg (a median increase of 50%).⁷⁷ Generally, a single increase in the dose of the strong opioid is all that is necessary.⁷¹

However, patients in specialist palliative care units often have more challenging symptoms, and may have received opioids for some time. In non-specialist settings, the proportion of patients and the dose required are likely to be correspondingly less. Thus, in a hospital survey:

- only 2/3 of patients dying from all causes required a strong opioid
- the median dose in the last 24h of life, expressed in oral morphine equivalents, was 30mg, ranging from 7.5–90mg.^{77,78}

Generally, pain will not be troublesome at the very end if relief has previously been good. However, even when the patient is close to death, careful evaluation is still necessary. Dying patients may call out to check whether someone is with them or when they are aware that they are unattended. These cries may be misinterpreted as pain, and be a source of concern to family and carers.

Some patients show signs of discomfort when being turned in bed, even when apparently deeply unconscious, and may moan or cry out. Although this may be pain caused by joint stiffness for example, it could instead be an 'alarm response' to an unexpected disturbance. Disturbance distress is likely to be reduced by warning a patient (even when unconscious) of any intended interventions by describing the procedure to be undertaken, and by gentle slow handling.

Even so, new pains are relatively common in the last days.⁷¹ Causes include:

- painful bedsores (consider the local application of a local anaesthetic gel \pm topical morphine)
- distended bladder (relieve by catheterization)
- NSAID withdrawal (restart by a non-oral route).

Most patients experience difficulty in swallowing PO medication in the last days of life. Continuation of a regular strong opioid by an alternative route is the norm in this circumstance. Abrupt discontinuation risks a return of pain \pm withdrawal symptoms. e.g. restlessness, diarrhoea.

Patients who have been taking an NSAID for metastatic bone pain may suffer a recurrence of pain after 12–24h if the NSAID is discontinued when swallowing tablets is no longer possible. Some NSAIDs are available in liquid, suppository or injection formulations, allowing them to be administered in this circumstance.

Severe breathlessness in the last days of life

Also see Chapter 4.

Patients often fear suffocating to death and a positive approach to the patient, their family and colleagues about the relief of terminal breathlessness is important:

- no patient should die with distressing breathlessness
- failure to relieve terminal breathlessness is a failure to utilize drug treatment correctly.

Because of the distress, inability to sleep and exhaustion, patients and their carers generally accept that drug-related drowsiness may need to be the price paid for greater comfort. However, unless there is overwhelming distress, deep sedation (reduced awareness/consciousness) is not the initial step. Some patients become mentally brighter when anxiety is reduced by light sedation, and there is an associated improvement in their breathlessness.

Even so, because increasing drowsiness also generally reflects a deteriorating clinical condition, it is important to stress the gravity of the situation and the aim of treatment to the relatives.

Drug treatment typically comprises:⁷⁹

- parenteral administration of an opioid and a sedative-anxiolytic, e.g. morphine and midazolam or lorazepam by CSCI and p.r.n.
- haloperidol if the patient develops an agitated delirium (may be aggravated by a benzodiazepine (see Box 13.H, p.433)).

Death rattle

Death rattle is a term used to describe noisy rattling breathing which occurs in about 50% of patients near the end of life.⁸⁰ It is caused by fluid pooling in the hypopharynx, and arises from one or more sources:

- saliva (most common)
- respiratory tract infection
- pulmonary oedema
- gastric reflux.

Rattling breathing can also occur in patients with a tracheostomy and infection. Because the patient is generally semiconscious or unconscious, drug treatment for death rattle is mainly for the benefit of relatives, other patients and staff.

Non-drug treatment

- ease the family's distress by explaining that the semiconscious/unconscious patient is not distressed by the rattle^{80,81}
- position the patient semiprone to encourage postural drainage; but upright or semirecumbent if the cause is pulmonary oedema or gastric reflux
- oropharyngeal suction but, because it is distressing to many moribund patients, generally reserve for unconscious patients.

Drug treatment

For more information, see *PCF3*.

Saliva

An antimuscarinic is the drug of choice. This needs to be given promptly because it does not affect existing pharyngeal secretions. Such drugs are probably most effective for rattle associated with the pooling of saliva in the pharynx and least effective for rattle caused by bronchial secretions (as a result of infection or oedema) or related to the reflux of gastric contents.

In the UK, in this circumstance, antimuscarinics are generally given SC (Table 13.1). However, in some countries, the SL route is preferred. For example, glycopyrronium 0.01% oral solution prepared locally from glycopyrronium powder, 1 mL (100microgram) SL q6h p.r.n.

Table 13.1 Antimuscarinic antisecretory drugs for death rattle: typical SC doses

<i>Drug</i>	<i>Stat SC dose</i>	<i>CSCI dose/24h</i>
Glycopyrronium	200microgram	600–1,200microgram
Hyoscine <i>hydrobromide</i>	400microgram	1,200–2,400microgram
Hyoscine <i>butylbromide</i>	20mg	20–120mg

Note:

- by injection, the efficacy of the different drugs is broadly similar; the rattle is reduced in 1/2–2/3 of patients⁸⁰
- the onset of action of glycopyrronium is slower compared with hyoscine *hydrobromide*⁸²

- hyoscine *hydrobromide* crosses the blood-brain barrier and possesses anti-emetic and sedative properties,⁸² but there is also a risk of developing or exacerbating delirium
- atropine also dries secretions and, like hyoscine, it crosses the blood-brain barrier but it tends to stimulate rather than sedate, and could increase the need for midazolam or haloperidol.

Respiratory tract infection

Occasionally it is appropriate to prescribe an antibacterial in an imminently dying patient if death rattle is caused by profuse purulent sputum associated with an underlying chest infection:

- e.g. ceftriaxone, mix 1g ampoule with 2.1mL lidocaine 1% (total volume 2.6–2.8mL), and give 250mg–1g SC/IM once daily
- some centres use larger volumes of lidocaine 1% (up to 4mL) and administer a divided dose at separate SC/IM sites once daily or b.d.

Pulmonary oedema

Consider furosemide 20–40mg SC/IM/IV q2h p.r.n. Beware precipitating urinary retention.

Gastric reflux

Consider metoclopramide 20mg SC/IV q3h p.r.n., but do not use with an antimuscarinic because the latter blocks the prokinetic effect of the former.

Rattling breathing causing distress to a patient

In a semiconscious patient, if rattling breathing is associated with breathlessness, supplement the above with an opioid (e.g. morphine) ± an anxiolytic sedative (e.g. midazolam).

Noisy tachypnoea in the moribund

Noisy tachypnoea in the moribund is distressing for the family and other patients, even though the patient is not aware. It represents a desperate last attempt by a patient's body to respond to irreversible terminal respiratory failure ± airway obstruction.

Consider alleviating the noise by reducing the depth and rate of respiration to 10–15/min with diamorphine/morphine, best initially titrated IV to identify an effective dose. This may be double, or even treble, the previously satisfactory analgesic dose.

When there is associated heaving of the shoulders and chest, midazolam should be given as well, e.g. 5–10mg IV. The diamorphine/morphine ± midazolam can be repeated IV/SC hourly as needed.

Severe acute stridor as a terminal event

This may be caused by haemorrhage into a tumour pressing on the trachea. Administer diazepam/midazolam IV until the patient is asleep (5–20mg). If IV administration is not possible, alternatives include midazolam 10mg IM or diazepam solution 10mg PR.

Myoclonus

Multifocal myoclonus is a central pre-epileptiform phenomenon (see p.279). It is exacerbated by hypoglycaemia and, in the moribund, may be caused or exacerbated by dopamine antagonists (antipsychotics, metoclopramide) and opioids (particularly

at higher doses) or as a result of drug withdrawal (benzodiazepines, barbiturates, anti-epileptics, alcohol).

It is seen in cancer patients dying with encephalopathy associated with organ failure, e.g. renal failure, hepatic failure. It occurs with cerebral oedema and hypoxia, and also with hyponatraemia. Treat with a benzodiazepine (see p.279).

Generalized convulsive seizures

See p.279.

Delirium

Delirium develops in 80–90% of dying cancer patients at some stage during the last week of life.^{83,84} Delirium is generally best treated with haloperidol ± midazolam given p.r.n. or by CSCI in an individually optimized dose. If delirium is not controlled on haloperidol 10–15mg/24h, a more sedating antipsychotic should be given instead, e.g. SC levomepromazine (see Box 13.H, p.433).

INTOLERABLE SUFFERING

*'A realistic goal in palliative care is not to eliminate suffering but rather to alleviate it.'*⁸⁵

Palliative care professionals have to cope with the fact that it is not always possible to achieve 'a good death' for our patients (Box 13.G). Consider the patient with an eroded malodorous face or perineum.⁸⁶ There are times when a person's distress (or that of their family) seems unbearable.

Box 13.G Where was God?^a

Where was God when Brian shat from his mouth?
 Where was God when Elsie's belly eroded
 And liquid faeces rolled over her loins, soiled her sacred pubis
 And soaked the sheets of her bed?
 Where was God when spinster Jill couldn't fart or crap,
 Blew up like the expectant mum we believe she never was
 And cursed us all, supposedly behind our backs,
 Hurling insults and expletives through the side-room door
 On our departures, destroying our All
 And filling other patients with fear?
 I simply don't know where God was.
 All I know is that God was there.

a. by John Chambers, Specialist in Palliative Medicine.

Indeed, a doctor who has never been tempted to deliberately kill a distressed dying patient probably has had limited clinical experience or is not able to empathize with those who suffer. Further, it could be claimed that a doctor who leaves a

patient to suffer intolerably is morally more reprehensible than the doctor who performs euthanasia. This does not necessarily mean that euthanasia (intentional drug-induced death) should be a legally enshrined 'human right' for dying patients.^{87,88} However, it does mean that we must heed the emancipation principle of palliative care:

'No efforts should be spared to free dying persons from intolerable suffering which invades and dominates their consciousness, and leaves no space for other things'.⁸⁹

This principle stems from society's general commission to health professionals to relieve suffering. And occasionally the only possible way of easing the person's intractable and overwhelming distress is to decrease a patient's awareness deliberately, even to the point of drug-induced coma (see below).⁹⁰⁻⁹²

PALLIATIVE SEDATION

Palliative sedation is a term used to describe the intentional drug-induced reduction of awareness/consciousness in a patient who is imminently and irreversibly dying in order to relieve an otherwise intolerable refractory symptom.^{20,93,94} The term implies the use of appropriate sedative drugs titrated carefully to the cessation of symptoms, not the cessation of life (Table 13.2).

Table 13.2 Comparison of palliative sedation and euthanasia^a

	<i>Palliative sedation</i>	<i>Euthanasia</i>
Intention	Relief by reducing awareness	Relief by killing the patient
Method	Dose titration	Standard doses
Drugs	Sedative	Lethal cocktail
Proportionate	Yes	No
Criterion of success	Relief of distress	Immediate death

a. but if not imminently dying, continuous deep sedation = *slow euthanasia* unless time-limited + hydration. On the other hand, if death is imminent, artificial hydration is irrelevant, and is best discouraged.

Palliative sedation is an extreme treatment, for 'when all else has failed'. Although the incidence appears to vary widely, particularly from country to country,^{90,95} some of the variation relates to imprecise definition.^{20,96} In the Netherlands, a recent national study suggested that 7% of all deaths in 2005 were preceded by palliative sedation.⁹⁷ In contrast, in a palliative care centre in Belgium, the incidence fell from 7% in 1999 to 2.5% in 2005.⁹⁴ The decrease was attributed to an improved standard of palliative care and a team approach to decision-making.

Regrettably, sometimes palliative sedation is implemented with insufficient justification.⁹⁸ However, local guidelines should help to minimize this.^{20,99}

Indications for palliative sedation

The commonest indications for palliative sedation are:

- agitated delirium
- breathlessness
- pain.^{20,90}

In Japan, 1% of palliative care patients are deeply sedated primarily or solely because of persistent intolerable existential distress (see p.432).¹⁰⁰

Prevent the preventable

As always, prevention is better than cure. Because of present psychological turmoil, or past repressed bad experiences, the following are possibly at higher risk of developing a severe agitated delirium:

- adolescents and young adults
- parents with young children
- Armed Forces veterans
- concentration camp survivors
- victims of abuse or torture
- those who continue to deny that they are dying despite unremitting deterioration.

Ideally, patients in these categories (and anyone else manifesting severe emotional/existential distress) should be evaluated by a clinical psychologist, psychotherapist, or liaison psychiatrist, and continuing support provided if possible.

Further, the early recognition and prompt treatment of delirium may prevent matters from escalating out of control (see p.207).

Relieve physical symptoms

Palliative sedation is not an alternative to the provision of high quality palliative care. All feasible efforts must be made to relieve physical symptoms, e.g. pain or breathlessness, with appropriate non-drug and drug treatments, and advice sought from colleagues before concluding that a symptom is 'refractory'.

Choice of sedative drugs in the imminently dying

Note:

- mild delirium is not always easy to detect
- an antipsychotic is essential if a patient manifests features suggestive of delirium
- the use of a benzodiazepine alone may precipitate or exacerbate delirium¹⁰¹
- if in doubt, treat an agitated imminently dying patient with both an antipsychotic and midazolam.

Good practice dictates a step-by-step approach (Figure 13.2 and Box 13.H). Thus, sedation is not 'all or none' but a continuum, with p.r.n. sedation at one end and continuous deep sedation at the other.

Abrupt deep sedation is rarely necessary, e.g. sudden massive arterial haemorrhage. Particularly for existential distress, *respice* deep sedation for a few hours (up to 1–2 days in some centres) is an important intermediate step.

In the imminently dying, it is uncommon to lighten the depth of the sedation once the patient is settled. However, at one centre, after the patient's distress has been

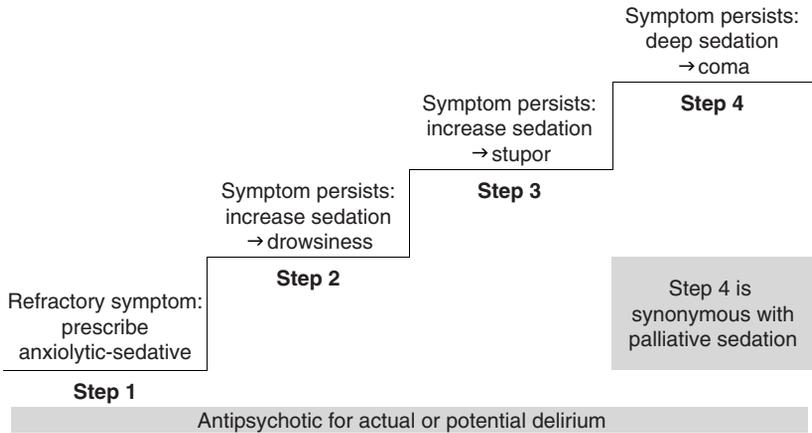


Figure 13.2 Progressive and proportionate treatment for an intolerable refractory symptom in the imminently dying.

relieved, medication is scaled down so that the patient is physically and mentally comfortable (albeit drowsy/sleeping for most/all of the time) but can be roused for short periods to permit meaningful communication: ‘our target in sedation is calming and comfort without lowering the level of consciousness deep enough to lose communication.’⁹²

REFRACTORY EXISTENTIAL DISTRESS

Suffering has been defined as a state of severe distress caused by events which threaten a person’s sense of integrity or intactness.¹⁰³ When defined in this way, it becomes self-evident that suffering can occur in the absence of any physical symptoms whatsoever. Bystanders may also suffer when obliged to witness helplessly someone else’s pain, particularly that of a loved one. Indeed, helplessness in itself is a potent source of suffering.¹⁰⁴

There are occasions when a dying patient may be physically comfortable but mentally severely distressed. The question then arises: is it legitimate to escalate to continuous deep sedation in someone who is experiencing intolerable existential suffering?

Logically the answer is ‘yes’, but following through the logic can be profoundly disturbing to health professionals. This is particularly so when, although ‘terminally ill’, the person does not completely fit the pen portrait of an imminently dying patient (see p.427):

- what if the patient’s prognosis is 2–3 weeks/months, rather than 2–3 days?
- can we be sure that the existential suffering is refractory?
- should artificial hydration and nutrition be provided?

Box 13.H Drugs for sedation in the imminently dying

For more information, see *PCF3*.

First-line drugs*Midazolam*

- start with 5–10mg stat and q1h p.r.n.
- if necessary, increase progressively to 20mg SC/IV stat
- maintain with CSCI/CIVI 10–60mg/24h.

Although some centres, if necessary, titrate the dose of midazolam up to 200mg/24h,⁹² it is probably better to add in an antipsychotic if midazolam 30–40mg/24h is inadequate to settle the patient.

Haloperidol

- start with 5–10mg q1h p.r.n. (2.5–5mg q4h in the elderly)
- if necessary, increase progressively to 10mg IV stat
- maintain with CSCI/CIVI 10–20mg/24h.

Second-line drugs*Levomepromazine*

Generally given only if it is intended to reduce the patient's level of consciousness:

- start with 25mg SC stat and q1h p.r.n. (12.5mg in the elderly)
- if necessary, titrate dose according to response
- maintain with 50–300mg/24h CSCI.

Although high-dose levomepromazine ($\geq 100\text{mg}/24\text{h}$) is generally best given by CSCI, smaller doses can be conveniently given as an SC bolus at bedtime or b.d., and p.r.n.

If levomepromazine is not available, use chlorpromazine; doses generally need to be higher, e.g. double those of levomepromazine.

Third-line drugs*Phenobarbital*

Because of the irritant nature of the injection, stat doses are generally given IM/IV, but can be followed by CSCI:

- start with 100–200mg IM/IV stat and q1h–q2h p.r.n.
- maintain with 600–1,200mg/24h CSCI (dilute with WFI, e.g. 10mL per 200mg ampoule; if necessary, changing the syringe every 8–12h)
- if necessary, increase the dose to 2,400mg/24h.

Propofol

Some centres use propofol instead of phenobarbital. This is a specialist only treatment, and necessitates an IVI and appropriate variable-rate syringe driver.¹⁰²

Experienced professional palliative carers will all have had patients seemingly trapped in refractory existential suffering but who over time (2–3 months, or even longer) have worked through to either a neutral acquiescence in, or a more positive acceptance of, their predicament.^{105,106}

In a report from palliative care services throughout Japan, 1% of patients (about 90/9,000) were treated by continuous deep sedation for refractory existential distress.¹⁰⁰ The reasons given were:

- meaninglessness/worthlessness
- burden on others/dependency
- death anxiety
- the patient's need to remain in control
- lack of social support/isolation.

Prerequisites for continuous deep sedation for existential distress

Although continuous deep sedation for refractory existential distress is disturbing to most health professionals, there will be occasions when doctors and/or nurses will find themselves being inexorably drawn towards it.¹⁰⁷ Thus clear criteria for its application should be established:

- the designation of symptoms as refractory must be done only after repeated skilled psychological evaluation
- the decision must be made by the team because individual feelings or burn-out can bias decision-making
- sedate initially on a respite (intermittent) basis.¹⁰⁸

Respite deep sedation should also be approached on a step-by-step basis. For example, initially offer the patient an afternoon sleep for several hours, in addition to 7–8h at night, by prescribing an after-lunch 'night' sedative:

'Because of the effort needed to cope with an ongoing illness, I can see that both your physical and psychological stamina are at a low point. And that 16 continuous hours awake each day is too much for your present resources. What I suggest we do is to give you a night sedative after lunch each day, so that you can sleep for at least 2–3 hours in the afternoons. This will break up the long 16-hour stretch, and that will be helpful...'

This may be enough. But sometimes, as a further step, a more prolonged period of deep sedation for, say, 48h becomes necessary. In the report from Japan, >90% progressed to continuous deep sedation only after periods of respite deep sedation.¹⁰⁰ The following data are also noteworthy:

- >50% were stated to be depressed (not all of whom were prescribed antidepressants)
- only 35% had specialist psychological evaluation
- <60% received specialist psychiatric, psychological or religious support.¹⁰⁰

Survival after the initiation of continuous deep sedation for refractory existential distress varied widely:

- about 2/3 = < 1 week
- about 1/3 = > 1 week, < 1 month
- only 1 patient > 1 month.¹⁰⁰

Although not stated, some, if not all, patients would have received IV hydration throughout this time.

It is important that health professionals continue to feel uncomfortable about continuous deep sedation for refractory existential distress.^{94,109} The following words from the 1950s are still relevant:

'Patients tend to be sedated when the carers have reached the limit of their resources and are no longer able to stand the patient's problems without anxiety, impatience, guilt, anger or despair. Perhaps many of the desperate treatments in medicine can be justified by expediency, but history has an awkward habit of judging some as fashions, more helpful to the therapist than to the patient.'¹¹⁰

WHEN ALL HAS BEEN SAID AND DONE

Palliative care developed as a reaction to the attitude, spoken or unspoken, that 'There's nothing more we can do for you', with the inevitable consequence for the patient and family of a sense of abandonment, hopelessness and despair. It was stressed that this is never true; there is always something which can be done. Even so, there are times when the doctor or nurse feels that they have nothing more to offer. In this circumstance one is thrown back on who one is as an individual:

'Slowly, I learn about the importance of powerlessness.
I experience it in my own life and I live with it in my work.
The secret is not to be afraid of it – not to run away.
The dying know we are not God.
All they ask is that we do not desert them.'¹¹¹

When there is nothing to offer except ourselves, a belief that life has meaning and purpose helps to sustain the carer. However, to speak glibly of this to a patient who is in despair is cruel. At such times, actions speak louder than words. The essential message is conveyed by the words of Cicely Saunders:

You matter because you are you.
You matter to the last moment of your life,
and we will do all we can,
not only to help you die peacefully,
but to live until you die.

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