

# Ethical care at the end of life

Elizabeth J. Latimer, MD

## Abstract

IN TREATING DYING PATIENTS, who by virtue of their physical and emotional situation are frail and vulnerable, physicians must meet a high standard of professional, ethical care. Such a standard is based upon a philosophy of care that recognizes the patients' inherent worth as human beings and their uniqueness as individuals. The ethical and virtuous physician will practise in accordance with the principles of biomedical ethics that form the foundations of thought and treatment approaches in this area and will seek to do the best for the patient and the family. "Doing the best" includes respecting autonomy through gentle truth-telling, helping the patient and family to set treatment goals, and providing for symptom control, continuing attentive care and accompaniment throughout the course of the illness. Total care includes physical, emotional and spiritual aspects, is sensitive to cultural values and is best provided by an interdisciplinary team. Practices of symptom control in routine care and in crisis situations, as well as the cessation and non-initiation of treatment, will have as their goals the relief and comfort of the patient. The ethical physician will not act with the intention of bringing about the death of the patient, whether by ordering medication in excess of that required for symptom control, administering a lethal injection or any other means.

## Résumé

LORSQU'ILS TRAITENT DES MOURANTS, que leur état physique et émotif rend frêles et vulnérables, les médecins doivent satisfaire à une norme élevée de soins professionnels et éthiques. Une telle norme est fondée sur une philosophie des soins qui reconnaît la valeur inhérente des patients comme êtres humains et leur caractère unique individuel. Le médecin éthique et vertueux exercera sa profession conformément aux principes de l'éthique biomédicale sur lesquels reposent la philosophie et les méthodes de traitement dans ce domaine, et il cherchera à faire ce qu'il y a de mieux pour le patient et les membres de sa famille. «Faire ce qu'il a de mieux» comprend notamment respecter l'autonomie de la personne en lui disant avec ménagement la vérité, aider le patient et les membres de sa famille à fixer les objectifs du traitement, prévoir le contrôle des symptômes et fournir des soins attentifs continus et un accompagnement pendant toute la maladie. Le soin total comprend les aspects physiques, affectifs et spirituels, tient compte des valeurs culturelles et est fourni idéalement par une équipe interdisciplinaire. Les méthodes de contrôle des symptômes en soins courants et en situation de crise, ainsi que l'abandon et la non-administration des traitements viseront à soulager le patient et à le rendre confortable. Le médecin éthique n'interviendra pas dans le but de provoquer la mort du patient, ni en administrant des doses de médicament supérieures à celles qui sont nécessaires pour contrôler les symptômes, ni en administrant des injections mortelles, ni autrement.

Ethical and appropriate care of patients at the end of life is a subject of continuing discussion in health care circles and in society at large.<sup>1-4</sup> Euthanasia and physician-assisted suicide remain a source of debate and lobbying, despite numerous statements and guidelines indicating that they should not be a part of medical practice.<sup>5-10</sup> The recently revised CMA Code of Ethics has been silent on this major controversy, which has given rise to the suggestion that more clear direction about the ethical physician's role in caring for the dying is required.<sup>11</sup> Incomplete information about certain high-profile cases lends an aura of mystery to the question of what constitutes effective symptom control and comfort care and what would constitute the crossing of the line into unethical practice.<sup>12</sup>

Because of this atmosphere of confusion and controversy, physicians may be anxious



## Education

## Éducation

**Dr. Latimer is Professor with the Department of Family Medicine, McMaster University, and Consultant Physician in Palliative Care and Pain Management, Hamilton Health Sciences Corporation, Hamilton, Ont.**

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about whether their manner of caring for dying patients falls within the realm of acceptable, ethical professional practice. The resulting uncertainty may produce ambivalence on the part of the physician about providing effective symptom control, which could lead either to undertreatment of symptoms or to unwarranted oversedation of patients at the end of life. The result is a failure to alleviate suffering.

This paper will articulate the components of ethical professional practice when physicians are caring for dying patients and their families.

## Philosophical and ethical basis for care

The philosophical and ethical basis of care for the dying patient and the principles of such practice have been described.<sup>13,14</sup> Care must be based on a philosophy that acknowledges the inherent worth of each person as a unique individual. Patients and their families have a right to respect, compassion, attentive and skilled physical and psychosocial care, and spiritual support.

The 4 ethical principles of beneficence, autonomy, non-maleficence and justice form the framework upon which treatment decisions and approaches to care are based.<sup>15-17</sup> Respect for a person's autonomy supports the practice of information-sharing, and beneficence obliges physicians not only to relieve suffering but also to promote the best interests of the patient by enhancing quality of life and peace of mind whenever possible. Nonmaleficence and justice dictate that patients are not allowed to come to harm and that they are given the care to which they are entitled. Harm can be of a physical or psychological nature. For example, blunt, unkind truth-telling that is assaultive in nature is as much a violation of the principles of nonmaleficence and beneficence as is any direct action to place the patient at physical risk.

Because of the vulnerability of dying patients, the physician's relationship with them approaches the nature of a covenant of trust that he or she will work for the best interests of the patients, seeking always to help and never to harm.<sup>18,19</sup> The physician should strive to exemplify the virtues in medical practice.<sup>18</sup> How will this be manifested in clinical care?

The following case scenario illustrates many aspects of ethical care in practice, which are described in detail in the sections that follow.

## Caring for Mr. A.J.

Mr. A.J. is a 52-year-old man who is admitted to hospital in late February for investigation of an 8-kg weight loss and back pain. Scanning and needle biopsy reveal adenocarcinoma of the head of the pancreas associated with local infiltration. Surgery is not an option.

Mr. J.'s family includes his wife, Sara, and 3 children, 2 daughters and a son, ranging in age from 16 to 22 years. Mr. and Mrs. J., born in Pakistan, have lived in Canada for 25 years. Mr. J. teaches at a community college and his wife works in the retail clothing business. The oldest children, Yasmine and Ahmed, are

at university. Daughter Sara is in grade 11 at high school. Yasmine will graduate with her engineering degree in May. The family are very proud of her and are looking forward to this event.

Once the results of the investigations become available, the physician approaches Mr. J., who requests that his wife be present when the news is given. The physician asks the social worker on the ward to join her for the interview, to provide additional support and expertise.

Although Mr. J. and his wife had been worried about "something bad," the diagnosis of cancer with no effective treatment available comes as a great shock and source of sadness to them. They ask that their children not be told about the illness, as it would be too upsetting for them at a time when they need to concentrate on their studies. The team members are concerned about this request and explain to Mr. and Mrs. J. why this is not a wise or kind path of action, even though it may seem a way to protect loved ones. The couple agree to think more about revealing the diagnosis to their children, and the team identifies this as something needing follow-up.

The short-term goals of care are to achieve symptom control, transfuse blood to correct a low hemoglobin level, which is creating significant light-headedness, and discharge Mr. J. home as soon as he feels ready to go. The need to consider decisions about cardiopulmonary resuscitation (CPR) and aggressive life support is introduced as something that Mr. and Mrs. J. will want to be thinking about, but they are reassured that this can be pursued during subsequent outpatient visits. Mr. J. is to be followed regularly in an ambulatory setting, with house calls and home care to be introduced when required.

Symptom control is initially readily achieved with sustained-release morphine for pain (100 mg given orally every 8 hours), haloperidol to prevent nausea (2 mg at bedtime) and a bowel regimen of stimulant laxative and stool softener.

After having some time to reflect at home, Mr. and Mrs. J. decide to tell their children about Mr. J.'s illness. The children ask to meet with the physician and the social worker to discuss some questions they have. Mr. and Mrs. J. attend this meeting.

Over the next 10 weeks, Mr. J. is seen every 2-3 weeks, always with his wife and sometimes with his children. These appointments are usually 1 hour long and involve a combination of adjustments to symptom control medications, physical care, and emotional and spiritual support. The physician, nurse clinician and social worker are involved at various times. Mr. J. receives spiritual support from his Muslim community and from reading the Koran. Over time, the whole family share their sadness and fears, as well as the love and humour that have been their strength.

Mr. J. decides that he does not want CPR or aggressive life support. However, he continues to choose treatment of intercurrent problems such as infection and low hemoglobin level, both to feel better and to reach his goal of attending his daughter's graduation. His opioid analgesic needs escalate over time, and he is given a continuous subcutaneous infusion pump for morphine. Over time the dose is raised to 30 mg/h (continuous dosing), with an extra bolus dose of 30 mg/h programmed into the pump for Mr. J. to use for breakthrough pain if needed.

Mr. J.'s major goal and source of focus become attending his daughter's graduation. The whole family shares in this goal. Yasmine's and Ahmed's college friends arrange to assist in his transportation to the ceremony, as he is by this time quite weak and frail. The graduation is a splendid event. Mr. J. is present to watch his daughter's degree being conferred and also attends a reception at the family home. The family has many photos of this event to treasure.

Shortly thereafter, Mr. J. begins to lose strength, spending most of his time in bed near a window looking out over the backyard garden. He speaks of his sense of peace and calm. He



declines further life-prolonging interventions and expresses his desire to stay at home "until the end." He reads his Koran daily and begins to prepare for death and to say good-bye to his family. The health care team inquires of the family regarding the practices of the Muslim faith at the time of death. These details are recorded in the care plan, so that on-call staff will also be aware. Mr. J.'s opioid requirements increase every few days in response to increasing back pain, but overall he is quite comfortable. His family and many friends are present much of the time. He has daily nursing visits, and his health care coverage from the college allows some extra nursing care hours at night.

Early one morning the physician receives an urgent call from Mrs. J. Her husband is suddenly having chest pain and a lot of trouble breathing. On arriving in the home, the physician diagnoses an acute respiratory event, likely pulmonary embolus. Severe air hunger is present, and Mr. J. appears cyanotic and has a respiratory rate of 48 breaths/min. The family affirms their desire not to return to hospital. The physician administers 2 extra 40-mg doses of morphine sulfate 30 minutes apart, as well as 2 doses of lorazepam (1 mg each, administered subcutaneously) 20 minutes apart. The continuous morphine infusion is increased from 40 to 45 mg/h. Mr. J. gradually relaxes and lapses into sleep with greatly decreased distress. Because death seems imminent, the community nurse elects to stay in the home. Over the next hour and a half, Mr. J. rests quietly, opening his eyes from time to time and squeezing his wife's hand. His breathing, now at 20 respirations/min, is quite peaceful. He needs one more extra dose of morphine and lorazepam to treat a brief period of restlessness and dyspnea. Scopolamine (0.4 mg every 4 hours as needed) is ordered in case of upper airway secretions, but this symptom does not develop. Mr. J. dies peacefully with his family at his side.

The physician returns to pronounce the death and spend some time with the family in support and in saying good-bye. In accordance with his faith, Mr. J.'s body is conveyed to the mosque before afternoon prayer time. The physician and the health care team confirm their plan to see the J. family in the next 2–3 weeks and urge them to call if they need help before then.

## The components of ethical care

### *Careful physical assessment and diagnosis*

Patients suffering from advanced illness require careful, detailed assessment of their physical status at various points as the illness progresses. Such points include the time of initial diagnosis and when significant new problems or changes of status arise. The physician should attempt to find the cause of any deterioration and changes in physical status, so that appropriate treatment may be instituted and so that the patient and the family can be informed of the situation in a meaningful way. Expected outcomes can also be conveyed with more confidence once the nature of the physical problem is known. Diagnostic tests may be used when indicated; careful consideration must be given to the burden and benefit of these tests to the patient and the likelihood that they will guide treatment consistent with the goals of care for the patient.

### *Ethical communication*

Ethical communication of information has 4 compo-

nents: it must be timely and desired by the patient, it must be accurate, it must be provided in words that are understandable to the patient and the family, and it must be conveyed in a gentle, respectful and compassionate manner. "Truth with tenderness" best exemplifies the essence of communication with the patient and the family.

Communication should be with the patient and, upon the consent or the understanding of the patient, with family members. Information should be conveyed throughout the course of the illness, from initial explanations about the nature of the life-threatening illness to regular updates as the disease progresses, particularly at points of significant physical change.<sup>20–22</sup>

Communication involves not only sharing information, but also emotional support and care. The physician and the care team should arrange regular opportunities for the patient and the family to share concerns, thoughts and feelings and to seek answers to questions of a practical and philosophical nature. The great stress, emotional tension and fatigue that attend a serious life-threatening illness often make it necessary for families and patients to hear the same information several times so that they can absorb it and feel reassured. Understanding and kindness on the part of physicians and the health care team do much to ease fear and isolation and enhance a sense of security for the patient and the family.

### *Setting goals of care*

Physical assessment and communication are united in the process of setting goals of care for the patient. The patient, the family and the health care team should be involved in this important step in care. Goals of care have several important dimensions: they are empowering to the patient, the family and the health care team because they identify a path to follow in a time of uncertainty. They provide clarity about treatment choices. They are dynamic and will evolve and be refined as the illness progresses. Finally, they affirm that the patient, the family and the health care team are working together. Fig. 1 illustrates the steps in the process of setting goals of care with the patient and the family.<sup>23</sup>

The nature and progression of the illness should be carefully considered by the physician and the team, and all available information gathered before meeting with the patient and the family. Such information is derived from a careful review of chart notes and test results, consultation with colleagues, and knowledge of the disease itself and how it usually progresses. Answers to the following questions should be sought: What are the expectations of the illness, including current problems, possible future developments and potential trajectory of prognosis over time? What are the possible options for treatment and care? What



is the recommended or most wise approach to treatment?

The particular patient under care must be considered: Who is this unique person who has the illness? Knowledge about this person will provide the particular context and circumstances in which the illness will play out. What are his or her values, choices, life circumstances, personal goals and plans for the time remaining? What is his or her perception of the illness and experience of it? What would he or she like to see happen? What is possible, given the nature of the illness?

The goals of care can then be articulated in both general and specific ways. The degree to which life prolongation is desired and possible, and by what means, should be gently ascertained. This allows for timely consideration of treatment decisions, such as the use of hydration, antibiotics and artificial feeding, in terms of their benefit and burden to the patient and their potential to enhance the goals of care. It also fosters consideration of and conversation about the issue of CPR and other life support procedures, the burden of which may far outweigh the benefit to a dying person.

Fig. 2 illustrates a way of thinking about the patient's wishes for prolongation of life and the approaches to care that follow in each situation.<sup>23</sup> When patients express their wishes about prolongation of life, it is essential to clarify their meaning in some detail. To ascertain that they are making informed choices, it is essential to determine that they have a good understanding of the nature of their illness and the advantages and limitations of various treatment approaches. A patient's wishes for prolongation of life often evolve over the course of the illness. Hence, this issue can be revisited as the situation changes.

Given appropriate information about the illness and a

gentle, compassionate atmosphere in which to reflect, most patients are able to indicate their wishes for treatment and their goals of care. When patients are unable to speak for themselves, the process of proxy decision-making should be followed according to appropriate legal and medical practices. Generally, this will involve family members, powers of attorney for personal care and advanced directives where these are in place.

The goals of care, including the treatments to be used and those not desired by the patient, must be clearly recorded on the patient's chart and made known to all members of the health care team. If the patient is at home, a Travelling Record® chart can be used to make information about treatment decisions readily available to health care professionals in all settings.<sup>24,25</sup>

### Relief of pain and suffering

The medical profession has a strong moral imperative to do all that can be done to prevent and treat physical symptoms, such as pain, and to work toward the alleviation of suffering. Ethical care requires that patients be provided with symptom control by methods that are in keeping with current standards of practice.<sup>26,27</sup> The physician must be aware of these standards and make the control of pain and other symptoms a top priority in caring for the patient. Unrelieved symptoms must always be seen as an urgent and sometimes emergent problem and dealt with accordingly by physicians and the health care team.

The treatment of symptoms, particularly the effective use of opioid analgesics, is not an option that the physician can decline to employ on the basis of personal bias,

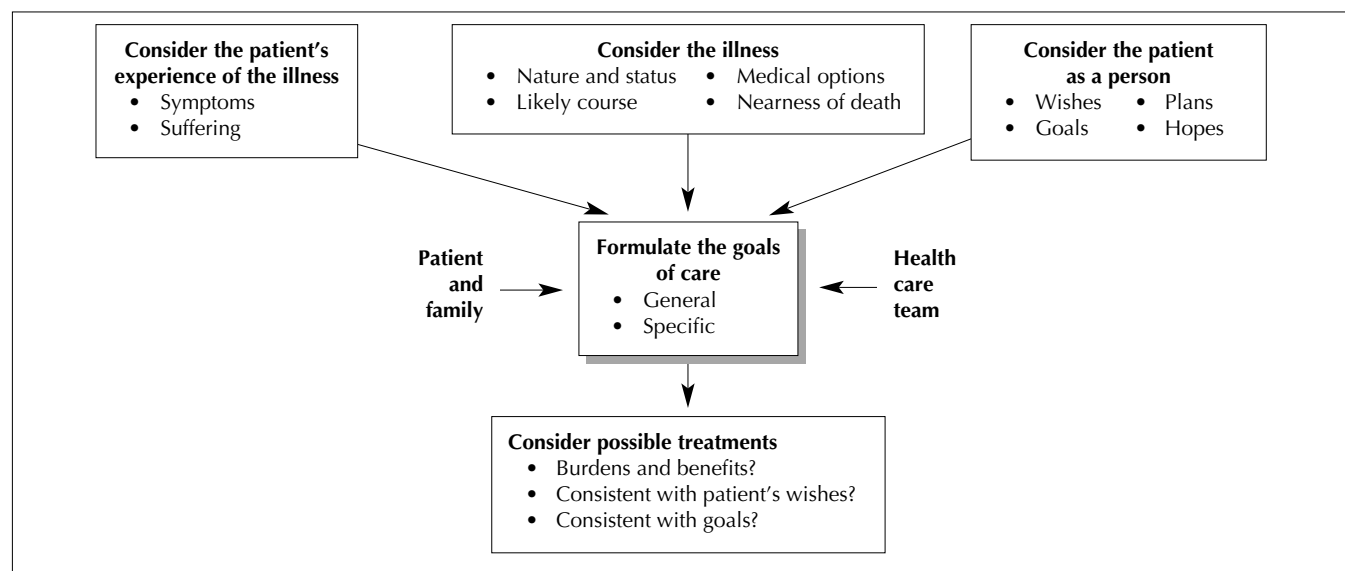


Fig. 1: An approach to formulating the goals of care and treatment plans for seriously ill and dying patients. Adapted by permission of Elsevier Science from "Ethical decision-making in the care of the dying and its applications to clinical practice," by E.J. Latimer, *Journal of Pain and Symptom Management* vol. 6, p. 329-36. © 1991 US Cancer Pain Relief Committee.



misinformation or lack of knowledge. The ethical physician will actively seek advice and consultation about symptom control from colleagues in medicine and other professional disciplines such as nursing and pharmacy. The physician will take the initiative in asking patients about their symptoms and create a climate in which the patient can report pain and be reassured that action will be taken to provide timely relief.

Emotional and psychological suffering should also be addressed.<sup>26,28</sup> Physicians should ask about the patient's pattern of sleep and any feelings of depression, sadness, fear and hopelessness. Appropriate treatment should be instituted. This may include reassurance and validation that such feelings are natural in the situation of serious illness, counselling, medications, psychiatric consultation and the involvement of interdisciplinary team colleagues. Patients should be assured of continuing care and should be reassured that they will not be abandoned.

### ***Ongoing attentive care***

Fidelity to trust requires that attentive care be provided to the patient and the family throughout the course of the illness. Not only is dying a life passage, it is also a life crisis for patients and their families. Dying patients, being physically fragile and unstable, are at risk of new problems and symptoms. For these reasons, they and their families require regular attentive care, and they need to be able to reach the physician and the health care team readily when necessary. Effective systems must be in place to allow this responsive and skilled care.

### ***Practising with an interdisciplinary approach***

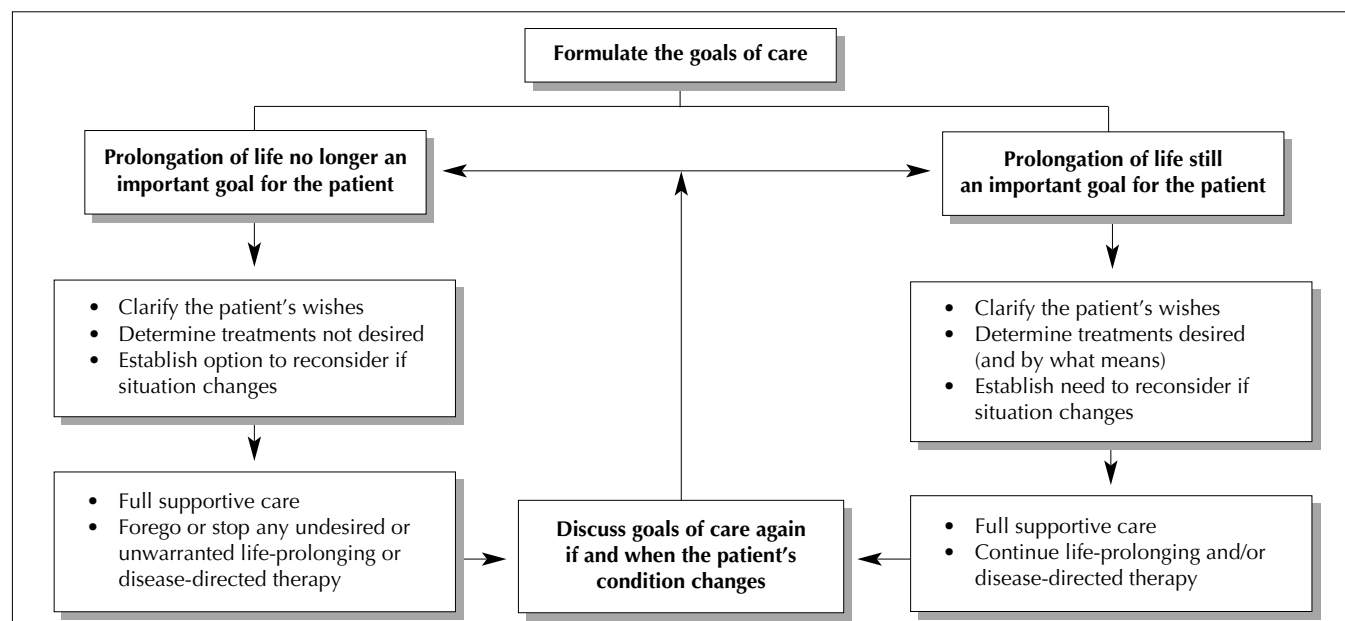
The complex and diverse needs of dying patients and their families make the interdisciplinary team approach the most effective model for care. Colleagues from selected medical specialties, nursing, social work, pastoral care, pharmacy, nutrition services, occupational therapy, physiotherapy, volunteer services and other disciplines have unique skills to bring to care. The team also provides a forum where the ethical dilemmas of care can be discussed and input sought. Ethical practice is likely to be enhanced in this way.

### ***Practising in a cultural context***

As a significant life passage, dying is an event that is deeply influenced by cultural mores and practices. The ethical physician will seek to learn about and respect the cultural values, beliefs and practices that are held by the patient and the family. Truth-telling, the concept of autonomy and informed consent are 3 important areas particularly open to cultural variability, although there are many other diverse ways in which culture may influence the practices that surround death.<sup>29</sup> Wherever possible, the physician will seek to create an atmosphere that fosters mutual understanding. It is often possible to modify practice to adapt to cultural ways while supporting the standards of ethical professional care and the best interests of the patient.

### ***Use of medications in usual situations***

Not all dying patients require medications, but many



**Fig. 2: Patients' wishes for prolongation of life: an approach to decision-making and care.** Adapted by permission of Elsevier Science from "Ethical decision-making in the care of the dying and its applications to clinical practice," by E.J. Latimer, *Journal of Pain and Symptom Management* vol. 6, p. 329-36. © 1991 US Cancer Pain Relief Committee.



do. The purpose of medications is to control symptoms and thereby to enhance quality of life throughout the course of the illness. As death draws near, medications may also be required to allow for peaceful death. Patients should be neither undertreated nor oversedated. In general, the goal should be the relief of symptoms and, where possible, the maintenance of an alert sensorium.

Various medications may be ordered for their ability to treat particular problems. These include sedatives, anxiolytics, major tranquilizers, antidepressants, anticonvulsants, opioid analgesics, antinauseants, medications to control secretions, steroids and others.<sup>26,27</sup> The doses required vary greatly depending on the nature of the problem and the particular patient. This is particularly true of opioid analgesics and sedatives.

The ethical physician will be familiar with approaches to symptom control, will provide for regular assessment of the patient's symptoms and will not hesitate to order medications with the intention to control symptoms and provide a state of comfort for the patient. The doses ordered will be appropriate to the particular clinical context. The ethical physician will not seek to hasten death by ordering medications in excess of what is required by the patient for control of symptoms.

### ***Use of medications in symptom control crisis***

A crisis in symptom control presents a morally compelling situation for the patient and the family and for the health care team. Examples of such a crisis include severe intractable pain that is out of control, suffocation due to airway obstruction, pleural effusion or massive pulmonary embolus, and severe agitated delirium.

These are very difficult situations to assess and to manage. Often there is fear that medication in the doses required to ease the crisis may shorten the patient's life. Such fear may lead to inaction on the part of the physician and the team, to the detriment of the patient and the great distress of loved ones.

Such crises require urgent management on the part of the physician. Patients need the physician to be present, in active attendance, until comfort and a restful state are restored. The family members need an explanation of the nature of the crisis, the steps being taken to alleviate it and the risk of death, if such exists. They and the patient also require comfort and reassurance.

Medications such as opioids and sedatives must be ordered at the same time as the assessment is carried out. Doses may need to be repeated and increased if no improvement in comfort level occurs. Sometimes a rapid increase in drug dose is necessary to alleviate the symptom crisis. The types and doses of medications given, their observed effect or lack thereof, the physical state of the pa-

tient and the ongoing medical assessment and clinical judgements of the physician should be recorded in the chart notes. Dialogue with nursing and other team colleagues ensures that the approaches to care and reasons for medications are understood by all.

When managing such a situation, the physician will not intend to hasten the death of the patient. Rather, he or she will be working toward relief of distress through medications and other procedures that may help (e.g., thoracentesis for effusion). However, it must be recognized that, during the management of symptoms resulting from a crisis, death may occur because of the pathological process that has developed. The treatment of dyspnea secondary to large pulmonary embolus is a situation in which symptom management is needed for a patient who is at high risk of dying from the complication being treated.

The meta-ethical principle of "double effect" will assist in delineating the ethical basis of the use of medications in a symptom crisis.<sup>15,16</sup> This procedural principle is used in helping to decide if some harmful effects can be accepted as a result of a particular action. It differentiates between the intended effects of an action and the non-intended although possibly foreseen effects. The intentions and actions of the practitioner must be clearly toward a desirable, positive outcome, for example a restful state for the patient in distress. The possibility of shortening life by necessary treatment may be recognized but should not be the intention of the physician.

In the treatment of a symptom control crisis, the double-effect principle requires that there be a morally compelling reason to act (severe distress of the patient), that failure to attempt to help would be a moral failure and that the physician does not intend to bring about the death of the patient by his or her actions in treatment.

If the possibility of a crisis in symptom control can be anticipated, for example in a patient with increasing pressure and airway obstruction from a head and neck lesion or in a patient at risk for respiratory crisis from end-stage heart failure, orders for emergency symptom control should be left on the chart. The orders should include specific, detailed instructions about the purpose of the medications and how to use them in a crisis situation.

### ***When sedation is necessary***

In certain situations, it may be necessary to sedate the patient until death occurs from the underlying disease. Severe end-stage dyspnea, agitated end-stage delirium and intractable pain are 3 problems that may necessitate sedation when all other methods of symptom control have proven ineffective.<sup>26,27</sup> The family should be a part of decision-making about this approach to compassionate care. Patients in such circumstances are usually too ill to partic-



ipate in discussions, but if able they too should be involved. Because the burden of such decisions can be stressful, the physician and the health care team may wish to review the approach to managing the case with a skilled colleague or a knowledgeable clinical ethics committee.

The minimum doses of medication required for peaceful rest should be used. Attempts to reduce medication from time to time may be warranted, but only if they do not result in patient distress and agitation or the return of the symptom for which the sedation was initiated.

### Use of treatments and procedures

Artificial feeding, transfusion, hydration, antibiotics, thoracentesis and paracentesis are all examples of interventions that can enhance quality of life for some patients. Regrettably, patients are not always offered these treatments by physicians because of the mistaken belief that care of the dying should be non-interventionist in nature.

Dying patients should not be denied treatments and procedures that may be of help to them. Neither should they be overtreated. The consideration of whether to proceed with treatments and procedures requires a careful consideration of the delicate balance between the benefit and the burden involved. The previously articulated goals of care for the patient provide the context within which the role of possible treatment interventions can be assessed for consistency and for their ability to contribute to these goals. Wherever possible, the patient, with guidance from the physician and the team, will be the one to make decisions about procedures and treatments. A trial of therapy can sometimes be undertaken and subsequently continued or stopped, depending on the patient's experience of its benefit and burden.

### Cessation and non-initiation of treatment

In keeping with the goals of care, the wishes of the patient and the principles of informed consent, respect for autonomy and the competent patient's right to forego treatment, it can be ethically sound practice not to undertake certain treatment or to cease certain treatment once started. Careful consideration should be given to such treatment decisions, particularly in ascertaining that the clinical context is appropriate and that the wishes and best interests of the patient are foremost. Such decisions, being of a life-and-death nature, should not be forced or made in haste. Cessation of treatment should be carried out in the most gentle, compassionate manner with the use of appropriate sedatives and analgesics as required for symptom control and comfort.

Non-initiation and cessation of treatment can be seen as relieving patients of treatments that have been determined, by the best assessment possible, to be against their wishes and not in their best interests, given their overall

situation. If death occurs, it is as a consequence of the primary underlying disease process or condition and its sequelae, in the absence of which the patient would not die.<sup>30</sup>

### Not seeking to hasten death

The ethical physician will not act with the intention of bringing about the death of the patient, whether by ordering medication in excess of that required for symptom control, administering a lethal injection or any other means.

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**Reprint requests to:** Dr. Elizabeth J. Latimer, Palliative Care Office, Henderson General Hospital, 711 Concession St. E, Hamilton ON L8V 1C3