

Compassion in Dying

**Response to the General Medical Council
consultation paper**

***End of Life Treatment and Care: Good practice
in decision-making***

About Compassion in Dying:

Compassion in Dying is a charity that focuses on research, education and advice on all aspects of the end-of-life process. Our charitable objectives are to conduct research and to provide advice, information and guidance to all those affected by the end of life; including patients, carers and health professionals.

In this section we explain what we mean by life-limiting conditions and end of life care. It sets out the types of situations and cases the guidance is intended to cover, as well as flagging up the importance of broader care issues such as palliative care.

Question 1.

Do you agree that the Introduction (paragraphs 9-12) sets out the scope of the guidance clearly?

YES

Comments:

Compassion in Dying welcomes the emphasis on guaranteeing a good quality of life for people who are nearing the end of life, and the recognition that good end-of-life care is care that helps people to live as well as possible until they die.

The proposed guidance confirms that doctors should not strive to prolong life at all costs. Doctors should always assess the benefits and the burdens of treatment or non-treatment. This is supported by the findings of a survey commissioned by Dignity in Dying¹ in May 2008 which found that 79% of people think it is important to have a choice about when they die and not to have their life prolonged against their wishes.²

Compassion in Dying also welcomes the emphasis on the importance of good palliative care for people who are nearing the end of life and those with life-limiting conditions. We would suggest including a reference to progressive neurological conditions in the paragraph (9) setting out different types of life-limiting conditions.

It should be made clear in these paragraphs that guidance specifically addressing neonates, children and young people is set out in paragraphs 74 to 82.

Paragraphs 13 to 15

Human rights principles and equalities law have particular importance in decisions about end of life care. This section of the guidance is intended to highlight this point. The guidance here is in terms of high level principles. Other parts of the guidance address how these principles apply in practice.

¹ Compassion in Dying is a registered charity which was founded in 2007. We work for the welfare of people who are at the end of their lives alongside the non-charitable lobbying organisation Dignity in Dying. Compassion in Dying was set up to take over and expand the charitable work identified by Dignity in Dying as a by-product of their campaign for greater choice, control and access to services at the end of life. The two organisations share premises and some staff but have distinct aims and are governed by separate Boards.

² ICM poll, commissioned by Dignity in Dying, May 2008. Dignity in Dying campaigns for greater choice, control and access to services at the end of life. Compassion in Dying was set up to take over and expand the charitable work identified by Dignity in Dying. The two organisations share premises and some staff but have distinct aims and are governed by separate Boards.

Question 2.

Do you think there are other general problems or issues in relation to equality, diversity and human rights that we should flag up in this section?

YES

Comments:

Ensuring that all patients receive the same standard of care at the end of life across the UK remains a challenge. For example, in terms of access to hospice care, this varies significantly depending on the place where people live.³ In addition, the majority of people getting access to hospice care tend to be white and middleclass.⁴ It is positive to note that the guidance highlights this challenge.

Rose Marie Kelly:

During the course of my illness I have had very different experiences in two different hospitals. The first hospital I went to was terrible . the pain relief and nursing care were not sufficient and I saw several people die in agony. The second hospital was much better at providing care for the dying, but there clearly aren't enough hospice spaces for everyone who needs them. I was lucky enough to have family who could look after me at home whilst I was extremely ill from chemotherapy but not everyone has that kind of support. I really feel that there is a postcode lottery of treatment and it simply isn't fair. +

Rose Marie Kelly is 64, and she lives in London.

Although this guidance is aimed at doctors, it would be helpful to reinforce the importance of making sufficient information easily accessible to patients so that they know what standards of care they are entitled to at the end of life and what rights they have. Doctors have an active role to play in educating patients about the care and treatment they are entitled to. Empowering patients will help to achieve equality in accessing good quality end-of-life care.

With regard to human rights, it is extremely important that doctors are aware of the applicable human rights framework and that they understand how these human rights relate to each other. The interface between article 2 (right to life) and article 8 (right to respect for private and family life) is particularly challenging in this context.

Paragraph 16 sets out the principles which underpin the advice in later parts of the guidance, in particular the section on assessing the overall benefits of treatment options (paragraphs 36-42). It emphasises the presumption in favour of prolonging life and the need to balance this with the consequences for the patient and the patient's own wishes about treatment. We believe that the advice in paragraph 16 strikes a reasonable balance between ensuring:

- a. patients receive treatment where they need and want it; and
- b. patients who are dying are treated with dignity and not subjected to burdensome treatment.

³ National Council for Palliative Care, *National Survey of Patient Activity Data, Specialist Palliative Care Services, MDS Full Report for 2007 – 2007*. MDS_full_report_0607.pdf

⁴ Speech by Professor Gurch Randhawa on cultural/ personal beliefs and decision-making at the at the GMC Consultative Conference on end-of-life care issues, 3 June 2009.

In answering the following question, you may find it helpful to also consider the advice in paragraphs 36-42 of the draft guidance.

Question 3.

Do you agree that the advice in paragraph 16 strikes a reasonable balance between these factors?
NOT SURE

Comments:

Rather than emphasising the presumption in favour of prolonging life, Compassion in Dying suggests that the emphasis is on patients' best interests. Compassion in Dying believes that this better reflects the fact that the wellbeing and the wishes of the patient are the doctor's first concern, rather than prolonging life.

In the final sentence of paragraph 16, Compassion in Dying would suggest that '...or have been refused by a patient with capacity' is replaced by '...or have been refused by a patient with capacity at the time of the refusal', in order to make it clear that treatment can be refused by a patient *in advance* of losing capacity.

Paragraphs 21 to 24

This section of the guidance reminds all doctors, even those with considerable experience, about key difficulties in practice that are not always recognised outside palliative care. One well known difficulty is diagnosing how long a patient has to live. Another problem is that many doctors think of palliative care as something that is only relevant to the last days of life. The guidance encourages doctors to think, at an early stage, about the likely progression of a patient's condition and the need to think about and plan for palliative care.

Question 4.

Do you think the guidance will prompt doctors to think early enough about the likely progression of a patient's condition and the need to plan for palliative care? If not, please include any suggestions for how the guidance could achieve this.
NOT SURE

Comments:

A large number of doctors will meet people with a limited prognosis at some point in their career. Compassion in Dying therefore suggests that a reference is made to the importance of training on end-of-life care for the workforce as a whole. Palliative care specialists undoubtedly have an important role to play but it is crucial that all health and social care professionals feel confident working with people who are dying.

It is particularly important that they have the necessary skills to have meaningful conversations with people who are nearing the end of their lives. Past initiatives to improve communication skills have greatly aided both patients and care providers.⁵ Every health and social care professional must be fully equipped to have appropriate conversations with their patients and therefore must receive specialised communication skills training. This will enhance health and social care staff's confidence in having these conversations and in

⁵ Dr Susie Wilkinson, Senior Lecturer Palliative Care at the RCN Palliative Care Nursing Forum, Annual Conference, 7 September 2007

initiating a conversation about people's concerns and wishes for the end of life, whenever this is deemed appropriate.

When planning for palliative care, it is crucial for doctors to be aware of their responsibility for involving the carers of the patient in all care planning from diagnosis to discharge and beyond. Family members and carers need to be treated as experts and care partners other than in circumstances where their views and aspirations are at odds with the person using the service or they are seeking to deny a family member the chance to experience maximum choice and control over their own life, as put forward in the Carers Strategy.⁶

It may be helpful at paragraph 22 to refer back to the point about life-limiting conditions (paragraph 9) as opposed to terminal conditions, in order to ensure that palliative care is considered, not just in a patient's last few days, but much earlier, for patients who face years of life with progressive conditions. Members of the public contacting Compassion in Dying and Dignity in Dying sometimes reveal that doctors are reluctant to refer to palliative care specialists, or fail to consider that this may be an option for some patients who are not dying, but are in considerable pain or discomfort.

Furthermore, it is vital that alongside measures such as the End of Life Care Strategy⁷, which in part aims to redress the traditional focus of palliative care services on patients with cancer⁸, individual doctors are made aware of their duty to make the best practice of palliative care available to patients with other illnesses and conditions.

Paragraph 22 highlights the need to give early consideration to the patient's palliative care needs, and to consider how to manage any pain, breathlessness, agitation or other distressing symptoms that they may be experiencing. It also gives advice on what doctors should do if they are uncertain about how to meet patient's needs.

Question 5.

Do you think that the guidance is sufficient to ensure that patient's needs for symptom management and pain relief will be met adequately, regardless of where they are receiving care?
NOT SURE

Comments:

As explained above, appropriate training on end-of-life care for the workforce as a whole is crucial in order to achieve this objective. However the guidance could make it clearer that doctors should seek relevant advice on how to manage a patient's symptoms, regardless of the setting in which the patient is based.

Paragraphs 25 to 32

The clinical issues towards the end of a patient's life can be complex, and it may not

⁶ Department of Health, Prime Ministers Strategy on Carers; Carers at the heart of 21st Century families and communities, 2008, para 5.43-5.44

⁷ Department of Health, End of Life Care Strategy . promoting high quality care for all adults at the end of life, 16 July 2008

⁸ A survey by the National Council for Palliative Care found that cancer patients receive approximately 90% of the available specialist palliative care: National Council for Palliative Care, *National Survey of Patient Activity Data, Specialist Palliative Care Services, MDS Full Report for 2007 – 2007*.
MDS_full_report_0607.pdf

be possible to arrive at clear decisions without starting treatments which then have to be withdrawn. The scope for misunderstanding (between patients, carers and members of the healthcare team) about the clinical issues is high. This can be further complicated by the emotional distress that patients and carers and members of the healthcare team might be facing at the time. The advice at paragraphs 25-32 is intended to highlight these problems and suggest helpful ways for doctors to respond.

Question 6.

Do you think the guidance will lead to more patients, family members and carers receiving the support they want and need when they are coping with complex or distressing information?
NOT SURE

Comments:

Decisions about care and treatment at the end of life can be very complex and emotionally challenging. It is crucial for patients and their loved ones to receive information they can easily understand so that they can be fully involved in the decision making process and so that they know what is happening at any given time. Compassion in Dying therefore welcomes the emphasis on good and clear communication with the patient, those close to the patient and the healthcare team involved in a patient's care. It is essential that information about the illness and the options for care are communicated by professionals who have the necessary expertise and training to do so with honesty and sensitivity.

Patients require access to good and simple information in order to feel empowered and in order to feel able to make informed decisions about the care and treatment they would or would not like to receive at the end of their life.⁹ In addition, health and social care professionals need to be aware of the importance of informing patients' carers and involving them in all aspects of a patient's care, as set out in the Carers' Strategy.¹⁰

Question 7.

Do you think that these sections include sufficient advice about good communication and means of supporting patients, those close to them and members of the healthcare team?
NO

Comments:

Communicating with people who are nearing the end of their life requires specific communication skills. Past initiatives to improve communication skills have greatly aided both patients and care providers.¹¹ Compassion in Dying recommends that the guidance sets out more clearly that every health and social care professional must be fully equipped to have appropriate conversations with their patients and therefore must receive specialised communication skills training.

⁹ These general principles are also clearly set out in the GMC Guidance on *Consent: Patients and doctors making decisions together*, 2008

¹⁰ Department of Health, Prime Ministers Strategy on Carers; Carers at the heart of 21st Century families and communities, 2008, para 5.43-5.44

¹¹ Dr Susie Wilkinson, Senior Lecturer Palliative Care at the RCN Palliative Care Nursing Forum, Annual Conference, 7 September 2007

Compassion in Dying recommends that Paragraph 28 is changed to reflect the importance of discussion not just with other clinicians, but also with the patient's family and loved ones, if there is uncertainty about the benefits of treatment to a patient who lacks capacity. As mentioned in the Carers Strategy, family members and carers need to be treated as experts and care partners other than in circumstances where their views and aspirations are at odds with the person using the service or they are seeking to deny a family member the chance to experience maximum choice and control over their own life, as put forward in the Carers Strategy.¹² Furthermore, if Paragraph 31 refers to emotional difficulties in end-of-life decision making for patients with capacity, then the patient, not just those close to the patient, must be consulted.

Good communication; and the provision of sufficient and easily accessible information to patients and those close to them is crucial in order to empower people to have a say about the care and treatment they would like to receive.

Paragraphs 33 to 35

We have expanded on existing GMC advice on resource constraints. The guidance sets out what we believe are the key points that doctors should take into account, to ensure that they address the full range of ethical issues in any given situation.

Note: this guidance is not intended to cover situations of national emergency, such as a flu pandemic, which is covered by other [guidance](#).

Question 8.

Can you think of any other situations or cases that could not be dealt with effectively by following the guidance? If yes, please tell us what these are.

NO

Comments:

The draft guidance strikes a good balance on a difficult subject. The emphasis on providing the best service possible, working within agreed policy to prevent discrimination, balancing need and best interests and being honest and open is welcomed.

Paragraphs 36 to 42

For some people, it can be difficult to understand or accept that the ethical and legal duty to protect life can be outweighed by other considerations. The guidance in paragraphs 36-42 sets out the circumstances where a potentially life-prolonging treatment might not be provided (expanding on paragraph [16](#)), including towards the end of life when the focus of care should change from active treatment to ensuring that a patient's dignity is respected and they are kept comfortable and their pain and other symptoms are properly managed. Paragraphs 36-42 should be read alongside paragraph 16, which sets out the underpinning principles.

Question 9.

¹² Department of Health, Prime Ministers Strategy on Carers; Carers at the heart of 21st Century families and communities, 2008, para 5.43-5.44

Do you agree that this guidance provides a sufficiently clear basis for reaching sound judgments about when to stop or not to start a potentially life-prolonging treatment?
NO

Comments:

As an organisation that works to empower individuals to exercise their rights and make sure the choices that they make around the end of life are implemented, Compassion in Dying would like to see a greater emphasis on respecting a patient's wishes when considering in which instances life-prolonging treatment must not be started or continued. More specifically, under paragraph 37, we would like to see a reference to patients who have refused life-prolonging treatment in advance of losing capacity by making a valid and applicable Advance Decision to refuse treatment; or by appointing an attorney who was given the power to make this decision. It is vital that doctors' statutory obligations under the Mental Capacity Act are made clearer throughout the guidance.

Compassion in Dying welcomes the reaffirmation of the importance of giving sufficient information to the patient, in order to enable them to make an informed decision about the care and treatment they would (not) like to receive at the end of their life. Patients need to be empowered so that they can make their own decisions about their care and treatment.

We are also pleased to note that the proposed guidance reiterates the fact that doctors must not substitute their own values when assessing the preferences of patients who cannot decide for themselves and that they must not rely on their personal views about a patient's quality of life. All health professionals must comply with the GMC Guidance on Personal Beliefs and Medical Practice.¹³ The guidance acknowledges that personal beliefs and values, and cultural and religious practices are central to the lives of doctors and patients and states that doctors must not unfairly discriminate against patients by allowing their personal views to affect adversely their professional relationship with them or the treatment they provide or arrange.

Paragraphs 43 to 53

This section provides information about the benefits of holding early discussions about future care, with patients and their families. It highlights the issues we believe patients may want to explore, and points to sources of help for doctors in managing these conversations.

Question 10.

Do you agree that paragraphs 43-53 include all of the key issues that are relevant to advance care planning? If not, please tell us what other issues should be included.
NO

Comments:

Compassion in Dying greatly welcomes the fact that the proposed guidance promotes early discussion and planning about how best to manage the patient's care and treatment at the end of life. Advance care planning is essential in order to help ensure that people are treated in accordance with their wishes for care and treatment at the end of life.

¹³ General Medical Council, *Personal Beliefs and Medical Practice*, March 2008

A survey commissioned by Dignity in Dying in May 2008 showed that 65% of people think they would be more likely to have a dignified death if they could discuss and record their wishes around care and treatment at the end of their lives. 67% of people thought that an End-of-Life Care Plan is a good idea. Yet 40% of people have never discussed their wishes for care and treatment at the end of their lives with anyone. Health and social care professionals clearly have an important role to play in order to enable people to express and record their wishes.¹⁴

Under the list of items to discuss (paragraph 46), Compassion in Dying would like to see point d) extended to include other specific types of treatment that the patient might wish to refuse in advance in an Advance Decision to refuse treatment; or by nominating an attorney to make these decisions on their behalf.

Initiating and having these sensitive discussions can be difficult, as highlighted under paragraph 47. In addition to the reference to guidelines on good practice in advance care planning, Compassion in Dying proposes that a reference to the availability of communication skills training programmes, which have been especially developed to this end and which have delivered huge benefits to both the patient and the health or social care professional is included.

Doctors will often be the first point of contact for initiating a discussion on whether or not to make an Advance Decision to refuse treatment (or to appoint an attorney with the authority to make these decisions); and for discussing the content of such a decision. It is therefore important that all doctors are fully aware of advance decisions to refuse treatment and their legal status. As the leading provider of Advance Decisions to refuse treatment, Dignity in Dying is sometimes contacted by people whose doctor refuses to assist them in filling out their advance decision without referring them to a colleague for assistance. This is often a distressing experience for patients. In these instances, patients should be referred to a colleague who is willing to take over this role.

Rose Marie Kelly:

I used to be a nurse and I saw some terrible suffering in the course of my career. When I was diagnosed I knew I wanted treatment to fight the cancer, but I immediately thought about making an advance decision to ensure that if I got to the end stage of the disease, my death would not be prolonged unnecessarily.

However, I had a hard, lonely time in making provisions for my wishes to be respected. I was absolutely horrified that several of the otherwise kind, sensitive and professional doctors who treated me, including an oncologist, were completely unaware of advance decisions. At one point, just before I went into major surgery both the anaesthetist and the registrar refused to look at my advance decision. I was left terrified that if something went wrong, I could spend months in intensive care waiting to die, because the doctors would not respect my wishes. They were not even willing to listen to what I had to say. It was a cruel way to be treated, and my experiences have left me convinced that much more needs to be done to educate doctors on advance decisions, and patients' rights to refuse treatment.

Rose Marie Kelly is 64, and she lives in London.

¹⁴ ICM poll, commissioned by Dignity in Dying, May 2008. Dignity in Dying campaigns for greater choice, control and access to services at the end of life. Compassion in Dying was set up to take over and expand the charitable work identified by Dignity in Dying. The two organisations share premises and some staff but have distinct aims and are governed by separate Boards.

Finally, Compassion in Dying attaches great importance to the legal status of advance care planning, which has not been made sufficiently clear in this section of the guidance. The guidance must clearly refer to the relevant section of the Mental Capacity Act 2005 (section 4(6)), which requires to consider, so far as is reasonably ascertainable, a person's past and present wishes and feelings - and, in particular, any relevant written statement made by him when he had capacity - when assessing best interests. By including this section, the Mental Capacity Act 2005 has given advance care plans legal status.

Paragraphs 54 to 61

In paragraph 55 we address situations where the treatment is already being provided and the patient is a few days/or hours away from death. The guidance provides that it is usually appropriate to stop the treatment (while focusing on meeting the patient's needs for palliative care and symptom management) where the burdens of continuing the treatment outweigh the possible benefits. However, where the patient has previously expressed a wish for the treatment to continue in these circumstances, the guidance says that doctors must weigh up the harm that might be caused by:

- a. going against the patient's wishes; and
- b. continuing to provide the treatment

in reaching a decision about what course of action would be of overall to the patient.

Question 11

Do you agree that going against the patient's advance wishes to receive a particular treatment should be treated as a potential harm to be weighed with the other factors, in deciding what course of action is of overall benefit to the patient?

YES

Comments:

Compassion in Dying agrees with the provisions in the guidance in relation to going against a patient's advance wishes to receive a particular treatment. These provisions are in line with the Burke case (*Burke v GMC*), which trumpeted the patient's right to decide what treatment is in her or his best interests, especially at the end of life.

Good communication with the patient in advance of losing capacity, and good communication with those close to the patient and the health care team will be crucial.

Question 12.

Can you think of any obstacles to following the guidance in respect of particular treatments or in different settings, including where care is provided in the patient's home?

YES

Comments:

If the care to the patient is being provided in the home or in a nursing home, doctors must ensure that they are communicating regularly with the primary carer, and the health and social care staff present, in order to ensure that medical support, including around decision-making is available when needed.

In the context of care being provided at a patient's home it is crucial that the primary carer is consulted about whether or not care can be provided for at home. The carer must be included in discussions about where the patient will be cared for right from the start in order to ensure that this decision is supported by both the patient and the carer.

Paragraphs 54-61 cover advance refusals of treatment. The advice in this section takes account of differences in the laws and codes of practice governing advance refusals of treatment, across the UK. We have done our best to set out the issues in a clear, uncomplicated way and avoid repeating detail from the codes of practice.

Question 13.

Do you think the guidance makes clear how doctors should decide whether a patient's advance refusal of treatment should be acted on?

NO

Comments:

Since the enactment of the Mental Capacity Act (MCA) 2005, Advance Decisions to refuse treatment are legally binding under statutory law. Only Advance Decisions to *refuse* treatment can be legally binding under the Mental Capacity Act 2005. If the Advance Decision is valid and applicable the treatment cannot be lawfully given. The MCA sets out very clearly under which circumstances an Advance Decision to refuse treatment must be considered valid and applicable. Compassion in Dying welcomes the fact that the proposed guidance is in line with the wording of section 25 of the Mental Capacity Act 2005 when explaining the validity and applicability of Advance Decisions. However, there is an important point missing from this section: the guidance must make it very clear that not respecting a valid and applicable Advance Decision may expose a health professional to civil liability or criminal prosecution.

In general, we are of the opinion that the difference in legal status of advance requests for treatment on the one hand and advance decisions to refuse treatment on the other hand is made insufficiently clear. It must be made very clear that while patients can request treatments, they do not have the right to do so, but that they do have the right to refuse particular treatments.

In terms of terminology, the Mental Capacity Act 2005 refers to 'advance decisions to refuse treatment'. Compassion in Dying strongly recommends that the proposed guidance uses the term 'advance decisions to refuse treatment' in a consistent manner throughout the document. The use of the term 'advance refusal of treatment' can potentially be confusing.

Paragraphs 62 to 65

This section provides advice on the importance of clear lines of communication between members of the healthcare team about the decisions made and actions taken in relation to patients. These principles apply to all patients but those who are dying will often move between different care settings and come into contact with a range of health and social services where care is provided by multi-disciplinary and multi-agency teams. It is, therefore, particularly important in this context that there is good communication and that lines of accountability and responsibility are clear. The guidance in paragraphs 62-65 aims to address the factors which can help and hinder the provision of good care to patients in these

circumstances.

Question 14.

Do you think that there are other factors that can help or hinder timely and clear sharing of information between everyone involved in a patient's care?

YES

Comments:

Compassion in Dying and the MedicAlert Foundation believe there is an urgent need for a recording system for Advance Decisions to refuse treatment. Given the legal obligation for health professionals to comply with valid and applicable advance decisions to refuse treatment under the Mental Capacity Act 2005, it is crucial that health professionals are aware of the existence of an Advance Decision.

Compassion in Dying and Dignity in Dying regularly advise health professionals and the public on Advance Decisions (formerly known as living wills), and we receive frequent calls from relatives whose loved ones' wishes were not respected, because there is no central recording system to ensure that health professionals are made aware of patients' advance decisions . particularly in emergency situations.

As it stands today, patients are, in effect, themselves responsible for making their health care team aware of their Advance Decisions at all times. This is clearly not practical as the Advance Decision would need to be enacted after the patient has lost capacity.

Dignity in Dying has previously campaigned for Advance Decisions to be included in the NHS Summary Care Records.¹⁵ Recording the existence of Advance Decisions in the Summary Care Records alongside other important medical information in one central database, would ensure that health professionals could act in accordance with their patients' wishes and it would protect health professionals from prosecution.

Many people have told us that whilst they might wish to restrict other personal information on their record, they would welcome its use for communicating the existence of Advance Decisions to health professionals.

It is vital that the nationwide registration of Advance Decisions happens sooner rather than later to ensure that all people who make decisions in advance of a loss of capacity have those decisions respected at the end of their lives.

In the absence of a national registration, MedicAlert offers a long-established, successful national registration system. MedicAlert is a registered charity providing a life-saving identification system for individuals with hidden medical conditions and allergies. Each member of MedicAlert receives an Emblem that is engraved with the wearer's main medical condition(s) or vital details, a personal ID number and a 24 hour emergency telephone number which accepts reverse charge calls that allows emergency and medical professionals to access their details from anywhere in the world in over 100 languages.

¹⁵ In 2006, Dignity in Dying campaigned with the support of Baroness Greengross, the College for Emergency Medicine, the MS Society, the National Pensioners' Convention, Action on Elder Abuse, Counsel and Care, and the British Kidney Patients Association, amongst others in its demand for a recording system for Advance Decisions to refuse treatment.

Many people already record their Advance Decisions with MedicAlert in order to ensure that their wishes will be known and respected by medical professionals.

Given the legal obligation for health professionals to comply with Advance Decisions to refuse treatment under the MCA, it is crucial that doctors are reminded of the importance of checking with relatives of the patient if they are aware of an Advance Decision, as well as checking the patient's medical record and contacting MedicAlert if the patient is wearing an emblem.

Conscientious objections (paragraph 67)

This paragraph gives advice about situations where a doctor's personal beliefs (rather than their clinical judgement) conflict with a patient's refusal of treatment or the decision of a healthcare team or consultant not to provide, or to withdraw, a treatment. The guidance makes clear that while a doctor may withdraw from a patient's care in these circumstances, there is an obligation to make sure that arrangements are made for another doctor to take over their role.

The advice does not apply to situations where there is a disagreement based on clinical judgement about whether a treatment should be provided (see paragraph 42 of the guidance).

Question 15.

Do you agree that the guidance makes clear the circumstances in which a doctor can withdraw from a patient's care where they have a conscientious objection to the withdrawal or withholding of a life prolonging treatment?

YES

Comments:

Compassion in Dying welcomes this section in the proposed guidance and particularly welcomes the reference to the duty to refer the patient to a colleague in case of conscientious objection, in order to prevent that a patient is left with nowhere to turn.

Question 16.

Can you think of any obstacles that would prevent doctors from following this advice in the different settings in which patients receive care?

YES

Comments:

Compassion in Dying does receive calls from people whose doctor refuses to be involved in decisions to refuse treatment. Doctors should be made more aware of their duty to refer to a colleague in these instances.

Paragraphs 68 to 72

There have been a number of concerns raised with us in recent years about the way some doctors deal with patients' relatives, including bereavement support and death

certification, and about encouraging greater sensitivity to cultural and religious practices. The guidance is intended to ensure that doctors properly consider the issues at the appropriate time.

Question 17.

Do you think this section gives sufficient detail about the key issues that need to be considered after a patient's death?

NOT SURE

Comments:

Following a death, the well-being of family and those close to the individual is paramount. Health and social care staff are often the first point of contact for family members in dealing with the death of a loved one. Compassion in Dying agrees that more attention should be given to care after death and welcomes the inclusion of a separate section on this issue in the proposed guidance.

A survey for Dignity in Dying has shown that general support from health and social care workers is seen as important by 85% of all respondents.¹⁶ Health and social care professionals should have the necessary skills to provide good quality care after death. Compassion in Dying would like to see high quality bereavement skills training for health and social care staff.

In this context it is worth mentioning that attitudes towards death and the grieving process vary significantly across different cultures. This aspect will need to be taken into account.

Question 18.

Do you think the guidance will encourage doctors to raise organ donation with those close to the patient without imposing an obligation to raise organ donation when it is not appropriate?

YES

Comments:

In light of respecting a patient's wishes with regard to organ donation it is helpful for the guidance to encourage doctors to raise the issue of organ donation, whenever appropriate. This will give those close to the patient the opportunity to disclose a patient's wish for organ donation if that is the case.

The advice in paragraph 72 is based on the understanding that the team providing treatment to a patient will not also be responsible for making any decisions about whether the patient would be a suitable candidate for organ donation.

Question 19.

¹⁶ ICM poll, commissioned by Dignity in Dying, May 2008. Dignity in Dying campaigns for greater choice, control and access to services at the end of life. Compassion in Dying was set up to take over and expand the charitable work identified by Dignity in Dying. The two organisations share premises and some staff but have distinct aims and are governed by separate Boards.

Do you agree that this separation of roles will always be practicable?

Comments:

Compassion in Dying does not have any specific expertise in relation to organ donation.

Paragraphs 74 to 82

This section focuses on the particular anxieties and difficulties when making decisions that affect the lives of children and young people, and especially premature babies.

The guidance builds on the advice in *0-18 years: guidance for all doctors (2007)*, which sets out all doctors' obligations towards children and young people, whether or not they routinely see them as patients. *0-18 years* does not specifically deal with end of life decision making but it gives detailed advice on important matters such as assessing capacity, making best interests assessments and resolving disputes.

This guidance does not seek to duplicate that advice but provides some additional advice on some of the particular difficulties that arise when decisions are being made for very ill babies or other children and young people. The guidance seeks to highlight both the clinical complexities and emotional difficulties and signpost to other sources of information available to help doctors making these decisions.

Question 20.

Do you know of any particular concerns about the treatment of neonates, children or young people that are not adequately covered in this guidance?

NO

Comments:

Compassion in Dying welcomes the fact that the proposed guidance emphasises the importance of respecting young people and children's views about their health. They should be involved as much as possible in discussions about their care. The importance of partnership and good communication with the parents is also sufficiently highlighted.

Paragraphs 83 to 97

We have replaced the traditional term 'artificial' with the term 'clinically assisted' nutrition and hydration (paragraph 85) to address the confusion that seems to be caused for members of the public by the use of the term 'artificial' nutrition and hydration. Since neither the techniques/equipment nor the food and water can be accurately described as 'artificial' it seems sensible to find an alternative way of describing the use of tubes, PEGs and cannulas to provide nutrition and hydration. We believe the term 'clinically assisted' makes a better distinction between helping a patient to take food and drink by mouth and using tubes, lines and other clinical interventions to meet patients' nutrition and hydration needs.

Question 21.

Do you agree that the term 'clinically assisted' nutrition and hydration is better than

'artificial' in describing the techniques used to feed and hydrate patients who cannot take food or water by mouth, even with support?
NOT SURE

Comments:

Compassion and Dying recommends that legal opinions are sought before recasting %artificial+nutrition and hydration as %clinically assisted+nutrition and hydration, in order to ensure that this change of terminology would not impact on existing case law and legal precedent in this area.

From a more general point of view, Compassion in Dying is also concerned about confusing the general public's understanding even further by making these changes. This already is a very complex and controversial area of end-of-life decision making. Therefore, it is of crucial importance to provide people with clear, understandable and consistent information on what is meant by %artificial+nutrition and hydration.

There is some evidence that older patients, in care home and hospital settings, may not get the help they need to enable them to eat and drink. There is also concern that in some cases, where patients are unable to take food and drink by mouth, the possibility of providing clinically assisted nutrition and hydration may not be properly considered.

Question 22.

Do you think that the guidance in paragraphs 83-84 emphasises clearly enough a doctor's responsibility to establish whether a patient's needs for assistance with oral nutrition and hydration are being met?
YES

Comments:

Compassion in Dying agrees that it is important to highlight a doctor's responsibility to establish whether a patient requires assistance with taking in oral nutrition and hydration. The relevant section makes this sufficiently clear.

Deciding what forms of assisted nutrition and hydration are appropriate in the treatment and care of an individual patient is often more clinically complex than many people appreciate. In addition, the emotional distress in end of life decision-making can be felt particularly strongly when clinically assisted nutrition and hydration are being considered. This is because some

people see these interventions not as medical treatment but as part of basic care. To address these issues, the guidance sets out (in paragraphs 85-87) the clinical uncertainties and other non-clinical factors that can complicate decisions about the needs of individual patients.

Question 23.

Do you agree that setting out these complicating factors is helpful?

YES

Question 24.

Do you think that there are any other factors that should be included in paragraphs 85-87?

Comments:

It might be helpful to highlight in these sections that following on from the fact that this is a form of medical treatment, artificial or clinically assisted nutrition and hydration can be refused, both by a competent patient or by an incompetent patient in advance of losing capacity (by making an Advance Decision). At the same time, it is important to emphasize that patients cannot refuse basic care and that they will be kept comfortable at all times.

Some patients may want to request in advance that clinically assisted nutrition and hydration be provided up until the moment they die, because they see these interventions not as medical treatment that can be withdrawn or withheld but as part of basic care. Paragraphs 54-55 of the draft guidance set out general principles about responding to advance requests for treatment and paragraph 93 applies these principles to clinically assisted nutrition and hydration.

Question 25.

Are there any specific considerations for responding to requests for clinically assisted nutrition and hydration that are not addressed by the guidance in paragraphs 54-55 or 93?

NO

Comments:

Compassion in Dying agrees with the provisions in these sections (see our response to Question 11).

Given the importance that many people attach to clinically assisted nutrition and hydration, there are some situations, involving patients who lack capacity to make their own decision, where the public may want additional reassurance that any decision not to start or to continue with clinically assisted nutrition or hydration will be made on a sound basis.

Question 26.

Do you agree that paragraphs 90-97 provide clear advice to doctors to enable them to make sound decisions about clinically assisted nutrition and hydration involving patients

who lack capacity?
YES

Comments:

We agree that these paragraphs provide clear advice to doctors. In addition, we would like to suggest including a reference to the Liverpool Care Pathway (LCP), which has been developed to provide high-quality end-of-life care for people who are imminently dying, i.e. within hours to a few days, in a hospital setting. As pointed out in the proposed guidance, the evidence does not support that artificial hydration or nutrition has a role to ease symptoms and suffering and may, in fact, be an extra burden for the patient.

The Liverpool Care Pathway is helpful in the way that it reminds clinicians of the importance of thinking about providing, continuing or discontinuing ANH in Goal 3 of the pathway, which describes discontinuation of inappropriate treatments.¹⁷ Here, decisions about whether interventions such as blood tests, antibiotics and the administration of IV fluids and medications are still felt to be conferring benefit to each individual patient commenced on a pathway are made.

Paragraph 91 addresses situations where a patient's death is not imminent (i.e. expected within hours or days) and where, while clinically assisted nutrition and hydration is likely to prolong their life, the doctor judges that providing it would cause the patient suffering which would be intolerable in all the circumstances. The purpose of this guidance is to ensure that the patient's interests are thoroughly considered prior to any final decision about whether to provide treatment.

We expect that such circumstances might arise in relation to, *for example*, a new born baby with a very poor prognosis who has one or more severe conditions whose treatment involves invasive painful procedures which may be of doubtful overall benefit.

Question 27.

Do you think that the guidance would apply in these circumstances?
YES

Comments:

Compassion in Dying agrees with what is set out under paragraph 91. The best interest of the patient must be central to each decision about whether to provide treatment, even if this decision might have a life-shortening effect.

Question 28.

Can you suggest any other situations where this guidance would apply?
YES

Comments:

¹⁷ <http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/pdfs/LCP%20HOSPITAL%20VERSION%2011%20%28printable%20version%29.pdf>

This will also apply in the instances in which the patient has expressed a wish for the treatment to be discontinued. This can be a refusal of treatment by a competent patient or a refusal of treatment by an incompetent patient who has made a valid and applicable Advance Decision to refuse treatment.

Question 29.

Do you think that the advice in paragraph 91 about seeking a second or expert opinion, is practicable in all healthcare settings?

YES

Comments:

The procedure set out in paragraph 91 is sensible. Compassion in Dying recommends that the guidance states that doctors have a responsibility to request a policy in this area from their employers if they feel the procedure for securing a second or legal opinion in their place of work is not adequately clear.

Paragraphs 98 to 112

This section of the guidance addresses concerns raised by patients and the public that decisions about future cardiopulmonary resuscitation (CPR) attempts may be made without informing or consulting with the patient and/or the patient's family. It also takes account of other public concerns that patients should not be subject to unnecessary, distressing discussions where their wishes are known or CPR clearly would not work. The guidance aims to achieve a reasonable balance between a) informing and b) consulting patients or those close to them about decisions to attempt, or not attempt, CPR.

Question 30.

Do you agree that the guidance in this section achieves this balance?

NOT SURE

Comments:

In general, it is crucial that doctors clearly communicate with patients and their loved ones on this subject. Patients and their loved ones must be involved in these important decisions. This should always be the starting point.

Paragraph 104 does not accurately reflect the legal power of the welfare attorney (LPA). Rather than the treating health professional making the decision not to attempt CPR and informing the attorney, the attorney is first in line to make the decision on behalf of the patient. Health professionals must comply with the decisions made by a legally appointed attorney who acts within his or her capacity.

Again, doctors must be made fully aware of their legal responsibilities under the MCA, and this guidance should clearly set out those responsibilities.

Where CPR has only a very small chance of working and a patient wishes CPR to be attempted, the guidance (paragraph 108) asks the doctor to leave a decision about

attempting CPR until the time of any cardio-respiratory arrest. In the event that the patient suffers a cardio-respiratory arrest, a decision would be made based on the patient's condition at the time and taking account of the importance they attach to CPR being attempted.

Question 31.

Do you agree this is the right approach to dealing with these situations? Please tell us why you agree or disagree.
NOT SURE

Comments:

In this paragraph it is important to reinforce the difference between requesting and refusing some form of medical treatment. While people have the right to refuse medical treatment, they do not have the right to request treatment. It therefore seems logical that it will be up to the treating health professional to decide whether or not the requested treatment should be provided at a given time.

In the context of doctors deciding whether or not to attempt CPR, it is crucial to remind doctors of the fact that they must not substitute their own values when assessing the preferences of patients who cannot decide for themselves and that they must not rely on their personal views about a patient's quality of life. This is a huge concern for a group of disabled people. Baroness Campbell of Surbiton, chairwoman of the all-party disability group, regularly explicitly expresses this concern. All health professionals must comply with the GMC Guidance on Personal Beliefs and Medical Practice.¹⁸

Working in teams

The guidance includes a number of references to the role of teams in making decisions about end of life treatment and care. It recognises that the care for patients who are dying is often provided by healthcare professionals working in multi-disciplinary teams, and across different healthcare settings, including in the patient's home.

The guidance draws attention to the issues that can arise in relation to teams. These include issues in relation to communication and coordination of care (particularly across service boundaries) as well as the support that teams may need to make complex and often emotionally difficult decisions and to provide support to patients, their families, carers and others close to them.

Question 32.

Do you think that there are any important issues about team working in end of life care that are not sufficiently addressed by the guidance?
YES

Comments:

The importance of good communication and coordination within a team and between teams cannot be over-emphasized. Given the legal obligation for health professionals to comply

¹⁸ General Medical Council, *Personal Beliefs and Medical Practice*, March 2008

with valid and applicable Advance Decisions to refuse treatment, we believe some kind of system for flagging up the existence and content of Advance Decisions to refuse treatment is indispensable. We believe that a recording system for Advance Decisions to refuse treatment will help to ensure that this crucial information about a patient is shared across different healthcare settings. This system may also be used to flag up the existence of a lasting power of attorney, who has the legal power to make welfare or healthcare decisions for a person who has lost capacity to make these decisions.

It is also important to keep in mind that end-of-life care often involves both health and social care services.

General questions

Question 33.

Can you point to any guidance produced by other organisations, or examples of good practice at a local or national level, that it might be helpful to flag up in particular sections of the guidance?

YES

Comments:

The Department of Health funded Dignity in Dying¹⁹ to produce an *Advance Decisions Toolkit for Health Professionals*.²⁰ It would be very useful to make reference to this toolkit in the guidance as the primary purpose of the toolkit is to offer practical guidance on Advance Decisions to health professionals. The toolkit is available in hard copy and is downloadable from our website. Hundreds of copies have been downloaded by organisations concerned with the implementation of the Mental Capacity Act 2005 and the sections relating to Advance Decisions to refuse treatment (e.g. NHS Trusts, hospitals, hospices, educational institutions).

We plan to develop some additional materials to accompany the guidance. The purpose of these materials is to help to bring the principles of the guidance to life, for example by using case studies or examples of good practice to demonstrate how the guidance might apply in different practical situations or different healthcare settings.

Question 34.

Are there any particular issues in the guidance that you would like to see covered in these additional materials?

YES

Comments:

Compassion in Dying suggests the following issues to be covered in the additional materials:

¹⁹ Dignity in Dying campaigns for greater choice, control and access to services at the end of life.

Compassion in Dying was set up to take over and expand the charitable work identified by Dignity in Dying. The two organisations share premises and some staff but have distinct aims and are governed by separate Boards.

²⁰ <http://www.dignityindying.org.uk/includes/spaw2/uploads/files/Advance%20decisions%20toolkit.pdf>

- How to communicate most effectively with patients and their loved ones, acknowledging the sensitivity of these conversations and the need for health and social care staff to acquire appropriate communication skills.
 - Available training and education programmes on the provision of good end-of-life care in general (with the emphasis on communication skills training).
 - Good practice in effectively working together and sharing information within teams and across teams.
 - Good practice examples on discussing and implementing Advance Decisions to refuse treatment and advance care plans.
 - An oversight of the different categories of people that can be appointed under the MCA 2005 to be involved in welfare and health care decisions after a person has lost capacity.
-

Impact on standards of service and care

In further developing this guidance we want to know about any changes that doctors, or the organisations in which they work, might have to make to their existing practice or arrangements for providing healthcare services to patients (and those close to them) in order to meet the standards set out in the guidance.

We also want to assess any ways in which the guidance would impact specifically on the quality of care experienced by particular patients or groups of patients (and those close to them).

The following three questions are intended to gather evidence on these points.

Impact on existing practice

Question 35.

Can you identify any changes that would be needed in order to meet the standards set out in the guidance? (for example, in service organisation or delivery, or in the resources needed to provide treatment and care to patients towards the end of life)

No comments.

Impact on equalities and human rights

Question 36.

Do you think the guidance places sufficient emphasis on the importance of equalities and human rights considerations when making decisions about end of life treatment and care?
NO

Comments:

At a recent case at the House of Lords (the case of Debbie Purdy), the Director of Public Prosecutions conceded that Article 8 of the European Convention on Human Rights extends to the manner and quality of death, as the quality of death is undeniably linked to the quality of life. Although no decision has been reached yet in the case, the engagement of Article 8 reflects the weight that is given to personal autonomy, self-determination and quality of life.

Compassion in Dying recommends that the guidance clearly acknowledges the relevance of Article 8 of the European Convention on Human Rights throughout the guidance, for example by including it under paragraph 100c. Through article 8, human rights law gives a legal basis to a person's autonomy to make decisions about their health, including what is happening to them at the end of their life.

Question 37.

Do you think that the guidance will have a different impact - either positive or negative - on particular groups of patients? (for example, on the basis of a person's age, colour, culture, disability, ethnic or national origin, gender, lifestyle, marital or parental status, race, religion or beliefs, sex, sexual orientation, or social and economic status).

NOT SURE

Comments:

The guidance must emphasise the importance of communicating clearly with all patients, and ensuring all patients have the opportunity to discuss their wishes and needs for the end of life, and have their choices respected, regardless of their background.

Question 38.

We would welcome any additional comments you have on the draft guidance. These may include, for example:

- a. anything that is missing from the guidance that you think should be included
- b. areas of duplication or where you think the guidance could be shortened
- c. whether you think the level of detail in the guidance is about right/too much/too little

Comments:

Under paragraph 17c, Compassion in Dying recommends that a reference is made to the right to refuse treatment in advance of losing capacity, by making an Advance Decision to refuse treatment.

Paragraph 18d does not acknowledge the difference in legal status between Advance Decisions to refuse treatment and advance care planning. Health professionals have a legal obligation to comply with valid and applicable Advance Decisions to refuse treatment. This paragraph does not make this sufficiently clear.

Paragraph 18e does not accurately reflect the legal power of the attorney to make welfare and healthcare decisions for a person who has lost capacity. Health professionals must comply with the decisions made by a legally appointed attorney who acts within his or her capacity. Rather than the treating health professional making the decision and seeking agreement from the attorney, the attorney is first in line to make the decision on behalf of the patient.

The proposed guidance fails to clearly explain the legal tools created by the MCA 2005: Lasting Powers of Attorney (LPA), Independent Mental Capacity Advocates (IMCA), Health

Care Proxies. Given the power of LPA \S to make healthcare decisions, including decisions to refuse life-sustaining treatment, their role and powers should be more carefully spelled out in the proposed guidance.

The guidance should also make clearer mention of Independent Mental Capacity Advocates (IMCA \S), who will be provided for people who lack capacity and who have no friends or family. Finally, the guidance should also explain the role and function of a Health Care Proxy, who is someone people can nominate to hold a copy of their advance decision, to be with them if they have to go into hospital and to be involved in any decisions about their care. It will be important to emphasise that they are not able to override an advance decision to refuse treatment.

Compassion in Dying also suggests that the guidance states that doctors have a responsibility to request training in a particular area if they feel they have not been given adequate training. This could include training on advance care planning, advance decisions to refuse treatment, communication skills or palliative care in general.

In terms of structure, it might be worth considering having a separate guidance on the subject of artificial nutrition and hydration, as this is a particularly complex and controversial area of end-of-life decision making that deserves particular attention.

Compassion in Dying, 17 July 2009