Memorandum

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Regulating doctors
Ensuring good medical practice

To: Peter Rubin
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Date: 17 May 2010

Treatment and care towards the end of life: Good practice in decision making: press briefing, 19 May 2010.

Attendees

The following journalists have so far confirmed they will be attending the briefing in Room 2.05, GMC offices

(names to be added)

Agenda

9.00 for 9.15 Arrival and breakfast: End of Life vodcast playing

9.15 – 9.30 GMC presentations from panel:

Niall Dickson 5 mins

- *Welcome and introductions*
- *Short explanation of why we are here (launching new guidance on treatment and care towards the end of life, following major consultation, guidance developed over two years)*
- *Thanks to those individuals and organisations who have helped shape the guidance through their contributions*

- *The major theme emerging from the consultation was that poor communication is a major barrier to good care- how the guidance will help address this*
- Introduce Peter Rubin

Professor Peter Rubin 5mins

- *How this guidance can support doctors and patients*
- *End of life treatment and care from a clinician's perspective*
- *Why this guidance is needed: doctors have asked us for further guidance, it will support doctors and improve standards of care at the end of life*
- *Introduce Jane O'Brien*

Jane O'Brien 5 mins

- *Brief background on the development of the guidance (the factors that prompted the new guidance and the process of developing the guidance)*
- *What we learnt from the consultation, and how the responses we received informed the development of the guidance (particularly highlighting issues relating to communication)*
- *New areas covered in the guidance*
- *The GMC's plans to help doctors use this guidance- vignettes launched now, further work being planned to help doctors implement guidance*

9.30 – 10.15 Journalists' Q&A session with panel (chaired by Stephanie McNamara and with Sharon Burton also on the panel)

- *Professor Peter Rubin and Niall Dickson to handle questions about the aims and purpose of the guidance*
- *Professor Peter Rubin to highlight his own experiences as a doctor treating patients towards the end of life*
- *Jane O'Brien and Sharon Burton to handle questions requiring detailed answers about the guidance*

10.15 – 10.45 Time for follow-up interviews

Note on evidence from the consultation: Poor communication as a major barrier to good care at end of life:

Overview:

The major theme that emerged through the consultation was the importance of good communication between doctors, the wider healthcare team, patients and their family/ carers.

Many respondents highlighted ways in which poor communication can lead to poor care at the end of life, for example where it leads to doctors (and others) not knowing enough about or failing to take sufficient account of a patient's personal preferences or concerns about aspects of their treatment and care. Poor communication between doctors, team members and others involved in providing health and social care services for patients can mean that care isn't coordinated in a way that meets the particular (often complex) needs of a dying patient and their families.

Patients and patient groups responding to the consultation placed importance on doctors giving patients opportunities to talk about death and dying; what they might want in terms of their treatment and care towards the end of life; and other sensitive issues such as what they might want to happen after they die.

The GMC has taken on board all of these messages in the updated guidance. We have given more prominent advice about the role of family members and others close to the patient; the role of the healthcare team; and the benefits of advance care planning in ensuring that patients have the opportunities they want or need to explore the issues that they consider important.

Points made by respondents to the consultation:

- Communication problems cited included difficulties around out of hours provision and the frequent movement of patients between settings at the end of life. These were key times when things fall apart in relation to communication and coordination

- Importance of good communication with members of the healthcare team and wider multi-disciplinary care team

- Importance of improving communications with family and carers while balancing this with the need to respect patients' wishes about who information should be shared with

- Importance of doctors having training and support in communication skills

- Doctors and other professionals can forget that people don't understand the language/terminology that they use.

- Several of the groups noted that language can be a real barrier to people getting access to good care towards the end of life

- Doctors need to understand how to communicate with patients with a learning disability (Mencap)

- Doctors should think about things early and give people time to take in information and ask questions.

- A number of respondents (including Mencap, Age UK and NMC) highlighted the need for doctors and other healthcare professionals to take time to answer questions and to give patients and those close to them time to make decisions

- The BMA and other organisations said that doctors' ability to improve communications was dependent on the amount and quality of support available locally and on resource or time constraints

Key messages

Headline message:

- Poor communication/ Communication breakdown is a major barrier to good care towards the end of life

Top three messages:

- This guidance will help doctors navigate the complex decisions and ethical dilemmas that can arise when patients are approaching the end of life and help them to provide better care to patients
- Doctors must work together with patients, their carers and with other professionals in order to ensure patients receive high-quality care towards the end of life.
- Doctors need to listen to patients and create opportunities for patients to talk about their death, where they want to die and any other wishes or concerns they may have. This guidance helps doctors to ensure they are communicating effectively with patients as they approach the end of life.

General messages on end of life care:

- Everyone should expect high standards of care from their doctors towards the end of life
- Everyone is going to die, and so everyone needs to think what they might want at the end of life and talk to their doctor and family when the time is right.
- Every death is individual- every patient has different personal views, beliefs and circumstances and the guidance makes it clear to doctors that every patient must be treated as an individual. They must not rely on preconceptions of what kind of care particular groups of patients – for example, people with disabilities, the elderly, or those from ethnic minority groups – want towards the end of life
- Decisions at the end of life can be very difficult, and medical advances have added to the complexity, not least when the patient is a very young child. This guidance will help doctors when they are making these difficult decisions.

Key points about the guidance:

Consultation:

- The guidance has been developed following an extensive consultation with doctors, patients with life limiting or terminal illness and their carers, family members and health and social care teams. The GMC considered 529 written responses to the consultation and engaged with over 600 people at consultation events across the UK

Guidance- role and what's new:

- For the first time the guidance covers decisions involving neonates and infants; the benefits of and issues to raise in advance care planning; how to respond to a patient's advance request for treatment; doctors' responsibilities after a patient has died; conversations with families about organ and tissue donation. These were all issues around which doctors and patients asked the GMC for guidance.
- This guidance should give patients greater assurance that doctors have a duty to treat them as individuals and take steps to ensure that they receive the treatment and care they want towards the end of life.
- This guidance recognises the key role that family and carers play towards the end of life and makes clear to doctors that they should be involved and supported throughout.

Importance of good communication:

- Both doctors and patients need to be open about dying if patients are to have the end of life care they would like.
- The GMC is responsible for overseeing doctors' education and training and is working to improve doctor's training on communication with patients who may be dying. We have included training for medical students working with patients and their families towards the end of life in the new guidance for medical students' training, *Tomorrow's Doctors.* The curricula for doctors in the foundation years, and many of those for specialists, also identify the need for doctors to have a range of clinical and communication skills in providing care for patients at the end of life.
- All doctors working with patients approaching the end of life should be seeking to improve and develop their skills in this area and there are some excellent training resources available to help doctors

- The GMC is working with the 'End of Life Care for All' programme, a Department of Health e-learning project that makes online learning resources available to help doctors across the UK. We are developing an e-learning session that shows how the principles in our guidance might apply in some difficult situations that many doctors will find familiar. These resources will be launched in the summer.

Poor communication and discrimination:

- Many people receive high standards of care towards the end of life, but the reality is some do not. A major theme emerging from our consultation was that poor communication can prevent people receiving the care they would wish for at the end of life. This guidance aims to help change this, by highlighting the areas where problems can arise and the steps doctors can take to avoid this through, for example, advance care planning.

- The guidance makes clear that doctors must make sure they do not discriminate against patients, for example because of their age, disability or ethnic group. We know some of these groups have received poorer standards of care towards the end of life (through previous reports and responses to the consultation), and this is unacceptable. Doctors should be aware of these concerns and satisfy themselves that patients have sufficient information and support to be able to access high-quality care when they need it.

Resources:

- Doctors need time and resources to deliver good standards of end of life care, and these resources need to be available, even as NHS resource come under pressure/

- Patient safety comes first, and if patients are not being provided with an adequate standard of the care, the guidance makes clear that doctors must put that right where they can, and draw it to the attention of local managers or national bodies who are responsible for patient safety and standards of care.

Lines on specific topics within guidance:

Presumption in favour of prolonging life

- When providing care, a doctor must not be motivated by a desire to bring about the patient's death, and must start from a presumption in favour of prolonging life. But this does not mean that life prolonging treatment must always be provided, regardless of the patient's wishes or the burdens and risks it may bring.

Advance care planning

- Some patients worry that towards the end of their life they may be given treatments they don't want. Others worry that they will be under-treated or will not receive treatments they want until the very end of life.

- The wishes of people approaching the end of life are not always known by doctors, the wider healthcare team and patient's families, and this can lead to patients not getting the care they want, in the setting where they would want to receive it.

- Patients should be given the opportunity in advance to discuss what they might want during the later stages of their illness- including what treatments they may or may not want in an emergency; and other preferences like who they might want to make decisions for them.

- Advance care planning is a continuing dialogue with a patient, their family and carers, about how they want to be cared for when they become very unwell, and extending to conversations about where they would prefer to spend the last days of their life and what should happen to their body after they die. Recording an advance care plan will help ensure that everyone involved in treating the patient can understand and follow their wishes.

- Clearly advance care plans should be reviewed and updated as the patient's condition progresses.

- Everyone will die, and so we shouldn't be afraid to talk about what we want when the inevitable happens.

Organ donation

- When patients are close to death, and organ or tissue donation is likely to be a possibility, doctors should be prepared to explore whether the patient had expressed any views about donation, with the patient's family or others close to the patient.
- There is guidance available to support doctors in approaching families, including information about how the major faiths view the acceptability of donation.

Neonates, children and young people

- If children are able to express a view and make decisions, doctors must listen to them and take account of what they have to say

- Identifying the best interests of children and young people who may be approaching the end of life can be very challenging and complex and emotionally demanding decisions often need to be made. For example whether to continue intensive care for a very young, very sick baby whose prospects for survival are very poor.

- Doctors must recognise the important role of parents. They should work in partnership with them when considering which options for treatment are clinically appropriate and likely to be in the child's best interests.

- Doctors should be familiar with local services that offer support to parents and children and could help to resolve any disagreements or tensions that may arise between a child's healthcare team and the parents.

Clinically assisted nutrition and hydration

- When a patient is unable to eat or drink normally towards the end of life, providing clinically assisted nutrition and hydration may bring benefits but it may also cause patients distressing symptoms and complications and unnecessary suffering

- Doctors have to weigh up the benefits, burdens and risks that clinically assisted nutrition and hydration (e.g. through a tube in their stomach) might bring for a patient approaching the end of life. Doctors must always offer (or provide) clinically assisted nutrition or hydration when it would be clinically appropriate or of [overall] benefit to the patient.

- If a patient cannot make the decision, and has not made a binding advance refusal of the particular treatment, the doctor must decide whether the treatment would be of overall benefit to the patient, taking into account what is known about the patient's wishes and any previous request they made to receive that treatment.

- Where the benefits, risks and burdens of treatment are finely balanced, a patient's request for treatment will usually be the deciding factor.

- The guidance includes a number of safeguards to ensure that this is how decisions are made, including the need for a second opinion, and recommends that doctors get legal advice where necessary.

CPR

- CPR is an emergency intervention that tries to get the heart and breathing started and the circulation going, when a patient has a cardiac or respiratory arrest. Although CPR can do this in some cases, generally it has a low success rate. CPR can cause rib fracture and other harmful side effects, so if it's not successful attempting CPR may mean the patient dies in an undignified and traumatic manner

- If having a cardiac or respiratory arrest is an expected part of the dying process for a particular patient, then making a Do Not Attempt CPR decision (DNACPR) in advance can help to ensure the patient dies in a peaceful manner, and that the patient can spend their last hours or days at home or other community setting rather than in hospital after an emergency admission.

- It may also be necessary to consider making a DNACPR decision in advance for those patients where a judgement has to be made about whether the benefit of successful CPR would be outweighed by the burdens and risks for the patient, as this would be a difficult judgement to make in an emergency.

- These conversations can be difficult and distressing, for patients and their family and for members of the team caring for a patient. Unusually in the case of CPR, a decision, that it should not be attempted because it is not clinically appropriate, has to be made known to the healthcare team and recorded as part of the patient's care plan. If the patient isn't informed, but becomes aware of the decision, they may become very distressed.

- Doctors need to sensitively explore the issues with patients. There are many ways that this can be done and the guidance does not require doctors to force information on patients who do not want it.

Terminal sedation

- Pain relief at the end of life is an important issue and many patients have expressed concern about whether they will receive effective pain relief and other symptom management towards the end of life, especially in primary care settings.
- This is essentially a clinical issue. However, the guidance highlights the importance of palliative care, including effective management of pain and other distressing symptoms.
- We also stress the importance of ensuring that clinical decisions are based on up to date evidence and, where necessary, input from more experienced clinicians. A feature of the new guidance is the reference section which points to guidance published by other organisations such as the Royal Colleges and NICE. And the online version of the guidance provides hyperlinks to the relevant websites to make it easier for doctors to find this information.

ONLY IF PRESSED:

- We understand some people worry that doctors may use sedation inappropriately for managing pain in dying patients. Guidance on good clinical practice in this area is available from a number of sources.

- Doctors' treatment decisions for dying patients must be based on an assessment of the benefits, burdens and risks of treatment for the particular patient and any treatment provided must be of overall benefit to the patient.

Assisted suicide:

- This guidance is not about assisted suicide, or euthanasia, which are illegal in this country.

- It is for Parliament and for society to debate whether or not assisted suicide or euthanasia should be legalised, not the GMC

- The debate about assisted suicide is a very small part of the overall picture - over half a million people die every year in the UK but only around 25 people died through assisted suicide at Dignitas last year. Other vitally important issues, around providing good standards of end of life care, should not be overshadowed by the debate.

- We hope this guidance helps patients have confidence that their doctor will help them to receive high-quality care towards the end of life.

ANNEX

Q and A (to be added)

High profile cases

Code A - accused of 'irresponsible and reckless' treatment of 18 patients who died shortly after he gave them irresponsibly high doses of morphine- case ongoing.
Line to take: Code A has been suspended by the GMC since September 2004. As he is currently the subject of an ongoing hearing, it would be inappropriate to comment further

Dr Jane Barton- conditions on registration, doctor now retired
Line to take:

This was a complicated and difficult case which has caused anguish and upset to a great many people. We understand and support the view of the CHRE that Dr Barton should have been erased from the medical register but also understand and accept the legal position in relation to an appeal.

The aim of this new guidance is to help doctors make complex decisions at the end of life, and help to improve the standards of end of life care that patients receive, not to make it easier to erase doctors. However, the GMC will investigate any complaints that doctors are seriously or repeatedly failing to adhere to the good medical practice set out in the guidance. Serious or persistent failure to follow the guidance may put doctors' registration at risk.

Code A erased from the GMC register in 2005. Code A has admitted publicly that he has helped several people to die, including by helping them to travel to Dignitas. Code A wrote to the DPP in April inviting criminal charges, to expose the 'hypocrisy' of the current system.
Line to take:
Our guidance is very clear that all doctors must act within the law. Assisted suicide is illegal in the UK, so, if patients are concerned that their doctor is breaking the law, they should inform the police.

Code A accused of hastening babies' deaths, at an FTP hearing in 2007 his fitness to practise was found not to be impaired. Code A is fully registered with a licence to practise medicine.
Line to take:
We hope this guidance will help all doctors make complex decisions at the end of life, and help to improve the standards of end of life care that patients receive. The purpose of this guidance is not to make it easier to erase doctors. However, the GMC will investigate any complaints that doctors are seriously or repeatedly failing to adhere to the good medical practice set out in the guidance. Serious or persistent failure to follow the guidance may put doctors' registration at risk.