Code A

Memorandum

General
Medical
Council

Regulating doctors
Ensuring good medical practice

To: Peter Rubin
Niall Dickson
Jane O'Brien
Sharon Burton

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From: Rachael Bruce Code A

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Paul Philip
Ben Jones
Stephanie McNamara
Press Office Team

Date: 14~~7~~ May 2010

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

Attendees

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

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James Meikle, *Guardian*
Danny Buckland, *Daily Mirror*
Sophie Borland, *Daily Mail*

All of the outlets we have contacted have expressed an interest in attending but have so far not been able to confirm the name of the journalist who will cover the story.

We will confirm the full list of attendees on Tuesday 18 May.

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Agenda

9.00 for 9.15 **Arrival and breakfast: End of Life video 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)*
- *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*
- *The GMC's plans to help doctors use this guidance- vignettes launched now, further work being planned to help doctors implement guidance*
- *Introduce Peter Rubin*

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Professor Peter Rubin **(5 mins)**

- *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*
- Thanks to those individuals and organisations who have helped shape the guidance through their contribution
- 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*

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

Peter and Niall to handle questions about the GMC's role in providing guidance and the general aims of the guidance

Peter to highlight his own experiences as a doctor treating patients towards the end of life

Jane and Sharon to handle questions requiring detailed answers about the guidance, including questions about:

- Advance care planning and the role of palliative care
- Acting on advance requests for treatment
- Assessing overall benefit when a patient lacks capacity to decide
- Approaching conversations about organ and tissue donation
- Decisions involving neonates and infants
- Acting on advance refusals of treatment
- Discussing DNA CPR decisions
- The sensitivities involved in meeting patients' nutrition and hydration needs, and making decisions about providing nutrition and hydration by drip or tube.

10.15 – 10.45 Time for follow-up interviews

Why we are highlighting poor communication as a major barrier to good care at end of life:

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 – creating opportunities for patients to raise issues or discuss their concerns
- 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 statistics:

- There are just under 600,000 deaths a year in the UK (579,690 deaths in 2008)- around 1600 deaths a day

This includes:

- Half a million deaths a year in England and Wales (509,000 deaths in 2008): Source ONS:
- http://www.statistics.gov.uk/pdfdir/bdths0509.pdf

- 32,000 died in Wales in 2008 (Source ONS)

- 55,700 died in Scotland in 2008 (Source: National Register of Scotland)

- 14,900 died in Northern Ireland in 2008 (Source: NISRA)

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.

Q and A

Development of the guidance:

Q: Why did you decide to produce this new guidance?

A: A number of developments made it necessary to update our previous guidance *Withholding and Withdrawing Life-Prolonging Treatments* (2002). These include changes in the law; requests from doctors to clarify some areas of the guidance such as that around CPR; developments in Government policies around the provision of end of life care; and ongoing public concerns about the standard of end of life care provided to some patients such as people with disabilities or dementia.

To keep the guidance up to date and fit for purpose, we clearly had to reflect the new legal requirements which affect decision making for adult patients who lack capacity or have impaired capacity to make their own decisions. And there have been a number of court cases since 2002 which have provided greater clarity on a number of issues in end of life treatment and care.

Q: What have been the changes to the law?

A: Since we published guidance in 2002 there have been significant changes to legislation – including the Mental Capacity Act 2005 (England and Wales) which established a framework for making decisions about medical care and treatment for people who are unable to decide for themselves. We were also learning how the Adults with Incapacity (Scotland) Act 2000 was working in Scotland.

Case law in this area has also been taken into account; for example the factors to be considered in decisions involving very young children (NHS Trust v MB, 2006) and how doctors should respond to advance requests for life-prolonging treatment (Burke v GMC, 2005).

Finally, there have also been changes to public policy - Government across the UK has placed greater priority on improving the availability and quality of end of life care for all patients, including ensuring that the needs of more vulnerable groups are specifically addressed.

Q: What were the specific components of the previous guidance which required amendment and why?

A: All the sections of the guidance that dealt with patients who lacked capacity needed updating – these included;

- advice on assessing capacity
- assessing the patient's best interests
- advance refusals of treatment

There were also some consequential changes needed on:

- resolving disagreements about best interests
- treating children
- the legal background

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We also needed to add guidance to cover the introduction of Lasting Powers of Attorney (including Welfare Attorneys)

Apart from the legal issues, we needed to update the guidance to bring it into line with new guidance on *Consent: patients and doctors making decisions together* which proposed a model for a doctor/patient partnership in decision-making.

Q: What's new in this guidance?

A: 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.

Q: What has changed in the guidance since you put the draft out for consultation?

A: Guidance on treating premature babies and children, a doctor's responsibilities after a patient has died, advance care planning and responding to advance requests for treatment are areas where there has been significant development following the consultation.

A new section has been added in that recognises the key role that family and carers play towards the end of life and makes clear to doctors that they should be involved, following feedback during the consultation that the role of family and carers needed to be clearly defined in the guidance.

Q: How did the GMC decide what the guidance should say?

A: 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

Q: Will this guidance make it easier for the GMC to discipline or erase doctors?

A: The aim of this 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.

Q: The GMC is responsible for regulating doctors' medical education and training. What are you doing to ensure that doctors are properly trained to help patients at the end of life?

A: 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 responsible for overseeing doctors' education and training and will be working with the medical schools, postgraduate deaneries and other training providers to ensure that doctors have the necessary clinical and communication skills to provide care that meets a patient's individual needs, wishes and preferences. The new requirements on medical schools are set out in *Tomorrow's Doctors* 2009 and will start being implemented in 2011.

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The GMC is also 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. These resources will be launched in the summer.

Resources:

Q: How much is it going to cost to implement this guidance? Can the NHS afford this?

A: Patient safety is the main priority, and it is vital resources are available to give patients a good standard of end of life care. Investment in end of life care is important, but there are also ways of working more efficiently and effectively which will make the money available work better. Communication is vital as this often avoids patients having treatments they don't want, or being treated in a hospital when they would prefer to be cared for at home.

Q: The guidance tells doctors to blow the whistle if they feel there is a shortage of resources for their patients at the end of life. Did you think it was important to include this as we approach an era of austerity for the NHS?

A: 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.

Q: How can you expect doctors to blow the whistle on a lack of resources in the NHS, when there have been so many high-profile cases of doctors being suspended or sacked after doing so?

A: Doctors can take confidence that the GMC guidance supports them in making known any significant lack of resources. Doctors have a duty to prioritise the needs of their patients and 'make the care of the patient their first concern' (Duties of a Doctor, Good Medical Practice 2006).

Advance care planning

Q: Will doctors be struck off if they deny patients' wishes in a living will?

A: This would depend entirely on the circumstances of the case, and all cases are considered individually. This guidance is not about striking off more doctors, it is about responding to the profession's requests for more guidance to help them make complex ethical decisions, and providing a framework for doctors to help them provide good standards of care to patients at the end of life.

Q: What takes precedence - a living will or a doctor's judgement?

A: Patients' decisions *to refuse treatment* have precedence, whether the decision is made at the time treatment is offered or in advance, by a patient who thinks they may lose capacity.

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.

Q: Is this the first time the GMC has told doctors that they need to follow patients' advance care plans and decisions to not have life-saving treatment?

A: This is the first time that the GMC has issued guidance for doctors on developing and using advance care plans.

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.

The new guidance takes a different approach – focusing on planning with patients how to deal with the patient's condition as it progresses and the patient's life draws to a close. This allows patients to make informed choices, for example about where they want to receive care – the practical help their family can expect to receive if this is the case; and any treatments that they might want, but cannot usually be provided in the community.

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.

Q: What happens if a patient changes their mind?

A: 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.

Q: Will the guidance stop doctors discriminating against patients?

A: 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.

Organ donation

Q: What's the GMC's justification for telling doctors to ask all patients about organ donation?

A: 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.

In the consultation process, a strong message from patients and carers was that they wanted doctors to create more opportunities to talk about organ donation. However, the guidance is very clear that doctors shouldn't push people to have these conversations and no-one should be persuaded or coerced into donating organs.

There is guidance available to support doctors in approaching families, including information about how the major faiths view the acceptability of donation.

Neonates and children

Q: What does the guidance say about treating children and babies?

A: 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.

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.

Q: Is this guidance in response to concerns that parents are being cut out of decisions about their babies?

A: In our experience doctors really want to help parents as much as possible and reach a consensus about how to proceed. 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

Q: Doesn't this guidance explicitly empower doctors to starve their patients to death?

A: 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.

We recognize that decisions about CANH are particularly sensitive, and so the guidance includes a number of safeguards o ensure that doctors are considering all the relevant criteria when assessing overall benefit; these include obtaining a second opinion and regularly reviewing the patient's condition.

Q: Can you give an example of when you might stop providing hydration?

A: Rarely, there may be clinical reasons for doing so, but the GMC does not give clinical advice. The guidance is addressing the ethical (and legal) principles and the criteria to be used when deciding whether to provide nutrition or hydration by tube or drip. The main points are:

1. Nutrition and hydration by tube or drip are regarded in law as medical treatment. We follow this position in our guidance..

2. The same issues arise for CANH in deciding whether a treatment is clinically appropriate and of overall benefit to the patient as for other treatments.
3. We set out the legal and ethical framework for decision making and the criteria that should be considered in deciding whether to offer or provide a treatment. The GMC cannot say that a particular clinical decision would *never* be appropriate.

4. We address this issue in the guidance because it is a matter of concern to the profession and the public. Doctors have to use judgement to decide – weighing up all the benefits burdens and risks, patient's wishes and preferences etc, to decide what is of overall benefit in the circumstances.

5. Doctors must not discriminate against patients on the basis of unfounded assumptions about the impact a patient's disability, age, race etc has on their healthcare needs or quality of life.

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Q: Does the patient and their family not get a say in whether they receive food and water?

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

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.

Q: Won't the guidance on clinically assisted nutrition and hydration discriminate against patients with Alzheimer's or dementia, who are more likely to be denied food and water at the end of life?

A: The guidance makes it very clear that doctors should not discriminate against any patient because of their disability.

~~**Q: Can you give an example of when you might stop providing hydration?**~~

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CPR

Q: Why should doctors be able to make the decision on whether to attempt CPR? Why is your guidance on talking to patients about CPR different than for other treatments?

A: The reason our guidance is slightly different for CPR is because CPR is always given to patients if they arrest unless there is a DNAR order already in place- with any other treatment, an active decision is made to provide it.

Some patients prefer not to talk about whether they would want to be resuscitated, as it can be a very distressing thing to think about. In these cases, doctors can ask patients for permission to talk to their family or carers so the doctor knows their views.

Q: What does your guidance say about CPR? Are you asking doctors to deprive patients of their right to this potentially life-saving treatment?

A: 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 for patients with life-limiting conditions.
CPR can have harmful side effects, and if not successful, may mean the patient dies in an undignified and traumatic manner

Making an advance Do Not Attempt CPR decision can help to ensure a patient dies in a peaceful manner and can ensure the patient can spend their last hours or days where they wish to die, rather than in hospital following 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.

~~Q: Why is your guidance inconsistent about CPR? Are you asking doctors to deprive patients of their right to this potentially life-saving treatment?~~

Comment [j1]: Is this the right question? Not sure what the answer addresses... do we need this?

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~~A: 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 therefore 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

Q: Does this guidance not allow doctors to sedate someone to death? Shouldn't the GMC be trying to prevent this, especially after the cases of Dr Barton and Code A?

A: This guidance does not allow doctors to cause someone's death by giving them too much sedative, and the fitness to practise hearings against Dr Barton and Code A Code A show how seriously we regard any such action. This guidance supports and complements clinical guidance.

Sedation at the end of life is a clinical issue – the guidance does not address this directly. Where doctors use sedation as a means of controlling otherwise uncontrolled symptoms, they must do so within the framework of the guidance and following guidance from specialist groups on best practice.

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.

Doctors also must regularly reconsider what treatments are of overall benefit to the patient, as their condition changes.

Q: Are doctors doing enough to prevent patients dying in pain?

A: 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 community settings.

Comment [j2]: Should we refer to other distress from loss of dignity and autonomy etc? It's not just pain that people fear....

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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.

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- 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.

Assisted suicide:

Q: Can doctors help patients to die?

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A: No. 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.

Q: How much does the guidance reflect the DPP's recent guidelines on assisted suicide?

A: 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

High profile cases (Questions to be answered by Niall or Stephanie)

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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.

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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.