

New guidance for doctors -
Treatment and care towards the end of life

General
Medical
Council

Regulating doctors
Ensuring good medical practice

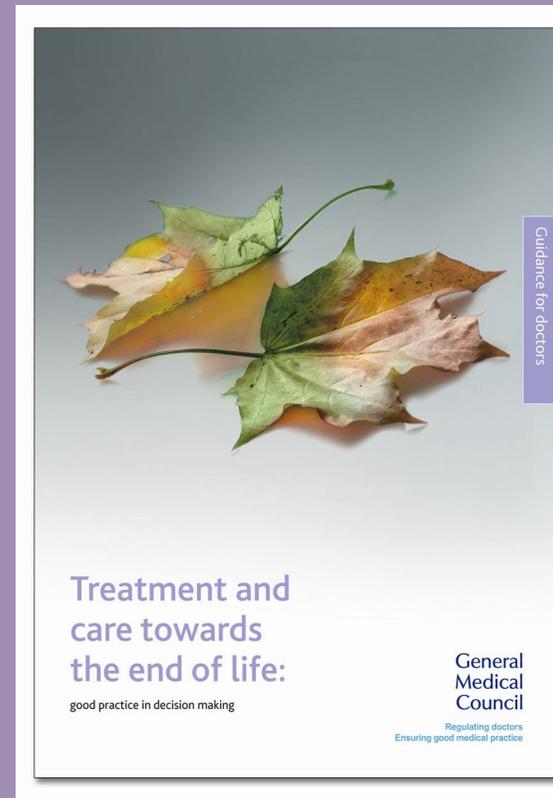
New guidance for doctors

Treatment and care towards the end of life: good practice in decision making

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End of Life Care Conference

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Today's session

- Overview
- New guidance on end of life treatment and care
 - The need to review the existing guidance
 - The process of development
 - What's new/what's different
- Making guidance relevant to practice

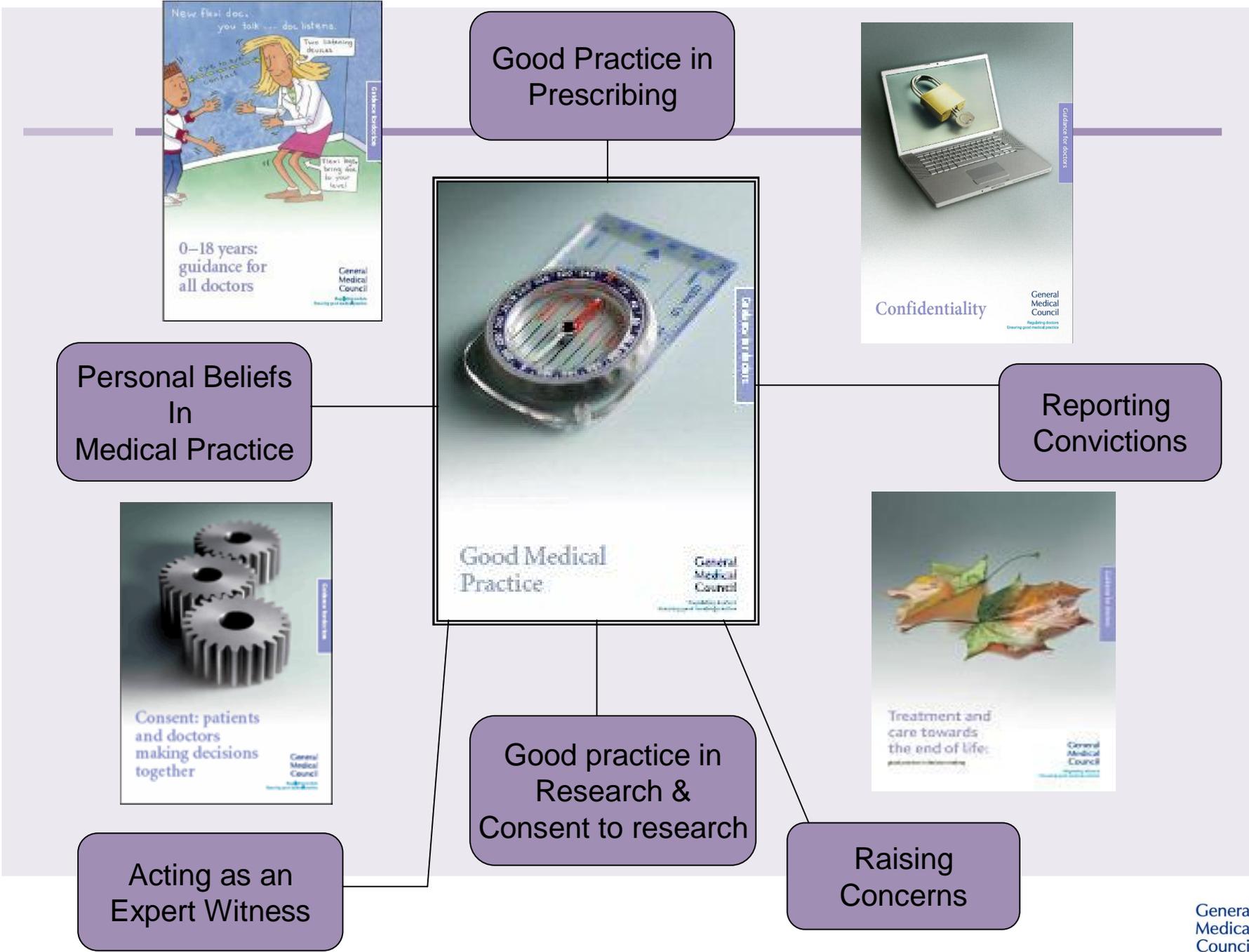
Ensuring proper standards in medical practice



The Medical Act

Medical Act 1983 (amended) gives GMC power to:

- ❑ 'Give advice to the profession on standards of professional conduct, professional performance and on medical ethics, as the Council think fit.'



Good Practice in Prescribing

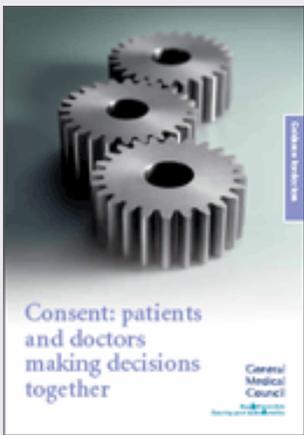


Reporting Convictions



Good practice in Research & Consent to research

Personal Beliefs In Medical Practice



Acting as an Expert Witness

Raising Concerns

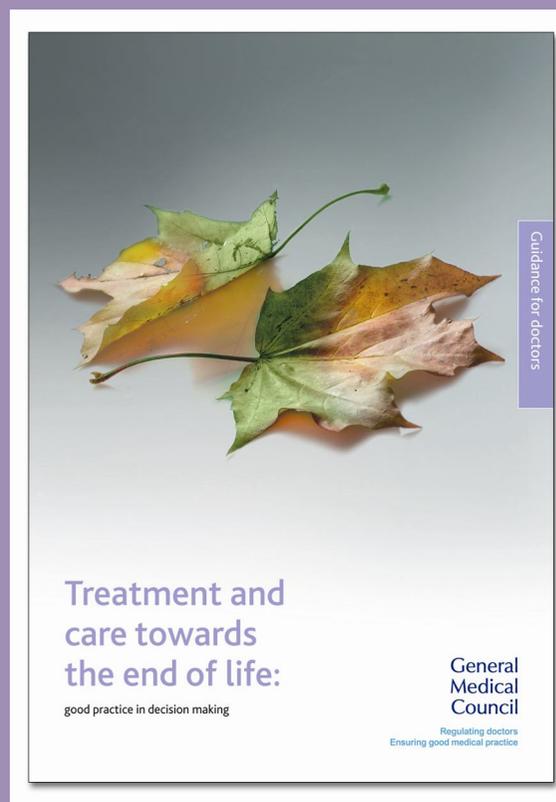
Scope of GMC guidance

- Statement of broad principles of good practice which apply to **all** registered doctors.
- Based on established ethical principles and consistent with current UK law.
- Representing common ground between the profession, public and service providers – through involvement in all stages of its development.
- NOT a rule book – doctors must exercise judgement in applying the principles to individual cases

How GMC guidance is used

- Primary role is to advise individual doctors but it also:
 - Tells patients, the public, service providers & other health and social care professionals, what is expected of doctors.
 - Informs the medical curriculum and is taught in undergraduate courses.
 - Provides a 'benchmark' to consider doctors' fitness to practise when complaints are made to the GMC.
 - Will form the framework for NHS and other appraisal systems, and for revalidating doctors' practice.

Treatment and care towards the end of life: good practice in decision making

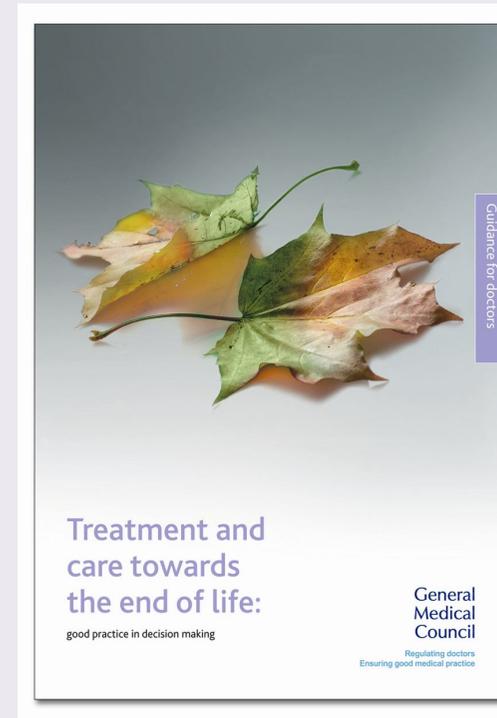


The need to review the guidance

- *Withholding and withdrawing life prolonging treatments: good practice in decision making* published in 2002.
- A number of developments prompted the review:
 - Changes in the law e.g. Mental Capacity Act 2005
 - Requests from doctors to clarify some areas of the guidance, for example on CPR
 - Developments in government policies around the provision of end of life and palliative care
 - Ongoing public concern about the standard of end of life care

Developing new guidance on end of life care

- Two year process
- Working group
 - Chaired by Lady Eames
 - A range of perspectives and experience, across the UK, including medical, nursing, law, patients & carers, faith groups
- Extensive consultation and engagement process



Formal consultation

- March – July 2009
- Long and short consultation questionnaires – 215 and 314 responses.
- UK consultative conference in London (150 delegates).
- 20+ events across the UK (approx 500 delegates).
- Research report (secondary analysis of 95 patient and carer interviews carried out by Healthtalkonline).
- Mumsnet online survey of parents (600+ responses).

What we learnt from the consultation

Key issues in the consultation feedback were:

- More needed on the role of families and carers
- Strong support for the importance of good communication; advance care planning and effective team working
- Support and criticism of our use of terminology
- More clarity needed on dealing with an advance request for treatment
- More advice on when/how to raise the possibility of organ donation
- More advice on neonates and infants, and the concerns of parents about their role in decision making
- More clarity about the principles underpinning decisions about CANH and CPR

What the guidance is/isn't about

- The guidance
 - Provides an ethical framework to help doctors provide good care
 - Recognises that decisions about end of life treatment and care can be clinically complex, and are emotionally difficult – for everyone involved.
 - Explores the role of patients, family and carers, legal proxies, health and social care teams, in reaching decisions
 - Does not include advice on assisted suicide or euthanasia – doctors are expected to work within the law.

Issues covered in the guidance

- Decision making models
- Equalities and human rights
- Presumption in favour of prolonging life
- Advance care planning (including palliative care)
- Advance requests for/refusals of treatment
- Organ donation
- Care of neonates, children and young people
- Clinically assisted nutrition and hydration (CANH)
- Cardiopulmonary resuscitation (CPR)
- Care after death

Key principles

- Doctors must start with a presumption in favour of prolonging life but not irrespective of the consequences for the patient or their views.
- Patients who are approaching the end of life must be given the same quality of care as all other patients.
- When patients cannot decide for themselves, decisions must be based on whether the treatment would be of overall benefit to the patient.

Decision making models

- The guidance has 2 decision making models
 1. Where patients have capacity to decide
 2. Where patients lack capacity to decide
- They set out the key elements of the decision making process
- Designed to be useful to doctors who need a quick overview of their ethical/legal responsibilities.

Advance care planning

- Early, sensitive discussion and planning with patients can help to avoid uncertainty and disagreement when a patient is no longer able to make their wishes known.
- Helps ensure good communication and coordination across healthcare teams and services, so patients receive the care they want, when and where they need it
- Not a one-off process - plans need to be reviewed as a patient's situation or wishes change.

Advance requests & refusals

- Some patients want to retain as much control as possible towards the end of their lives and may wish either to request, or refuse, a particular treatment in advance.

- Advance refusals
 - Must be valid and applicable to be binding
 - If not binding, still evidence of a patient's wishes

- Advance requests
 - Not legally binding (in the same way as refusals may be)
 - Will carry weight in future decision making about the balance of benefits, burdens and risks.

Organ donation

- For the first time we have given advice about discussing organ donation:
 - Creating opportunities for patients who want to, to discuss what should happen after their death, as part of wider advance care planning.
 - In appropriate cases - sensitively discussing the issue with the family, focusing on whether the patient had expressed views or wishes about donation prior to their death.

Clinically assisted nutrition and hydration & CPR

- Can be some of the most difficult decisions, particularly because of the importance many attach to these types of treatments.
- Principles for decision making are the same as for other treatments (ethically and in law).
- Guidance includes extra safeguards for CANH decisions when a patient is in the last stages of illness, but not expected to die in the next few days or hours.
- Where a patient requested CANH or CPR, and the benefits and burdens are finely balanced, the patient's request will usually be the deciding factor.

Making the guidance real

- Implementation
 - Disseminating the guidance widely among doctors, other healthcare professionals, patients and the public
- Bringing the guidance to life – already online:
 - Online version has links to all referenced publications
 - A flowchart with vignettes illustrates how the second decision making model can be applied in practice.
 - Case studies illustrate CANH and CPR decisions

Further information

www.gmc-uk.org/guidance

www.gmc-uk.org/end_of_life_care/learning

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**New GMC guidance
helping doctors
provide better
end of life care**



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