news reviews

Organ donation after death

Presumed consent controversies

Review by **Philippa Taylor**
CMF Head of Public Policy

The issue of organ donation after death has sparked a number of media news stories recently. There is a real shortage of organs available for transplant which has led to several proposals intended to increase the supply of organs.

The Welsh Assembly plans to introduce 'presumed consent' to organ donation within five years.[1] A public consultation on this begins soon. If Wales introduce it, then the rest of the UK is more likely to follow suit. The Northern Ireland Health Minister has said he would like to introduce presumed consent in Northern Ireland.[2] The BMA debated organ donation at their Annual Conference this year, voting to support presumed consent.[3]

Currently, individuals in the UK can only donate their organs after death if they have registered as a donor. Under a 'presumed consent'[4] law every person would automatically become an organ donor on death, unless he/she has specifically registered to 'opt out'. The Welsh Assembly is advocating a 'soft' system of presumed consent, in which relatives would be able to veto organ donation even if no formal objection to it had been made by the deceased person.

Adding to the debate, and offering another possible solution to the organ shortage, the Nuffield Council on Bioethics has suggested that the NHS could pay the funeral expenses for those who sign the Organ Donor Register and subsequently become organ donors on their death.[5]

CMF submitted a response to the initial Welsh Assembly consultation, setting out in more detail our thoughts on this issue.[6] In essence, while we fully support organ donation and welcome the increase of registered organ donors in the UK (30% are now registered, 18 million in total[7]) we are concerned that a system of presumed consent effectively equals no consent, unless there were to be an extensive public information programme, capturing the entire adult population, including those on the margins of society. Without this, it would be impossible to ensure that those who do not opt out have made a positive choice, rather than doing so by default, by ignorance, or by a lack of knowledge or understanding. Without consent, donation becomes 'taking' organs rather than 'giving' them.

There are further issues around the ascertaining and timing of a diagnosis of death, about bodily integrity, about trust in professionals and about the role of donation as an altruistic gift. It is also questionable whether legislative changes are necessary, or whether structural changes that make it easier to donate are effective.

As the pressure to increase donation rates grows, we need to ensure that organ donation after death remains a genuinely altruistic gift. If there is any undermining of this gift, either through a hint of financial incentives and/or an element of felt duty, the gift principle will be undermined fundamentally changing the nature of the exercise.

references

1 *bit.ly/uEHBjq*
2 *bit.ly/q7u7ea*
3 *bit.ly/iMzSxn*
4 *bit.ly/ur9KdU*
5 *bit.ly/mQHdik*
6 *bit.ly/tHxgzm*
7 *bit.ly/jNnZVy*

Judge rules in favour of life in M case

Encouraging but not surprising

Review by **Peter Saunders**
CMF Chief Executive

On 28 September the Court of Protection ruled in favour of life in the case of M, a 53 year old woman who suffered severe brain damage as a result of viral encephalitis in 2003.

M's sister and partner wanted artificial nutrition and hydration (ANH) given via a gastrostomy tube to be stopped with the explicit intention of ending her life. But the PCT caring for M and the Official Solicitor opposed them.

Since the 1993 Tony Bland decision,[1] 43 patients with permanent vegetative state (PVS) have died following court rulings to remove ANH but M was the first case with minimally conscious state (MCS), the next step up from PVS, to come before the courts.

In his judgment[2] Justice Baker found that M had some awareness of herself and her environment, and some understanding of language. She occasionally spoke, appeared to be able to appreciate some things that were said to her, and responded to music. She regularly experienced pain, but this was not constant or extreme, and her condition was stable. The prospect of any significant improvement in the level of consciousness was remote.[3] In reaching these findings he found, not surprisingly, that the carers who had daily contact with M had the greatest insight into her condition. It was their observations that squared most accurately with the more objective results from the 'Sensory Modality Assessment and Rehabilitation Technique' (SMART) and 'Wessex Head Injury Matrix' (WHIM) assessment tools.

The judge applied principles established by previous cases and affirmed by the Mental Capacity Act 2005 (MCA). ANH can only be removed if it is in the best interests of the patient[4] and the burden of establishing this rests on those who want it withdrawn.[5] In determining best interests a balance sheet approach is used,[6] but the assessment is holistic, including not just medical considerations, but also the patient's wishes, feelings, beliefs and values.

M had not given any indication before her injury about how she might like to be treated should she lose capacity. This meant that the deciding legal principle was the right to life. Justice Baker concluded: 'the principle of the right to life is simply stated but of the most profound importance. It needs no further elucidation. It carries very great weight in any balancing exercise.'

The decision was not surprising. The key problem enshrined in the MCA remains – it already allows legally binding advance refusals of ANH placing some vulnerable patients at risk – but this case has not taken us further down the slippery slope.

references

1. Fergusson A. 'Should Tube-feeding be Withdrawn in PVS?' *bit.ly/rSXrQ9*
2. *W v M and S and A NHS Primary Care Trust* [2011] EWHC 2443 (Fam) *bit.ly/q9wHuO*
3. Foster C. 'Judge rules for the preservation of life'. 30 September 2011. *bit.ly/pnp92g*
4. *Airedale NHS Trust v Bland* [1993] AC 789
5. *R (Burke) v GMC* [2005] QB 424
6. *Re A (Male Sterilisation)* [2000] 1 FLR 549

GMC consultation on 'Good Medical Practice'

Christian doctors should study the draft guidance and respond

Review by **Peter Saunders**
CMF Chief Executive

The General Medical Council in October launched a consultation[1] on the new draft of 'Good Medical Practice', its core guidance for doctors. The guidance, which was last published in November 2006, is reviewed every five years.

Anyone can respond and questionnaires are available on line. The consultation closes on 10 February 2012 and a new edition will be published later next year.

The draft guidance runs to 22 pages, quotes 18 other GMC documents and includes 83 numbered paragraphs. These outline doctors' responsibilities under four main headings: 'Knowledge, skills and performance', 'Safety and quality', 'Communication, partnership and teamwork' and 'Maintaining trust'.

Doctors have a duty to be familiar with the guidance and to follow it (p3) and are warned that 'serious or persistent failure' to do so 'will put your registration at risk' (p5).

Most of the content is reproduced from the previous edition, although there is some rearrangement of material meaning that direct comparisons are not straight forward.

Christian doctors will be encouraged to see a cursory nod (p13) to the importance of 'spiritual, religious, social and cultural factors' in history taking but will be wary, in an environment of growing hostility to biblical faith and values, to potential booby traps around the old chestnuts of sharing faith and referring patients for unethical procedures like abortion. Few will take issue with the requirement to 'treat patients fairly and with respect whatever their life choices and beliefs' (p49) but I wondered why 'advising patients on the effects of their life choices on their health' (p51) was presented as an option rather than a duty. The now familiar prohibition on expressing personal beliefs (including political, religious and moral beliefs) to patients 'in ways that exploit their vulnerability or that are likely to cause them distress' is repeated but the real question will be how patient complaints are to be handled.

There is a duty not to 'unfairly discriminate against patients or colleagues by allowing your personal views to affect your professional relationships or the treatment you provide or arrange' (p60) along with a duty to report colleagues to employers and regulatory bodies if they are felt to be denying patients their rights (p22). There is also a duty to 'give patients the information they want….' (p31)

The paragraph on conscientious objection (52) attempts to strike a balance between the right for a doctor not to participate in procedures he or she believes to be immoral and the duty to inform patients of their right to see another doctor and to 'ensure that arrangements are made for another suitably qualified colleague to take over'.

I encourage all CMF members to study the wording of the guidance carefully and to respond. Once set in stone it will be the standard we are all judged against.

reference

1. *www.gmc-uk.org/guidance/10780.asp*

Crisis in care?

The way of the Cross is the answer

Review by **Steve Fouch**
CMF Head of Allied Professions Ministries

The last few months have seen a series of reports from the Care Quality Commission (CQC)[1] and the Equalities and Human Rights Commission[2] showing that care for the elderly in our hospitals, care homes and even in people's own homes is falling far short of even the most basic acceptable standards.

This lack of care takes many forms, from call bells being deliberately placed out of reach, to curtains not being closed properly when patients were on bed pans or having bed baths. Elders being cared for at home were given the option of either getting dressed, washed or having a meal, but not all three!

We have also seen examples of blatant abuse, such as that at Winterbourne View where people with learning disabilities were physically and psychologically abused by staff on a systematic basis.[3]

While the negative aspects of these reports get the public's attention, often overlooking the majority of examples of good care, there is little doubt that there are real problems. Some are systemic (shortage of staff, a proliferation of providers, increased demand and funding that cannot keep pace). Others are more cultural; a society that does not value the elderly and disabled; a targets driven NHS more concerned with ticked boxes than people, etc. The CQC have also highlighted the failure of leadership at every level from NHS Trust Boards to clinical leadership at the ward level.

While action by government, regulatory and professional bodies is essential to improve these standards, there is also an individual professional responsibility. As CMF member Sarah Howles wrote in a recent piece for the CMF blog:[4]

'...as I lead that ward round, what am I teaching everyone with me? I'm telling my juniors that we as doctors shouldn't bother with people once we've "fixed" the list of medical problems. I'm showing them that if someone's a bit confused then there's no point in listening to them. I'm saying that if something's not "our job" we shouldn't engage with the problem. And it's not just the doctors who will be watching me; I'm showing the nurses and other ward staff what I think is an acceptable way to look after people. I'm modelling how to protect my own time and not work as a team.'

In the NHS's target driven culture and limited resources it is easier to follow the path of least resistance rather than modelling a more difficult, Christ-like approach to caring. This is the leadership we need in the NHS. As Paul puts it:

'In humility consider others better than yourselves. Each of you should look not only to your own interests but also to the interests of others.'[5]

references

1. Dignity and nutrition for older people, *Care Quality Commission Report*, 13 October 2011, accessed at *tinyurl.com/5tzmm2d*
2. Inquiry into home care of older people, *Equality & Human Rights Commission*, June 2011 accessed at *tinyurl.com/5sbnelo*
3. Winterbourne View 'failed to protect people', *BBC News*, 18 July 2011 accessed at *tinyurl.com/6gpex6c*
4. Changing attitudes, changing hearts - reflections on the Care Quality Commission report, *CMF Blog* 19 October 2011, accessed at *tinyurl.com/3lshtev*
5. Philippians 2:3-4