

Assisted suicide

Making laboured parliamentary progress

Review by **Peter Saunders**
CMF Chief Executive

Lord Falconer's Assisted Dying Bill^{1,2} reached Committee Stage in the House of Lords on Friday 7 November. It seeks to legalise assisted suicide (but not euthanasia) for mentally competent adults (aged over 18) with less than six months to live, subject to 'safeguards' under a two doctors' signature model similar to the Abortion Act 1967.

Opponents to the bill opted to strangle it slowly in committee rather than voting it out at second reading and so the whole House of Lords is now debating the bill line by line and considering 175 proposed amendments.³ Only four of 40 groups of amendments were formally considered on the first day of committee (7 November)⁴ so there is still a long way to go and the bill is fast running out of parliamentary time.

It may not even reach the third reading stage necessary for it to clear the House of Lords and, even if it does, those on both sides agree that there is no time for it to go through the House of Commons as well before the general election on 7 May 2015. This means almost inevitably that the bill will fall and that Lord Falconer will have to start all over again next summer.

The debate now however is still very important as it will form part of the parliamentary record and will influence future

discussions. So it is still essential that those opposed to the bill still write to peers urging them to reject it fully at third reading, if it should come to a vote.⁵

One development on 7 November was the 'acceptance' of an amendment by Lord Pannick that judges, not doctors, should take final decisions about whether someone should be given the go-ahead to take their own life. This amendment puts a fearsome onus on judges but also demonstrates one of the weaknesses of the bill, that its so-called 'safeguards' are not safe.

A fuller analysis of the bill and a paper giving warnings from Oregon where similar legislation was passed are both available on the Care Not Killing website.⁶

A similar bill to Falconer's, originally introduced into the Scottish Parliament by the late Margo MacDonald MSP but now sponsored by Patrick Harvie MSP, will be debated in Holyrood in March 2015 after oral evidence has been taken in February.

Harvie's bill is proposing to legalise assisted suicide using trained 'licensed facilitators' for mentally competent adults (aged over 16) with a 'terminal or life-shortening illness' or a 'progressive and terminal or life-shortening condition' who have concluded that the 'quality of their life is unacceptable'.

The bill has more holes than Falconer's

including relativistic definitions, poor reporting provisions, minimal penalties, a 'saving' clause protecting doctors acting in 'good faith', no specification of 'means' of suicide and the absence of a conscience clause.

Unlike Falconer's bill, its progress will not be halted by the general election. But it is even more dangerous, if that was possible, and needs to be defeated at the time of the first debate.

A new ComRes poll⁷ has shown that a clear majority of the public say there is no safe system of assisted suicide. More than four in ten believe assisted suicide will be extended beyond the terminally ill if the current law is changed.

The voice of the medical profession, and especially that of Christian doctors, will be crucial at 'such a time as this'.⁸ We must not be silent.

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5. For details of who to write to see: www.carenotkilling.org.uk/bill2014
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End of life care

Time to go beyond good guidelines

Review by **Steve Fouch**
CMF Head of Nursing

A survey published by the Royal College of Nursing in early November¹ suggested that the large majority of nurses felt unable to give the right level of care consistently to dying patients. This frustration was laid at the door of poor staffing levels, inadequate resources and lack of training.²

Over a year after the Neuberger Review³ scrapped the Liverpool Care Pathway (LCP), it seems that we are still not addressing end of life care in hospital or community. Shortly after the LCP was scrapped, a leading palliative care nurse expressed concerns that this would set back care of the dying in this country by years.⁴ Since then, a new set of inter-professional guidelines has been developed (*The Priorities of Care for the Dying*

Person),⁵ emphasising the involvement of the dying person and their family in individualised care planning, sensitive ongoing communication with the patient and within the care team.⁶ This is all very positive, but it is still early days for these guidelines, and this RCN survey suggests that nurses at least are still struggling – not for a lack of guidelines per se, but lack of resources or real training.

A 2010 review by *The Economist* ranked the UK as the global leader in end of life care.⁷ If we want to continue in that position, and enable and encourage other countries to improve their end of life care, it is vital that we go beyond guidelines on good practice to training and resourcing good quality end of life care throughout the NHS. Half a million people die every year in the UK; end of life care is not a minority concern!

The RCN survey also highlighted that nurses felt giving good quality end of life care was a huge privilege and responsibility, and one that they wanted to discharge to the best of their ability. As a society, we should be doing all we can to enable them to do this.

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Expensive 'mistakes'

Government pays out millions for 'wrongful births'

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

A recent reply by the Government to a Parliamentary question on the number and cost of so-called 'wrongful birth' cases elicited some startling findings.¹ Government figures show that since 2003, the NHS has paid out more than £95 million on 164 successful claims for damages from parents wanting compensation for the birth of a child. Defence costs for a further 83 claims that were unsuccessful are not included in this figure.

It has been commonly assumed that these kinds of 'wrongful birth' claims are mostly for damages based on the extra cost to parents for raising an unexpectedly disabled child. And in just over half of the successful cases, this has been true.

Claims based on the disability of a child included eight pay-outs to parents for babies born with Down's syndrome. These claims are controversial enough as they reinforce the view that the birth of a child with a disability is a harm for which one may be compensated. Although for some

parents there will also be a genuine need for practical support and financial help. However, nearly half of the claims granted were for *healthy* babies (45 out of 104 closed claims).

'Legal claims in such cases can be brought by the mother of the child who is born with the abnormality on the basis that, *had it been detected*, she would have been offered counselling and the option of termination *and would have chosen to terminate the pregnancy*' (emphasis added).²

The Government answer reveals that the pay-outs were made for healthy babies born after an 'unwanted pregnancy' (two), 'failed contraception' (eight), 'failed sterilisation' (24), 'inaccurate fertility advice' (one), 'failure to diagnose pregnancy' (one) and for 'failed terminations' (six).

Should the NHS (or anyone) be paying out millions for the birth of healthy babies? Where can a line ever be drawn in this expansion of the right to sue? If claims are successful for 'failed sterilisation and contraception', why not for all other failed contraceptives? If claims are successful

for 'inaccurate fertility advice' why not for failure to provide teenagers with contraceptives?

And what effect will these claims have, psychologically, on the children themselves, as they grow up, knowing full well that their birth was agreed to be an expensive 'mistake' and they should never have been born?

The financial cost of 'wrongful birth claims' is in the millions of pounds to the taxpayer, and this is likely to increase. But an even greater price being paid is the reinforcement of a culture that sees the birth of disabled *and* unplanned children as not just an inconvenient mistake and a financial burden, but to be avoided at all cost. It could hardly be more different to the psalmist's view of children as a blessing, a reward and a gift from the Lord (Psalm 127).

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One small step...

Groundbreaking treatment offers hope for paralysis

Review by **Rick Thomas**
CMF Public Policy Researcher

It is 45 years since Neil Armstrong uttered his now famous words. Within the last few weeks other noteworthy steps were taken that have been hailed as 'more impressive than man walking on the moon'. This is no tabloid hype, but the opinion of Prof Geoff Raisan, Chair of Neural Regeneration at UCL's Institute of Neurology. The 'steps' were those taken by Darek Fidyka, a forty year old Polish man, previously paralysed from the chest downwards as the result of stab wounds four years ago that almost completely severed his spine.

For 40 years, Prof Raisan has been studying how to repair the spinal cord. In animal studies he showed that olfactory ensheathing cells (OECs) injected into the rat spinal cord could reverse paralysis. OECs form part of our sense of smell; they act as pathway cells that enable nerve fibres in the olfactory system to be continually renewed. The breakthrough occurred using multiple

micro-injections of cells cultured from OECs taken from Mr Fidyka's olfactory bulb into the neural tissue either side of his cord transection. The 'gap' was bridged by tiny strands of nerve tissue, taken from the patient's ankle, acting as a scaffold. The OECs appear to have stimulated the spinal cord cells to regenerate, bridging the severed cord. MRI scans show the previous gap has filled in.

Three months after surgery Mr Fidyka noted new muscle growth in his thigh and after a further three months he was able to take faltering steps between parallel bars, using knee braces. Two years after the surgery, he can now walk outside, with only the aid of a frame. Bladder and bowel sensations are beginning to return.

The pioneering neurosurgery was undertaken by Pawel Tabakow at Wroclaw University Hospital who said: 'what we thought for many years was impossible [regeneration of the spinal cord] is

becoming a reality'. Any hype over the years has been about the promise of *embryonic* stem cells. This has led to millions of pounds of public money being ploughed into questionable research projects, destroying more than three million human embryos in the process. What is so wonderful about this case is that (once again) it demonstrates the potential of adult stem cells. Commenting on the news, Lord Alton declared: 'When good science and good ethics march hand in hand, it is an unbeatable combination and serves the highest interests of humanity.'

The final word goes to Prof Raisan: 'Our goal now is to develop this first procedure to a point where it can be rolled out as a worldwide general approach. We stand on the threshold of a historic advance.' Now that really would be 'one giant leap for mankind'.