



Dispelling the myths about the so-called 'death list'

■ Communication is essential when it comes to implementing new palliative care schemes

“ Recently, UK newspaper the *Daily Mail* reported that ‘GPs have been asked to select one in every 100 of their patients to go on a list of those likely to die over the next 12 months. The patients will be singled out for “end-of-life care”, potentially saving the NHS more than £1 billion a year’. The list is referred to in the title of the article as a ‘death list’.¹

In London, one of these so-called ‘death lists’ is being rolled out, but in practice it is precisely the opposite. Coordinate My Care (CMC) is all about living, and living in the final stages of life. Patients and professionals, consulted at all stages of its development, gave out a clear message: don’t call it a register and don’t call it death. Give it a name that tells us what it does: it co-ordinates, it gives care and it puts the patient at its centre.

CMC came into being in 2010. At its centre is the patient: their wishes about how they want to be cared for and treated are recorded in a CMC plan that has to be followed by health- and social care professionals. And at its heart is the maxim: ‘Nothing about me, without me’. Nothing can be changed on the record without the consent of the patient.

So the patient allows information about their health, and wishes about their treatment, to be available to any legitimate health- or social care provider – whether ambulance staff, out-of-hours GP, community nurse or 111 staff. If the patient does not want to go to A&E, they will not go.

CMC is a win-win initiative. Patients get the care they choose: the right care, in the right place, at the right time, from the right professionals.

Unnecessary hospital admissions are avoided, as well as the distress that goes with them. As for the National Health Service, CMC information about patients’ wishes helps staff tailor how and where they provide particular services. They can respond

more effectively and efficiently to what patients want and need – whether this might be expanded hospice care or clinical care in the home.

How has CMC done so far? A total of 3,021 CMC records have been created. Of these, 802 patients have died and of the documented deaths, 78% have occurred outside of hospital (care home 29%, home 35%, hospice 14%) and 76% have occurred in the patients’ preferred place.² More’s the pity that critics have been able to misinterpret what is truly a patient-centric, positive innovation. It is the responsibility of palliative care professionals to work with the Department of Health and service providers to ensure that the language is clearly understood and that communication to the public and professionals does not allow for misinterpretation.

Historically, palliative care has not had to publicise: the actions of the hospice movement spoke louder than words. But times have changed. Communication has changed. We need to make concerted efforts to get the language right and the communication flowing. We need to Twitter, to blog, to inform and overcome the negativity in the press with good news stories. Through strong communication, patients and the wider public will become confident in the professionals and the cynics will be silenced. Only then will patients truly be able to state that our services provide ‘nothing about them, without them’.

Diana Madill, *Journalist*

About the Coordinate My Care project, also read the article by Claire Henry and Anita Hayes on pp 17–19 of this journal.

Reference

1. Doughty S. Put 1 in 100 patients on death list, GPs told: Frailtest to be asked to choose ‘end-of-life’ care. *Daily Mail*, 16 October 2012. www.dailymail.co.uk/health/article-2218790/Put-1-100-patients-death-list-GPs-told-Frailest-asked-choose-end-life-care.html#ixzz2CaGRQZL8 (last accessed 03/12/12)

2. *BMJ*, 6th December 2012. [full reference details needed]