

In defence of the 'tick-box approach':

why end-of-life care is no exception

December 2015 saw the publication of the much anticipated National Institute for Health and Care Excellence (NICE) guideline on care of dying adults in the last days of life,¹ developed following the controversial removal of the Liverpool Care Pathway for the Dying Patient (LCP). After sustained negative mainstream media coverage which saw allegations of euthanasia² and use for income generation,³ an independent review was commissioned into the LCP. The Neuberger Review, *More Care, Less Pathway*, concluded that the LCP should be completely withdrawn from clinical practice in the UK, citing problems around the diagnosis of dying; communication with patients and relatives; and hydration and nutrition.⁴ The consequently formed Leadership Alliance for the Care of Dying People (LACDP) responded in the form of the *One Chance to Get it Right* document, setting out five 'Priorities for Care of the Dying Person'.⁵

The new NICE guidance closely reflects the themes identified in the Neuberger Review and LACDP response. The importance of careful communication with patients and 'those important to them' is prominently emphasised, as is the inherent uncertainty in the dying process.¹ More fundamentally, a strong focus on 'individualised care', with a clear reluctance to give specific clinical guidance regarding symptom management, demonstrates an active distancing from the perceived approach of the LCP.

In March 2016, the Royal College of Physicians (RCP) published its second national audit of hospital end-of-life care. Although the report does not claim statistical significance and slight wording differences make comparison challenging, it appears to show improvement in several domains compared with the previous audit, undertaken close to the time of the LCP withdrawal. However it also seems to show a fall in the proportion of patients prescribed anticipatory medications for pain, nausea, and agitation at the time of death, and highlighted other areas of ongoing deficiency. For example, more than one-quarter of patients who died non-suddenly after more than 24 hours in hospital did not have recorded evidence of a holistic patient assessment focused towards an individualised care plan.⁶

While the recommendations of each of

these documents are all laudable, they have all arguably still failed to demonstrate that the LCP was the root cause of the problem. As inferred in a previous editorial,⁷ although the LCP may have fallen into irredeemable disrepute, the concerns highlighted in the media and the subsequent Neuberger Review seemed more related to the general crisis in care culture in the NHS, than to any intrinsic problem with the LCP. Indeed, despite Neuberger noting an overall lack of high quality evidence,⁴ further favourable research has since emerged: a recently published controlled before-and-after study in Sweden demonstrated a significant reduction in both shortness of breath and nausea in patients on the LCP compared with controls, concluding that *'When implemented with adequate staff training and support, the [LCP] may be a useful tool for providing end-of-life care of elderly people at the end of life in non-cancer settings'*.⁸ Thus the recently demonstrated improvement in end-of-life care in hospitals may be more as a result of the current political prominence of palliative care coupled with a broader emphasis on improved openness and individualisation in general health care in the UK, than relating to the withdrawal of the LCP.

'TICK-BOX' CARE: FRIEND OR FOE?

The new NICE guidance has been heralded as a move away from the LCP's 'tick box, one size fits all' approach.⁹ In fact the phrase 'tick box' has arguably become the soundbite to epitomise all that was wrong with the LCP; and it is this which is possibly the most dangerous outcome of the whole saga. Referring to local protocols, the NHS Institute for Innovation and Improvement commended 'protocol-based care' as *'... standardisation of practice [which] reduces variation in the treatment of patients and improves the quality of care'*,¹⁰ while an Institute for Healthcare Improvement leader has said that *'A checklist can be very helpful and an important vehicle for ensuring safe and reliable care'*.¹¹ Perhaps the most prominent example is the widely adopted World Health Organization Surgical Safety Checklist, which has demonstrated strong impact in improving patient safety when enacted correctly.¹² Furthermore, referral and assessment pro formas are commonplace throughout clinical medicine, from hospital clerking documentation to

warfarin follow-up referral forms, with the unequivocal benefit of ensuring that consistently required information is consistently gathered and reported in clinical documentation.

End-of-life care is no exception to potentially benefiting from such an approach: as a hospital junior doctor, despite having a longstanding interest in palliative care, I would often still have been unsure how best to prescribe anticipatory medications for dying patients without the help of a local dying patient prescribing 'order set'. Recent research demonstrated that only 55% of junior doctors surveyed 'always' prescribe anticipatory medicines, and many who still had access to the LCP still relied on it unofficially for guidance on caring for dying patients.¹³ In the light of these findings, could the apparent recent fall in rates of anticipatory prescribing for certain symptoms (above) be an early warning sign of the gap left by the LCP?

THE CASE FOR 'TICK-BOX' END-OF-LIFE CARE

The new NICE guidance recommends ensuring *'... that shared decision making can be supported by experienced staff at all times'*, and advocates careful, individualised, and collaborative assessment and management planning for dying patients, all of which are admirable aims. The concerning reality is that we now find ourselves in a void: the LCP has gone, leaving junior doctors exposed, while senior cover is still painfully lacking, particularly out of hours. Many senior clinicians in specialties such as surgery are only on-call from home overnight, and even if they were present, they are currently likely to be similarly under-trained and reliant on specific guidance when it comes to delivering high quality palliative care. The RCP audit revealed that while out-of-hours specialist palliative care telephone advice is broadly available, only 37% of hospital sites offered face-to-face specialist services during office hours 7 days per week, and a mere 11% of trusts provide 24-hour access to in-person specialist palliative care.⁶ Professor Sam Ahmedzai, lead for both the NICE guidance and RCP audit, has emphasised the importance of 24-hour face-to-face input from specialists,¹⁴ but the reality is that sufficiently skilled and timely senior input for dying patients may often be an unavailable luxury.

The very real risk is that rather than being encouraged towards holistic and individualised care, inexperienced junior doctors, faced with ever-increasing workloads of acutely unwell patients, will be more likely to be paralysed into inaction, opting not to intervene: for some reason a passive mistake feels more palatable than an active one. This would leave patients lacking both the appropriate anticipatory prescribing and the patient-centred conversations the new guidance upholds. During a busy on-call shift, a junior doctor needs easy access to concise and specific information; not generic encouragement to treat their patients as individuals.

Of course, in the wrong hands, care pathways can lead to examples of terrible care: these have been well documented and the arguments against them have been eloquently expressed. But however imperfect such pathways may be, are we ignoring the potentially even greater danger of removing them altogether? Used well, tick-boxes serve as reminders of the key elements of care to the conscientious physician, allowing them to combine their years of training in clinical acumen and communication skills with an aide memoire which facilitates consistent and equitable care provision in a variety of settings.

The need for better training in palliative care is undeniable, and initiatives such as the GMC's recently launched educational campaign around end-of-life care¹⁵ are extremely welcome. However, improved training does not negate the need for accessible real-time guidance for practising clinicians. Examples such as the North of England Cancer Network's excellent *Palliative and End of Life Care Guidelines for Cancer and Non-Cancer Patients* demonstrate that concise and specific, yet broad-reaching advice applicable to patients of varying diagnoses is indeed possible.¹⁶ Documents such as these have the capacity to empower junior clinicians to give excellent care and indeed the RCP audit found that virtually all trusts had guidance on prescribing for the commonest end-of-life symptoms.⁶ However a national discourse which is actively distancing itself from specific advice risks driving these useful resources further into the closet. Conversely, this sort of guidance needs to be given greater prominence, arguably by direct incorporation into clinical documentation, and to be standardised nationally to give consistent, quick access for junior doctors who move frequently between places of work: a set-up which begins to look rather similar to the former LCP.

The LCP has gone, and nothing is gained in continuing to lament its passing. However, if it is true that it wasn't really broken in the first place, then trying to fix its perceived problems is likely to cause more harm than good. Rather than causing any recently documented improvements, the removal of protocols and tick-boxes from end-of-life care may have impeded even greater progress, where high standards can spread even to where expert support is sparse. Thus, could 'individualised care' simply be a pleasant-sounding phrase, masking the reality of the popular media's victory at the expense of consistently good end-of-life care?

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