

# Improving end-of-life care in the twenty-first century

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**ABSTRACT** This symposium appealed to a wide variety of professionals. The importance of anticipatory care planning was consistently stressed as a key means of improving end-of-life care in the twenty-first century. Such planning can be difficult, not least because of the differences in illness trajectories and the problem of identifying dying. Various initiatives, frameworks and care pathways have been devised to aid this planning process. Lack of palliative care training and support compromises the quality of end-of-life care provided in many care homes.

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Symptom management is obviously important and, if associated with impaired renal function, frequently necessitates modifications to drug therapy. Patient narratives were demonstrated as an invaluable insight into the patient's perspective. Discussions surrounding 'do not attempt resuscitation' (DNAR) decisions are often challenging, but new guidance has been produced. The day was closed with multi-professional case presentations debated by the panel of speakers.

**KEYWORDS** Advance care planning, 'do not attempt resuscitation', end-of-life, Gold Standards Framework, integrated care pathways, narrative, renal failure, renal impairment, symptoms, trajectories

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## SESSION I IMPROVING END-OF-LIFE CARE FOR ALL

Dr Joanne Lynn (Medical Officer, Centers for Medicare and Medicaid Services, US) presented the Stanley Davidson Lecture. The challenges of planning end-of-life (EOL) care were discussed. The importance of assessing individual patients and anticipating the way their illness will progress was stressed to allow the identification and proactive management of potential problems.<sup>1</sup>

The typical mode of death has changed dramatically over the past century; previously, fit young adults died suddenly; now, progressive chronic illnesses strike in older age causing debility for a number of years before death.

Three distinct illness trajectories for these modern causes of death were presented:

- **Cancer:** a plateau of high functional ability, followed by short decline before death.
- **Chronic organ failure:** gradual background deterioration in function with exacerbations of illness reducing functional ability, any one of which could result in sudden death.
- **Frailty and dementia:** a dwindling course of generally low functional ability for a prolonged period before death.

One of the challenges in providing care for those with fatal chronic illness is the uncertainty of an individual's prognosis. Care ought to be given according to the severity of the illness and need, not the prognosis. Different models of care should be provided, taking into account the likely course of the patient's illness, their wishes and needs:<sup>2</sup>

- Those with cancer may require intensive treatment in hospital, then a shift in care to home or hospice for the last few days.
- With organ failure, teaching self-care of exacerbations and the provision of a trained person to attend home in an emergency may prevent unnecessary and unwanted readmission to hospital, avoiding over-investigation and over-treatment.
- For those with neurological decline causing reduced function, longer-term care needs to be provided, either in care homes or at home with adequate caregiver support.

When planning care, it is important to remember the reduction in family caregivers: people generally have fewer offspring who often live further away and, as people are older when they die, their offspring may be too elderly and frail themselves to be able to care for their parents.

Dr Elizabeth Ireland (GP and Deputy Chair, Scottish Partnership Palliative Care) talked of the recent changes in primary care and the Gold Standard Framework (GSF) Scotland.<sup>3</sup> The GSF was developed to offer all patients approaching the EOL, regardless of diagnosis, the same access to palliative care and the opportunity to die at home. It advocates the identification and assessment of patients who would benefit from a palliative approach, and encourages staff to be proactive in planning care. Communication is crucial to its success. New tools can help identify patients who would benefit from advance care planning, such as Scottish Patients at Risk of Readmission and Admission (SPARRA). Opportunities to improve EOL care are provided by the Scottish Partnership for Palliative Care,<sup>4,5</sup> managed clinical networks, community health partnerships, the Scottish Government,<sup>6</sup> research, Audit Scotland and the expansion of the Electronic Care Summary.

Professor John Ellershaw (Professor of Palliative Medicine, University of Liverpool; Director, Marie Curie Palliative Institute, Liverpool; and Clinical Director, Directorate of Palliative Care, Royal Liverpool University Hospitals) updated us on the Liverpool Care Pathway (LCP):<sup>7</sup> a framework of care that facilitates a 'hospice level of care' in other settings, such as hospital wards, patients' homes and care homes. Some hospices have even adopted the pathway. Patients are started on the pathway when they are identified as dying (with no appropriately treatable cause for their deterioration) by the professional team responsible for their care. They are likely to be confined to bed, have a reduced level of consciousness or be unable to swallow oral medication or anything more than sips of fluid. The goals of the LCP cover physical comfort and psychological, religious/spiritual and communication domains. The pathway supports education around care in the last weeks and days of life and links it into everyday practice. A record sheet is provided to document each step of the pathway as it is undertaken.

A recent audit<sup>8</sup> has revealed 55% of patients dying on this pathway had non-cancer diagnoses. National pilot studies are testing the transferability of the pathway to patients with non-cancer diagnoses, for example cardiac and renal failure. Key challenges of the LCP have been the development of the care pathway, its implementation and linkage to national strategy and its sustainability. It is presently being encouraged throughout the UK as part of the Department of Health's End-of-Life Care Initiative,<sup>9</sup> through which £12 million has been allocated over three years to improve the care of patients nearing the end of their life. The pathway is also in line with the aims of the Scottish health programme, Delivering for Health.<sup>4</sup>

## SESSION 2 SYMPTOM MANAGEMENT

The typical treatment of nausea and vomiting was questioned by Dr Ian Back (Consultant in Palliative Medicine, Holme Tower Marie Curie Hospice, Penarth, and Pontypridd and Rhondda NHS Trust). It was claimed that there is little evidence for our current rationale for antiemetic choice.<sup>10</sup> Dr Back maintained that we are often unable to identify the pathways involved or the receptors in these pathways from our history and examination, and we also have an incomplete understanding of the pharmacology of antiemetics.

A summary of the receptors, including subtypes, identified to date (binding dopamine, serotonin, substance P, histamine, acetylcholine, endorphins, gamma-aminobutyric acid and cannabinoids), and some drugs that antagonise at these specific sites, is provided in a recent update on antiemetics.<sup>11</sup> Dr Back postulated that the mechanism of nausea and vomiting involves different receptors and pathways in different people, which possibly explains why some patients respond to one drug while others do not, despite having an apparent similar source of symptoms. This is clearly an area in need of further clinical research.

Although there may be little or no evidence for some therapies, this does not mean they are ineffective. It seems prudent to continue in the meantime with standard management<sup>12</sup> of empirical antiemetic therapy<sup>13</sup> in adequate regular and breakthrough doses, by the parenteral route if necessary, while treating the cause (where possible). In the case of intractable symptoms, it is reasonable to try combining antiemetics that act at different receptors. Research has shown the benefit of combining a serotonin (5HT<sub>3</sub>) antagonist with dexamethasone, and a neurokinin (NK1) antagonist for chemotherapy-induced vomiting and, to a lesser extent, nausea.<sup>11</sup>

Other less conventional drugs may also be beneficial for the treatment of nausea and vomiting, for example the antipsychotic olanzapine, which blocks multiple receptors,<sup>11</sup> and, in the future, synthetic analogues of ghrelin, a protective peptide secreted by the gastric mucosa that stimulates gastrointestinal motility and appetite.<sup>11</sup> The antisecretory agent octreotide has been shown to reduce vomiting in malignant bowel obstruction<sup>14</sup> and is a potential alternative to surgery in such patients.<sup>15</sup> Nausea and vomiting from other distinct causes are not very well researched and hopefully this will be addressed in the near future.

Numerous palliative care patients experience renal impairment, varying in severity from mild impairment to end-stage renal disease (ESRD). Estimated glomerular filtration rate (eGFR) can help assess renal function; however, this is less accurate in the cachexic,<sup>16</sup> elderly<sup>17</sup> or those suffering mild renal impairment<sup>18</sup> (like countless palliative care patients).

Many people with ESRD have considerable symptoms.<sup>19,20</sup> Dr Jo Chambers (Consultant in Palliative Medicine, Southmead Hospital, Bristol) urged us to become confident in treating patients with impaired renal function, despite their resultant altered handling of many drugs.

For pain, the principles of the WHO ladder should be followed with some adaptations.<sup>21</sup> Non-steroidal anti-inflammatory drugs (NSAIDs) should be avoided if preservation of renal function is desired. Non-renal side effects of NSAIDs are increased in patients with ESRD. If a step two analgesic is required, tramadol can be given (reduced dose). Fentanyl and alfentanil are the favoured step three drugs in severe renal impairment.<sup>22</sup>

The choice of therapy for other symptoms depends on symptom severity, previous treatments, concurrent medication, prognosis, coexisting symptoms, evidence of efficacy, availability and the burden of the proposed treatment and the toxicity profile of the planned therapy. Such toxicity can be limited by individualised care and close monitoring to facilitate titration using short acting/immediate release preparations. Reduced doses and an increased dosage interval may be required.

Guidance on drugs to be avoided or dosage modifications in renal impairment can be obtained from several resources.<sup>23–25</sup>

### SESSION 3 WHAT'S BEST FOR PATIENTS?

An appealing, interactive presentation on narratives at the end of life was given by Professor Trisha Greenhalgh (Professor of Primary Health Care, University College London). Using a thought-provoking example, Professor Greenhalgh clearly demonstrated how stories are open to interpretation, with the audience proffering their different analyses of the narrative under discussion. Examining patients' narratives can help us in EOL care as it allows understanding of patients' feelings and experiences in context. Clinicians have a duty to display narrative competence by 'acknowledging, absorbing, interpreting and acting on the stories and plights of others'.<sup>26</sup> Professor Greenhalgh has co-edited an excellent book concerning narratives in medicine.<sup>27</sup>

Dr Jo Hockley (Research Fellow/Clinical Nurse Specialist (Palliative Care), University of Edinburgh) compared cancer palliative care with EOL care in nursing homes, and discussed the challenges of such provision in care homes. There are greater consequences of 'living with' rather than 'dying from' chronic illnesses, and it can be difficult to identify dying. The ethos of functional rehabilitation, where death is viewed as failure, contrasts with that of palliative care, where natural dying is accepted. There are difficulties of recruitment and retention of staff in care homes, which are generally staffed by carers who are untrained in palliative care and commonly isolated from medicine of

the elderly and specialist palliative care. The Bridges Initiative<sup>28,29</sup> (1999–2004), an interesting action research<sup>30</sup> project involving eight nursing homes, identified these obstacles when trying to implement a care pathway at the end of life and concluded that both local and national policy changes are needed to promote quality EOL care in nursing homes. The EOL Care Intervention Study (2007–8), involving seven care homes in Midlothian, aims to improve anticipatory care planning and reduce inappropriate hospital admissions in the last weeks of life. Previous qualitative research<sup>31</sup> has shown that successful planning, including communication between those involved in caring for patients out-of-hours, was appreciated. The acute health service was thought not to facilitate the provision of quality palliative care, and alternative care and support services were not readily accessible.

### SESSION 4 PUTTING IT INTO PRACTICE

Discussion of resuscitation with patients and information regarding the newly updated national resuscitation guidelines<sup>32</sup> was covered by Dr Juliet Spiller (Consultant in Palliative Medicine, Marie Curie Hospice, Edinburgh, and West Lothian Palliative Care Service). Any patients at risk of cardiorespiratory arrest should have their resuscitation status considered: a medical decision can be made not to attempt resuscitation where this would be futile. This should be discussed with the patient (unless the overall impact on the patient of having such a discussion would be likely to be negative) in the context of future care planning. For patients who would like to have their family present when they are dying, a decision not to resuscitate would facilitate their wishes without compromising other aspects of their care. If resuscitation may be successful this should also be discussed with the patient. Many people have a falsely elevated expectation of the success of resuscitation attempts following dramatisation on television<sup>33</sup> and, only after being given accurate information, can they make such an important quality-of-life decision.

The question of who should have such discussions with patients was also addressed, the most appropriate person being whoever the patient chooses to discuss end-of-life matters with. This may be a doctor or, now, an experienced nurse.

The importance of ensuring communication of resuscitation decisions to all other professionals involved in the care of the patient and the patient's family was emphasised so that inadvertent scenarios, such as sudden-death situations at home where police become involved, can be avoided.

The day ended with the presentation of three cases by Dr Kate Henriksen (Palliative Medicine Specialist Registrar), Dr Peter Henriksen (Cardiology Specialist Registrar) and Dr Rayessa Rayessa (Stroke Medicine

Specialist Registrar). These were discussed by a panel of Professor Ellershaw, Dr Spiller, Dr Chambers and Dr Back. Interestingly, patients with malignant spinal cord compression may be suitable for neurosurgical palliative intervention, such as transcatheter arterial embolisation of tumour. In keeping with earlier themes, it was recommended that patients with implantable defibrillators inserted should have their use reviewed as part of EOL planning discussions. Magnets are available from A&E departments to switch off defibrillators out of hours if necessary.

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## CONCLUSION

This stimulating day, with many excellent speakers, was of relevance to professionals from most specialties. Good EOL care is something we should all be able to achieve. In order to provide this effectively in the twenty-first century we need to plan care around the individual, taking the patient's pattern of illness and wishes into account.

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