

# European Journal of Palliative Care



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# Palliative chemotherapy: are we asking the right questions?

**“** I endeavour to keep myself up to date with 21st-century management of patients with at least some of the diseases that I see commonly in my clinical practice. In pursuit of this quest, I have just read parts of a recently published report, the 2012 Annual Report of the National Oesophago-gastric Cancer Audit (NOGCA). It focuses on the results of an organisational audit and on longer-term follow-up and in-depth analysis of data collected in the first NOGCA between October 2007 and June 2009. I was impressed that data were submitted on 17,000 English and Welsh patients. It is available online (at [www.ic.nhs.uk/ogreports](http://www.ic.nhs.uk/ogreports)).

While I was interested in reading about the impact of the reorganisation of services to create fewer, more specialised, centres, my main interest was in the results pertaining directly to different treatments. I learnt that:

- Three-year follow-up of patients undergoing curative resection demonstrates better results than previously reported in the literature. For patients with oesophageal squamous cell tumours, the proportions undergoing curative treatment who survived one and three years were 73% and 41% respectively, and for oesophageal adenocarcinomas, 78% and 46% respectively
- Completion rates of patients receiving palliative chemotherapy are low (53%)
- Hospital admissions of patients on a best supportive care pathway are infrequent; only 6.75% of such patients being managed at home had an emergency hospital admission in the last month of their life.

I was particularly interested in data pertaining to the completion of palliative chemotherapy.

Among the 9,768 patients with a palliative treatment intent, 2,313 (23.7%) underwent palliative chemotherapy. Although this treatment was more commonly used among younger patients, and those with good performance status, 10% of patients were aged 75 plus or had a performance status of 2 or worse.

The overall rate of treatment completion was 53%. The rate of completion fell as the age of patients increased and, as patients' performance status got worse, the number of comorbidities

increased, as did the level of deprivation. There was marked variation in completion rates between hospitals.

The authors concluded that these results raise questions about appropriate patient selection and the benefit of palliative chemotherapy over best supportive care in patient groups less likely to complete therapy. They suggest that responding to this question may require a randomised controlled trial (RCT). I agree, but with a caveat. It is well documented that RCTs comparing an active treatment arm with best supportive care are hard to recruit for. Those consenting to the trial may well not be representative of the patient population. I cannot help but wonder whether such a trial will provide a definitive answer. Nonetheless, this important question needs answering and I wish those planning such studies good luck.

Since reading the report, I have started asking patients who have had palliative chemotherapy whether they would undergo it again. One very frail, ill man with lung cancer was adamant that even though 'it didn't work' for him, he would definitely 'have it again'. Chemotherapy had had no effect on his disease, which had progressed rapidly through treatment. Another man had had palliative chemotherapy for gastric cancer. In his notes, it was documented that he had tolerated the treatment well with few side-effects and, although there had been no objective tumour response, stable disease had been achieved. He was adamant that he would not choose palliative chemotherapy again.

Research into decision-making about palliative chemotherapy requires a range of studies with different methodologies. I realise that to inform my thinking I need to review the literature (unless a reader would like to do so and write it up!). In the meantime, it would be great if the palliative care community could work collaboratively to build a bank of qualitative evidence to help address some facets of the questions that need to be answered.

**Carol Davis**, EJPC Deputy Editor; Lead Consultant, Palliative Medicine, Countess Mountbatten House Hospice, Southampton, UK

# An overview of anti-emetic medications and the considerations for their use in palliative care

Palliative care situations bring special considerations to the use of anti-emetic medicine, even though nausea and vomiting are common in this group of patients. **Paul Glare, Tanya Nikolova, Roma Tickoo, Jeanna Miller and Marijana Bras** discuss the options

**N**ausea and vomiting are common, distressing symptoms in palliative care. Anti-emetic medications are the mainstay of treatment. The armamentarium is broad, covering many different drug classes. There are two different approaches to selection of anti-emetics in palliative care. Mechanistic prescribing is based on the putative aetiology of the symptom and the known receptor affinities within the implicated structures of the emetic pathway (see Box 1).<sup>1</sup> However, the relevance of the pathway to the clinical practice of palliative care is limited, and empiric prescribing is often just as effective. Whichever approach is used, palliative care clinicians need specialised knowledge of how to use these drugs safely and effectively.

The aim of this article is to provide a brief overview and update of the clinical

pharmacology of the prokinetics, dopamine antagonists, serotonin antagonists, antihistamines, benzodiazepines, corticosteroids, antisecretory agents and cannabinoids used to alleviate nausea and vomiting in palliative care. The doses and other information given here are only for chronic nausea and only for adult patients. The pharmacokinetics of these agents are summarised in Table 1.<sup>2</sup> An important caveat to this article is that the use of many of these agents in palliative care is 'off label'; only chlorpromazine, dexamethasone, hydroxyzine, prochlorperazine and promethazine are approved by the US Food and Drug Administration (FDA) for unrestricted use as anti-emetics (see Table 2).

## Metoclopramide and other prokinetic agents

Metoclopramide is the only prokinetic agent that is currently widely available. Mirtazapine and erythromycin have prokinetic properties but are not widely used for this purpose in palliative care. The data from several small clinical trials are conflicting, and a Cochrane review is under way.<sup>3</sup> Prokinetic agents stimulate the motility of the upper gastrointestinal tract by a variety of mechanisms. Some of these prokinetic effects are blocked by anti-muscarinic medicines including antihistamine anti-emetics, so these agents should not be prescribed together. Prokinetic agents should not be used when stimulation of muscular contractions might adversely affect the gut – for example, in

## Key points

- In end-of-life care, nausea and vomiting are common, and can be very distressing for the patient.
- There are a wide range of anti-emetic drugs, which have varying pharmacokinetic processes.
- The study data for the efficacy of most anti-emetic agents are limited and conflicting.
- The side-effects and interactions of anti-emetic drugs can be particularly problematic in the frail elderly.
- New agents and more research are needed to better serve the needs of the palliative care population.

complete bowel obstruction, gastrointestinal haemorrhage and perforation, or immediately after surgery. Metoclopramide works on the stomach and proximal small bowel, but has little effect on colonic motility. In addition to its prokinetic effects, at higher doses metoclopramide also antagonises dopamine type 2 (D2) receptors in the chemoreceptor trigger zone (CTZ) of the emetic pathway.

The prokinetic effect of metoclopramide is achieved with low doses of 10 mg half an hour before meals (ac) and at bedtime (qhs). At doses of 10 mg every four hours (maximum 100 mg/day), metoclopramide acts like a dopamine antagonist. Dose reductions are recommended in the elderly initially and in patients with moderate-to-severe renal impairment. The most common side-effects of metoclopramide are restlessness, drowsiness and fatigue. Involuntary movements can also occur and the FDA has placed a 'black box warning' on metoclopramide regarding tardive dyskinesia. Administration beyond 12 weeks is not recommended. Pretreatment with diphenhydramine will prevent the acute extrapyramidal symptoms (EPSs) of metoclopramide, but will block the peripheral prokinetic effect. Metoclopramide should be used with caution in patients with Parkinson's disease, high blood pressure, kidney problems, liver problems, heart failure or diabetes. Metabolism and/or transport effects of drug interactions involving cytochrome P450 are uncommon with

### Box 1. The emetic pathway and the chronic nausea of advanced cancer<sup>1</sup>

1. The emetic pathway has been useful in elucidating and teaching the neuropharmacology of anti-emetic agents
2. It focuses on the emetogenic effects of one aetiology: chemotherapy agents
3. In palliative care, other pathways and mechanisms may be relevant: systemic inflammation, bowel obstruction
4. In palliative care, there are often multiple aetiologies occurring concurrently
5. There is no role in advanced cancer for some components of the CTIE pathway (eg NK<sub>1</sub> receptors)
6. The pathway does not explain the mechanism of action of benzodiazepines, steroids or octreotide
7. The CTIE pathway may not be relevant to nausea secondary to other drugs (eg opioids)

CTIE = chemotherapy-induced emesis; NK<sub>1</sub> = neurokinin 1

metoclopramide. However, interactions with metoclopramide may enhance the adverse/toxic effects of many antidepressants, including the selective serotonin reuptake inhibitors, tricyclics and serotonin–noradrenaline reuptake inhibitors, such as duloxetine and venlafaxine. There is an increased risk of extrapyramidal symptoms, neuroleptic malignant syndrome, and serotonin syndrome, although the actual incidence is low.

### Dopamine receptor antagonists

Dopamine receptor antagonists include phenothiazines (chlorpromazine, levomepromazine), phenothiazine derivatives (prochlorperazine), other antipsychotic

**Table 1. Pharmacokinetics of selected anti-emetic drugs<sup>2</sup>**

Drug	BA (%)	Onset (h)	Tmax (h)	t <sub>1/2</sub> (h)	Duration (h)
Chlorpromazine	10–69	–	po: 2–4; IM: 0.5–1	8–35	> 24
Cyclizine		< 2	2.	7–24	4–6
Dexamethasone	61–86	8–24	1–2	4	36–54
Haloperidol	60–65	po: > 1; sc: 0.15–0.25	po: 1.7–6; IM: 0.3–0.5	14–36	–
Hyoscyamine	n/a	sl: 0.15–0.25	0.15–0.5	5–6	0.25–10
Levomepromazine	50	0.5	po: 1–3; IM 0.5–1.5	15–30	12–24
Metoclopramide	32–100	IV: 0.01–0.05; IM: 0.15–0.25; po: 0.5–1	< 1	4–6	1–2
Octreotide	n/a	–	< 0.5	1.5	8–12
Olanzapine	60–80		po: 5–8; IM: 0.25–0.75	21–54	–
Ondansetron	60–70	–	IV: 0.1; po: 0.5–2	2.5–5.4	–
Palonosetron	n/a	–	–	40	–
Prochlorperazine	12.5	–	1.5–5	6.8–9	–
Promethazine	25	–	po: 2–3	10–14	4–12

BA = bioavailability; IM = intramuscular; po = orally; sc = subcutaneous; sl = sublingual; t<sub>1/2</sub> = half-life

**Table 2. Labelled indications for nausea and vomiting of anti-emetics available in the USA**

Drug	Labelled uses	Unlabelled uses
Chlorpromazine	Control of nausea and vomiting	–
Dexamethasone	Anti-emetic	–
Diphenhydramine	Motion sickness	–
Dronabinol	Refractory CTIE	–
Granisetron	Prevention of CTIE; prevention and treatment of PONV	–
Haloperidol	–	Alternative therapy for PONV and CTIE
Hydroxyzine	Anti-emetic	–
Hyoscyamine	GI tract disorders caused by spasm; reduce pain and hypersecretion in pancreatitis	–
Lorazepam	–	CTIE
Medizine	Motion sickness, vertigo	–
Metoclopramide	Diabetic gastroparesis; gastroesophageal reflux; post-pyloric placement of enteral feeding tubes; CTIE and PONV; stimulate gastric emptying and intestinal transit in barium studies	–
Octreotide	–	Treatment of malignant bowel obstruction
Olanzapine	–	Prevention of chemotherapy-associated delayed nausea or vomiting
Ondansetron	Prevention of CTIE and PONV	Hyperemesis gravidarum; breakthrough CTIE
Palonosetron	Acute and delayed CTIE	–
Prochlorperazine	Management of nausea and vomiting	–
Promethazine	Anti-emetic; motion sickness	–

CTIE = chemotherapy-induced emesis; GI = gastrointestinal; PONV = postoperative nausea and vomiting

agents (haloperidol, olanzapine) as well as metoclopramide. The available evidence supporting their use in palliative care is scant,<sup>4,5</sup> but there is stronger evidence for their use in chemotherapy-induced emesis (CTIE) and postoperative nausea and vomiting (PONV). These agents block the D2 receptor in the CTZ. Clinically important polymorphisms

## The most common side-effects of metoclopramide are restlessness, drowsiness and fatigue

of the D2 receptor gene are known to affect their antipsychotic efficacy and toxicity,<sup>6</sup> but this has not been explored for their anti-emetic effects. Apart from haloperidol, which is a pure D2 receptor blocker, these agents are non-selective dopamine antagonists. Chlorpromazine, olanzapine and levomepromazine have a broad spectrum of activity, also blocking histamine, serotonin, alfa-1-adrenergic and muscarinic receptors. The antimuscarinic effects make them useful in malignant bowel obstruction (MBO).

The anti-emetic dose of prochlorperazine is 5–10 mg three times a day (tid) or four times a day (qid) orally (po), 25 mg twice a day (bid) or tid rectally, or 5–10 mg every three to four hours (to a maximum of 40 mg daily) intramuscularly (IM). Chlorpromazine is 10–25 mg every four to six hours po or 25–50 mg

every three to four hours IM. Dose reduction should be considered in the elderly and in patients with liver dysfunction. Dose-limiting sedation is a problem, but may be useful in a distressed dying patient. The dose for haloperidol is 1.5–5 mg bid or tid po or 0.5–2 mg IV every eight hours (this is lower than antipsychotic doses). Dose reduction is recommended in hepatic impairment.

The dose of levomepromazine is 6.25–25 mg po bid, or 25–50 mg/day via continuous subcutaneous infusion (CSCI). The dose for olanzapine is 2.5–5 mg qhs, increased as clinically indicated to 10 mg with close monitoring of orthostatic blood pressure. Dose reduction of all these agents is recommended in hepatic impairment. The side-effects, warnings and precautions for these agents are predictable from their receptor blockade profile. They may include sedation, confusion (prochlorperazine carries a black box warning for precipitating psychosis in elderly patients with dementia), EPSs (especially in those with Parkinson's disease or HIV), hypotension (alfa-1-adrenergic blockade), and anticholinergic side-effects (aggravating glaucoma and prostatism), so they can be problematic in the elderly. The phenothiazines, including prochlorperazine, may all cause corrected QT (QTc) interval prolongation and



agranulocytosis, and lower the seizure threshold. Chlorpromazine is more sedating than prochlorperazine and may cause respiratory depression. Levomepromazine is more sedating again. Haloperidol has similar effects, albeit with less sedation and hypotension, but more EPSs. Olanzapine is sedating, hypotensive and may cause agranulocytosis, but causes fewer EPSs and does not usually affect the QT interval at the low anti-emetic doses. The side-effects of increased appetite and weight gain may in fact be helpful in this population, but the other common side-effects of dry mouth, constipation, agitation, hyperglycemia and oedema would not be.

Chlorpromazine and haloperidol are important substrates and/or inhibitors of the cytochrome P450 isoenzymes CYP2D6 and CYP3A4. These potentially have an impact on the concomitant administration of important palliative care agents such as carbamazepine, glycopyrrolate, fentanyl, methadone and methylphenidate. These interactions have been reported to be of questionable clinical significance.<sup>7</sup> Olanzapine is only a weak inhibitor of CYP2D6 and CYP3A4, so drug interactions are not usually an issue, although it does interact with other central nervous system (CNS) depressants. The risk of serotonin syndrome or neuroleptic malignant syndrome when these agents are co-administered with antidepressants is independent of cytochrome P450.

## Antihistamines

Only the first generation of piperazine-class histamine type 1 (H1) receptor antagonists appear to be anti-emetic, but there are multiple agents in this class, including promethazine, cyclizine, meclizine, hydroxyzine and diphenhydramine. Prochlorperazine and the other non-selective dopamine antagonists also have some antihistamine activity. Antihistamines are often anticholinergic, giving them a role in bowel obstruction. There are few published data for using antihistamines as anti-emetics in advanced cancer, and no randomised controlled trials. Antihistamines block H1 receptors in the medullary vomiting centre, vestibular nucleus and CTZ. Antihistamines with more anticholinergic activity (such as cyclizine) decrease tone, peristalsis and mucosal secretory activity in the gut.

The anti-emetic dose for promethazine is 25 mg po/IV every four to six hours (maximum 100 mg/day). The lowest doses should be used, in divided doses to avoid side-effects. Meclizine's dosage is 12.5–25 mg bid, while hydroxyzine's is 25–100 mg tid or qid, po/IM (not IV). The main side-effect of the antihistamines is sedation, although tolerance usually develops quickly. Anecdotal evidence suggests that promethazine theoclate is well-tolerated and causes less drowsiness than promethazine maleate. Dizziness, EPSs, headache, and constipation and urinary retention may occur, and the seizure threshold may be lowered. Anticholinergic side-effects also occur and may cause confusion or aggravate symptoms of confusion in those with dementia. Caution is needed with narrow-angle glaucoma and prostatic hyperplasia. Caution is advised in patients with cardiovascular disease, severe hypertension, respiratory compromise, impaired hepatic function and epilepsy. Consequently, these agents have been given a high-severity risk on the Beers Criteria for Potentially Inappropriate Medication Use in Older Adults and are considered inappropriate for use in geriatric patients.<sup>8</sup> Being a moderate CYP2D6 inhibitor, diphenhydramine may diminish the metabolic activation and therapeutic effects of codeine, tramadol, and tamoxifen. The other drugs in the class are not known to inhibit cytochrome P450.

**There are few published data for ... antihistamines as anti-emetics in advanced cancer**

## 5-HT<sub>3</sub> receptor antagonists

Drugs in the 5-HT<sub>3</sub> receptor antagonist (5-HT<sub>3</sub>-RA) class include ondansetron, granisetron, palonosetron, dolasetron and tropisetron. Although evidence-based guidelines strongly support the use of 5-HT<sub>3</sub>-RA in CTIE, the evidence of benefit for refractory nausea in palliative and supportive care is much less strong. In this setting, they are generally reserved as third-line agents for refractory cases. There have been two randomised trials of 5-HT<sub>3</sub>-RAs in advanced cancer.<sup>9,10</sup> Although the study designs were very different, the results in terms of efficacy are conflicting. Their mechanism of action is blockade of 5-HT<sub>3</sub> receptors on enterochromaffin cells of the peripheral enteric nervous system, the vagus nerve, the

nucleus tractus solitarius and the CTZ. They have also been shown to be effective in bowel obstruction and renal failure, both of which are also associated with excess 5-HT release. Mirtazapine also has 5-HT<sub>3</sub>-RA activity. The anti-emetic effects of metoclopramide, olanzapine and levomepromazine are partly due to their activity as agonists and/or antagonists at various serotonin receptors.

The dose of ondansetron is 4–8 mg, given daily (qd)/bid. In severe hepatic impairment, the maximum dose is 8 mg/day. Side-effects of these agents are usually mild and transient, with constipation occurring in 5–10% of

### **Corticosteroids may be contraindicated in patients who are receiving chemotherapy**

patients; this is a potential problem in palliative care patients. They may prolong the QTc interval, especially when given IV. The electrocardiogram should be monitored when used

concomitantly with other with agents that prolong the QT interval (for example, methadone or haloperidol). 5-HT<sub>3</sub> antagonists may also cause bradycardia. All 5-HT<sub>3</sub>-RAs are metabolised by cytochrome P450 isoenzymes, although the extent of metabolism and the specific isoenzymes involved differs for each drug. This has potentially clinically significant implications for patients receiving multiple medications. Notably, 5-HT<sub>3</sub>-RAs may decrease the efficacy of tramadol.

### **Other agents**

#### ***Benzodiazepines***

The benzodiazepine lorazepam is frequently administered to nauseated cancer patients, but is only minimally effective as an anti-emetic. It is most useful when nausea and vomiting is associated with anxiety. The anti-emetic mechanism of action is unclear. Its sedative, anxiolytic and amnesic properties may enhance the effectiveness of anti-emetic regimens. It prevents the development of anticipatory CTIE. The dose is 1 mg po or IV every eight hours as needed (prn). Side-effects, warnings and precautions are the same as for all benzodiazepines. Drug interactions are due to CNS depression and are not related to metabolism or transport effects.

#### ***Corticosteroids***

Steroids have an established role in CTIE, MBO and raised intracranial pressure. They are

used as second-line agents for chronic nausea of advanced cancer, but the data are limited and conflicting.<sup>11</sup> The anti-emetic effect of steroids is unknown, but may include depletion of medullary gamma-aminobutyric acid, reduction of blood–brain barrier permeability to emetic toxins, and inhibition of brainstem enkephalin levels. The anti-emetic dose is 4–8 mg/day for chronic nausea, and up to 16 mg/day for MBO or raised intracranial pressure.

The side-effects, warnings and precautions for corticosteroids are extensive and beyond the scope of this article. In the palliative care population, caution should be exercised perioperatively, and in diabetics and patients with a psychiatric history or previous reactions to steroids. Corticosteroids may be contraindicated in patients receiving chemotherapy, due to the risk of sepsis or masking a fever. As treatment may be long-term, the lowest possible dose should be used for the briefest period, with withdrawal or reduction considered when maximal effect has been obtained, an adequate trial (seven to ten days) has failed to achieve the desired effect or side-effects occur. If they are to be continued in the long term, prophylactic cotrimoxazole and aciclovir are recommended. Dexamethasone is a strong inducer of CYP3A4, so may potentially reduce the level of some palliative care agents, such as methadone and fentanyl.

#### ***Hyoscyamine***

Anticholinergic agents such as hyoscyamine (hyoscine) are used in the medical management of terminal bowel obstruction. Like other anticholinergic agents, hyoscyamine relaxes smooth muscle and reduces gastrointestinal secretions via blockade of muscarinic receptors. The dose of hyoscyamine is 0.125–0.25 mg every four hours or prn (maximum is 1.5 mg/24 hours). A timed-release tablet (0.375–0.75 mg every 12 hours) is available. The parenteral dose (IM, IV, subcutaneous [SC]) is 0.25–0.5 mg; this may be repeated prn up to four times/day, at four-hour intervals. Its toxicities are the same as those of other anticholinergic agents described in detail in the antihistamine section. This makes hyoscyamine a potentially problematic drug in elderly palliative care patients. No drug interactions with metabolism or transport effects are known to occur.

### Octreotide

Octreotide, a somatostatin analogue, is approved for treating bowel obstruction.<sup>12</sup> It may assist with associated nausea and vomiting through a variety of mechanisms, but primarily by reducing the volume of bowel secretions. The dose used is 100 µg SC tid or 100–600 µg CSCI. The long-acting depot version may also be used. The most common side-effects are local skin reactions (pain, stinging, burning) and gastrointestinal effects. Octreotide should be used with caution in patients with diabetes mellitus, renal failure or hepatic impairment. No drug interactions with metabolism or transport effects are known to occur.

### Cannabinoids

There is little evidence for the efficacy of cannabinoids, which include dronabinol and nabilone, in nausea and vomiting. Although there are some data for them in CTIE and pain,<sup>13</sup> there have been no studies to evaluate cannabinoids as anti-emetics for the chronic nausea of advanced cancer and only a few case reports have been published.

The precise mechanism of action is unknown, but may be due to effect on CB1 cannabinoid receptors within the CNS. They may inhibit endorphins in the emetic centre, suppress prostaglandin synthesis, and/or inhibit medullary activity through an unspecified cortical action.

For CTIE, the dose of dronabinol is 5–15 mg/m<sup>2</sup> every two to four hours for a total of four to six doses/day. The appetite stimulant dose (for AIDS-related use) is 2.5 mg po bid before lunch and dinner, titrated to 20 mg/day maximum. The dose should be titrated slowly, with close monitoring for adverse effects. The dose of nabilone is 1–2 mg po bid (maximum 6 mg in three doses). The usual dosage of the tetrahydrocannabinol and cannabidiol spray (used for cancer pain) is four to eight sprays/day. Most patients require ≤12 sprays/day. The main side-effects are sedation and mood change.

Dry mouth, ocular changes and hypotension are common, so they should be used with caution in the fragile elderly. Pharmacokinetic drug interactions are uncommon, but the depressant effects on the CNS may be potentiated when used with other psychoactive drugs, sedatives and/or ethanol.

### Conclusion

Pharmacotherapy is the mainstay of the treatment of chronic nausea and vomiting in palliative care, but represents a therapeutic challenge for clinicians. The data for the efficacy of agents that are used are extremely limited, and where they exist they are often conflicting. These drugs have many side-effects that are problematic for fragile elderly patients. There is growing awareness and concern regarding drug interactions, and toxicities such as QTc prolongation. Novel agents are also needed, although the neuropharmacology of the anti-emetic pathway – used to develop new drugs for CTIE – may not be the most appropriate paradigm for chronic nausea from other causes. In the meantime, research is needed both of the existing drugs and the different approaches to selecting them (empiric versus mechanistic). Such studies will need to overcome many methodological challenges to provide valid result

### Declaration of interest

The authors declare that there is no conflict of interest.

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# The impact of cardiac resynchronisation therapy on palliative management of advanced heart failure

**Nadia Khan, Prithwish Banerjee and Dan Munday** explore the use of cardiac resynchronisation therapy in treatment of congestive heart failure, and discuss its implications for palliative care provision

**C**ongestive heart failure (CHF) is a complex syndrome occurring when the heart is unable to maintain an adequate cardiac output to meet the oxygen demands of tissues.<sup>1</sup> Improved survival after acute coronary events and an aging European population demographic has meant the prevalence of heart failure has steadily increased and is set to rise dramatically over the next few decades.

It is estimated there are currently approximately 10 million patients suffering from symptomatic CHF in Europe.<sup>2</sup> However, heart failure still carries a poor prognosis – 40% of individuals die within one year of diagnosis and survival rates for patients have been shown to be worse than those for breast, bladder and prostate cancer.<sup>3</sup> In addition, care of the condition places a significant financial burden on health services; in the UK, heart failure alone accounts for 2% of the national health expenditure.<sup>4</sup>

There has been a drive to widen the remit of palliative care to encompass non-malignant life-shortening conditions, within which heart failure has received a particular focus. The median age of patients dying of heart failure is around 75, ten years older than that of cancer patients. They suffer a similar level of symptom burden as those with lung cancer and have a poorer functional status, but they receive less palliative and community support.<sup>5</sup> As a result of their older age, they frequently have co-existing medical conditions and higher levels

of cognitive impairment, and experience more social isolation.<sup>6</sup> End-stage heart failure has one of the greatest impacts on quality of life (QoL) of any advanced disease.<sup>7</sup> It is, therefore, increasingly well recognised that advanced CHF patients benefit from the holistic management that is offered by a palliative care approach.<sup>8</sup>

Pharmacological optimisation of cardiac function with diuretics, angiotensin-converting enzyme (ACE) inhibitors, beta-blockers and aldosterone antagonists is the foundation of management of heart failure. In recent years, non-drug therapy has also become an increasingly important aspect of management. These developments include:

- Implanted cardioverter defibrillators (ICDs), through which sudden death from

**In recent years, non-drug therapy has also become an increasingly important aspect of management**

## Key points

- Congestive heart failure (CHF) is a chronic, life-limiting condition, and patients require substantial palliative care intervention at the end stages of the disease.
- Cardiac resynchronisation therapy (CRT) improves cardiac function by resynchronising the ventricles of the heart.
- CRT has beneficial effects for symptom burden, exercise capacity and quality of life.
- Insertion of a CRT device can be a useful trigger to consider the palliative care needs of the CHF patient.

arrhythmia in heart failure has become markedly less common

- Cardiac resynchronisation therapy (CRT), one of the most recent techniques developed to improve cardiac function.

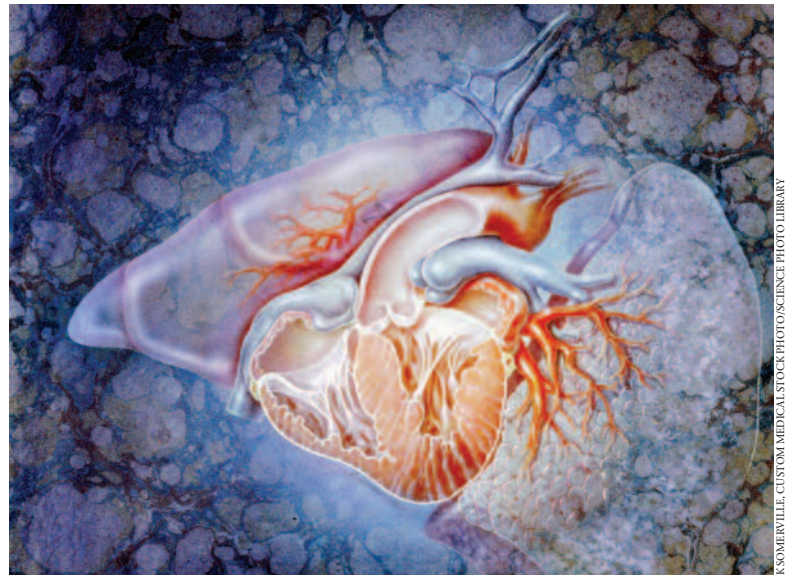
While the full therapeutic potential of CRT is still being explored, CRT is now a widespread, well established aspect of the treatment of advanced CHF. A level 1A evidence recommendation for CRT in a subgroup of moderate to severe CHF patients exists in the US and European guidelines for practice.<sup>9,10</sup> As such, the use of CRT is likely to become more widespread in the future and palliative care teams will, therefore, be involved in the care of advanced CHF patients who have a CRT device in place, or are eligible for consideration.

This article will review what CRT is, its impact on the advanced CHF patient, and its implications for professionals aiming to provide palliative care to such patients.

## CRT – development and role

CRT, also known as biventricular pacing, was initially reported 20 years ago and is considered to be the first successful non-pharmacological treatment of CHF. It has been developed upon the observation that a sub-set of CHF patients often have evidence of electrical conduction delay leading to cardiac dyssynchrony, where certain areas of the left ventricle contract while others move paradoxically. As a result, the heart pumps less efficiently, and the decrease in cardiac output exacerbates the symptoms of heart failure and results in a poorer functional status. In such patients, CRT aims to resynchronise contraction of the heart chambers to a more normal physiological state by pacing both right and left ventricles at the same time, leading to an alleviation of symptoms through an improvement in cardiac function. CRT may also even lead to anatomical re-modelling of the left ventricle.<sup>11</sup>

CRT devices are implanted under local anaesthetic in the upper chest. Fluoroscopic guidance is used to insert a pulse generator box subcutaneously, from which three leads pass through the subclavian vein and superior vena cava into the right atrium, right ventricle and coronary sinus. CRTs may have pacing function alone (CRT-P), or be combined with an ICD component (CRT-D), which can provide internal defibrillation when it senses



ventricular arrhythmias. The use of CRT is currently recommended in a subgroup of patients who remain in moderate to severe CHF (identified as stage III or IV on the New York Heart Association [NYHA] scale), despite optimal medication. Such patients are also required to have echocardiographic or cardiac MRI evidence of poor cardiac systolic function (ejection fraction  $\leq 35\%$ ), and a wide QRS interval ( $\geq 120$  milliseconds) on the electrocardiogram.<sup>10</sup>

A meta-analysis of randomised controlled trials (RCTs) in such a group of patients has shown a significant relative reduction in all-cause mortality of 22–29%.<sup>12</sup> In addition these trials have demonstrated a possible improvement in exercise capacity and a reduction in the symptoms of heart failure. Currently, studies are exploring the benefit of CRT in patients with less advanced but symptomatically troublesome heart failure, and other subgroups who fall outside the established indication criteria.

## Implications of CRT on quality of life in advanced heart failure

Meta-analyses of RCTs assessing the effect of CRT on survival and mortality have also suggested that CRT has a positive impact on QoL. In 2008, Turley *et al* considered four RCTs and five systematic reviews, including one review including 10,000 patients. CRT was demonstrated to lead to a significantly reduced hospitalisation, improved heart failure symptoms, increased peak oxygen consumption and improved QOL scores using the Minnesota Living with Heart Failure Questionnaire.<sup>13</sup>

■ Congestive heart failure occurs when the heart cannot provide sufficient cardiac output to meet the oxygen needs of the body

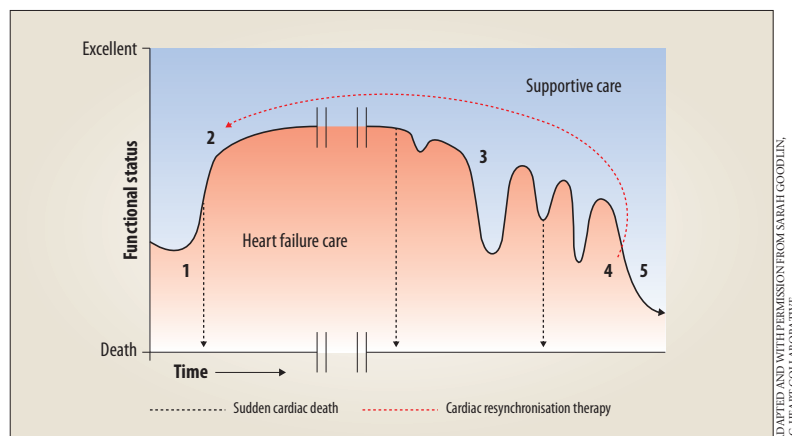
Risks associated with CRT are considered relatively small and are similar to those associated with the implantation of a pacemaker or implantable defibrillator. They include bleeding ( $\approx 1\%$ ), infection ( $\approx 1\%$ ), haematoma ( $\approx 1\%$ ), pneumothorax ( $\approx 1\%$ ), pericardial effusion with or without tamponade ( $\approx 1\%$ ), and myocardial infarction, stroke, and death (all  $\approx 1/500$ ).<sup>14</sup> Regular follow-up of the CRT device is required to optimise the CRT programming with respect to the individual patient's age and activity level.<sup>15</sup> Patients are normally seen on a three-monthly basis in an outpatient setting for this. Like ICDs, current CRT devices are not MRI-compatible. External defibrillation, if necessary, can be used in patients with implanted CRT-P devices.

## Implications of CRT on the CHF disease trajectory

In common with other progressive, non-malignant conditions, the disease trajectory of CHF has been characterised as a chronic, progressive decline in health status interspersed with acute exacerbations that may be life-threatening. Even after recovery, patients tend not to return to their previous level of functioning. Death may occur during a period of decompensation; it may be sudden or may result from co-morbidities, making it problematic to give a prognosis. The resulting prognostic paralysis, plus a failure to appreciate that a palliative care approach to management should not merely focus on the last days of life, means that patients may not receive a holistic approach to care or have an opportunity to discuss advance care plans.<sup>8</sup>

As the current indications stand, CRT is likely to be introduced at an intermediate time point in the disease trajectory, highlighted in Figure 1, as patients enter a stage of deteriorating, highly symptomatic heart failure. At this point, cardiological treatment interventions take on a double significance, as they become agents of palliation in addition to their original purpose of preventing disease progression. Inadequate optimisation of such treatment is likely to lead to a significant worsening of symptoms as well as increased mortality.

Emerging medical therapies that prolong life in advanced disease can significantly modify the disease trajectory of non-malignant organ dysfunction.<sup>16</sup> By reducing



**Figure 1.** Impact of device therapy on the disease trajectory of heart failure

mortality in advanced CHF,<sup>11</sup> CRT stands to have a significant impact on the very disease trajectory of heart failure. However, it is unclear if, and how, the palliative care needs of these patients may subsequently change. Do patients need less palliative support as they remain more 'well' for longer, more palliative support as their health decline extends over a longer period, or do their palliative needs simply change as other co-morbidities become the predominant causes for symptom burden before death? There is a clear justification for longitudinal studies of patients with CRT devices to explore these issues. In addition, the answer to this question may have significant financial and organisational implications for provision of palliative care in this group of patients.

## Implications of CRT for the delivery of palliative care in advanced CHF

The development of increasingly sophisticated technology, such as CRT and other device therapies in the field of cardiology, continually pushes the medical boundaries of therapeutic interventions that can be provided to patients. However, palliative care will remain a necessary component of care at the latter stages of heart failure, due to declining cardiac function and the resultant heavy symptom burden (mainly breathlessness and fatigue).<sup>5</sup> The holistic approach of palliative care still has much to offer in exploring, understanding and addressing the broader issues that make up the experience of advanced, severe heart failure, including the aims and goals of medical therapies within the patient-specific context and end-of-life planning.

Since a lot of uncertainty around life expectancy remains for the individual patient with CHF, a problem-based, rather than a 'prognostic-based', approach to palliative care



should be taken. The installation of a CRT device may be reasonably taken as one of the triggers to warrant the assessment of palliative care needs of CHF patients, and consideration of initiating advance care planning.

Deactivation of the CRT pacing device is not required at the end of life, as this may lead to exacerbation of symptoms due to symptomatic tachycardia or bradycardia<sup>17</sup> – pacemakers do not have a resuscitative role, and are very unlikely to prolong the dying process.<sup>18</sup> However, if the device is a CRT-D, it will need to be deactivated in order to avoid distressing electric shocks being delivered in the terminal phase. Discussions and decisions around ICD deactivation require a sensitive education of patients and their families, with the reassurance that ICD deactivation is not expected to immediately result in death.<sup>17</sup> It is recommended that discussion take place relatively early in the follow-up of end-stage patients to avoid dilemmas in the acute end-of-life setting.<sup>17</sup> With such timely discussions, the defibrillator component may be disabled in a controlled manner – local protocols based on cardiology–palliative care collaboration, such as those produced by the UK Coventry and Warwickshire Cardiovascular Network,<sup>19</sup> may be developed and used to guide this.

As the scope of specialist palliative care extends to non-cancer diagnoses including CHF, palliative care specialists are likely to require increasing familiarity with technological advances in medical management of these conditions. Understanding the role and potential implications of such interventions is needed in order to make the well-informed, often complex, judgements that are necessary in the care of patients with advanced CHF.

## Conclusion

CHF is a common, life-limiting chronic condition; with sufferers experiencing a high level of palliative care needs at advanced stages of the disease. CRT is a promising new technique that aims to improve survival time of heart failure patients, and has been suggested to have beneficial effects for symptom burden, exercise capacity and QoL experience in CHF. However, its widening use and its impact on the disease trajectory in CHF are likely have significant implications for the demand and provision of palliative care, which needs further exploration. Insertion of a CRT device

indicates that CHF is at an advanced stage and can be considered as a useful trigger to assess the palliative care needs of patients and initiate advance care planning discussion with them.

## Declaration of interest

The authors declare that there is no conflict of interest.

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Each masterclass comprises a detailed case history followed by a series of questions that are designed to give you food for thought at the key stages in the history. A discussion of this case study will be given in the next issue of the *European Journal of Palliative Care*.



## Case 63 Using a lidocaine patch for pain from a broken rib

■ Edna\* is a 74-year-old woman with multiple myeloma, which was initially treated with high-dose melphalan. After a relapse six months ago, she began a course of lenalidomide, but this was poorly tolerated, with recurrent bouts of sepsis and diarrhoea. She lives alone, has carers three times daily, and remains quite frail since the relapse. Edna is admitted from home under the care of the haematologists in order to manage right-sided chest pain.

This pain came on suddenly after she had suffered a fall in the bathroom and knocked her chest wall. In your role within the hospital palliative care team, you receive a referral to review her.

### Examination

A bone scan six months ago revealed lytic bone lesions throughout Edna's vertebral column and ribs. Back pain has been a feature for a while, and although the community team has tried adding codeine, and then morphine, to her regular paracetamol regime, Edna is unable to tolerate these opioids due to drowsiness.

Therefore, the community palliative care team, working in collaboration with her GP, switches her analgesia to normal-release oxycodone hydrochloride (OxyNorm®, Teva, UK) 2.5 mg, as required. She is using this once or twice a day on top of regular paracetamol and tolerating it well.

Upon admission, blood tests reveal normal C-reactive protein (CRP), liver function tests and

\* All names have been changed to protect patient confidentiality



urea and electrolytes, although Edna's estimated glomerular filtration rate (eGFR) is only 50 ml/min/1.73 m<sup>2</sup> (normal >90 ml/min/1.73 m<sup>2</sup>). Edna's haemoglobin is normal, but she has a diminished white cell count at  $2.4 \times 10^3/\mu\text{l}$  (compared with a normal range of  $3.8\text{--}10.8 \times 10^3/\mu\text{l}$ ) and platelets at  $63 \times 10^9/\text{l}$  (compared with a normal range of  $150\text{--}400 \times 10^9/\text{l}$ ).

## Pain and tenderness

Electrocardiogram demonstrates sinus rhythm at 76 beats per minute. On examination, Edna is clearly in a lot of pain and has point tenderness over the anterior aspect of her lower chest wall, which becomes worse with movement or on taking deep breaths. She holds this area just before coughing, as it appears to ease any worsening of pain. There is an audible pleural rub over this area. A chest X-ray confirms a broken right-sided seventh rib anteriorly.

## Initial pain management

Edna is already taking regular paracetamol 1 g four times daily and 2.5 mg OxyNorm as required (twice each day), but is still in a lot of pain. Her team commences her on modified-release oxycodone hydrochloride (OxyContin®, Napp, UK) at a dose of 5 mg twice daily and prescribed OxyNorm liquid 2.5 mg, two-hourly as required. This regime relieves her pain to a degree, but she is still finding movement difficult and the background pain does not dissipate altogether.

## Palliative care team input

Edna tells you that she is finding the taste of OxyNorm liquid not to her liking, but you feel that OxyNorm is an option worth pursuing to help relieve this pain. Therefore, you change the formulation to capsules, which she is able to swallow and finds more palatable.

You advise an increase of the OxyContin to 10 mg twice daily, and the as-needed dose of OxyNorm to

5 mg, to try and establish a better background analgesic effect. The following day, the pain has not improved significantly and is bad enough to wake Edna from sleep when turning.

You are aware of recent evidence in treating rib fracture pain with a 5% lidocaine patch that is placed over point of tenderness and replaced twice daily, thereby providing continuous pain relief.<sup>1</sup> However, the drug datasheet recommends that it is only worn for 12 hours at a time due to potential skin irritation.<sup>2</sup>

Edna is keen to try this and likes the sound of a 'plaster' over her painful lower chest. You are contemplating other options at this stage, should the patch not work. Ideally, you would have liked to have trialled a non-steroidal anti-inflammatory drug, but given Edna's poor renal function and low platelet count, this is not a viable option at this stage.

As the pain is at one intercostal level, a nerve block performed by

your colleagues in anaesthesiology is also being contemplated.

Within hours of application of this patch, Edna claims to be totally pain free. There is no recent increase in analgesic requirement or any other interventions. She sleeps very well and remains upbeat the following day. Plans are even being made for a discharge home.

## Unexpected side-effects

On the third day of wearing the lidocaine patch, Edna becomes profoundly drowsy. Occasionally, her arm or leg will jerk and when she is awake she complains of seeing insects crawling on the ceiling. She has no history of smoking or alcohol intake.

Her respiratory rate is not compromised, but along with her constricted pupils, it is clear that she is suffering from opioid toxicity. The OxyContin is stopped immediately, but the as-required dose of OxyNorm is kept at 2.5 mg, in case of rebound pain as Edna becomes more lucid. Two days later, Edna becomes fully alert again and the above-mentioned side-effects have gone. Even better, she is still totally pain-free with just the patch *in situ*.

She goes home a few days later after occupational therapy and physiotherapists have helped her achieve safer mobility within her home environment to try and prevent further falls ■

## Declaration of interest

The author declares that there is no conflict of interest.

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## Questions

- 1 How would you diagnose myeloma?
- 2 What is the management of a rib fracture?
- 3 What side-effects of opioids should patients be warned of?
- 4 In what setting is drug compliance a particularly important issue with patient care?
- 5 What tests would you do if a patient became opioid toxic without an increase in opioid dosage?
- 6 Explain the different indications for the use of 5% lidocaine patches.



## Case 62 answers Safeguarding a vulnerable patient and his wife

### 1. What is the differential diagnosis for the cause of Michael's weakness and deteriorating mobility?

Spinal cord compression is a palliative care emergency and a potentially reversible cause of weakness; the development of urinary retention is highly suspicious, but other causes should be investigated. While uncommon in prostate cancer, brain metastases can occur late in the disease course, and usually represent failure of hormone therapy and disseminated disease; the most common intracranial sites of prostate cancer metastasis are the leptomeninges, cerebrum and the cerebellum. Tumour cachexia and weakness may compound his known neurological deficits. New neurological deficits in an upper motor neurone distribution might suggest extension of an old stroke.

### 2. What factors should the multidisciplinary team take into account when discussing the treatment of hypercalcaemia?

The decision to treat recurrent hypercalcaemia is made on an individual basis. Ideally, the patient can be involved in the decision-making, and attention should be given to Advanced Decisions to Refuse Treatment. Best practice suggests a discussion with the next of kin. Michael has metastatic prostate carcinoma, conveying a five-year survival rate of around 30%. No further specific treatment is being actively pursued. In addition, medical co-morbidities and advancing age have adversely impacted upon Michael's quality of life. For some patients with unbearable symptoms or an expressed wish to avoid prolongation of life, withholding treatment is desirable.

### 3. It is not always possible to respect a patient's autonomy to achieve their preferred place of death. What other reasons are influential?

For patients, distressing symptoms, limited symptom control options, and unpredictability of when death will occur

are important. Service provision to support death at home is variable. Care often relies upon family members, who may not be physically or financially able. Some carers may feel emotionally pressured into the role, or lack motivation. As healthcare professionals (HCPs), we must remember that respecting autonomy sometimes requires holding back from imposing our beliefs and authority on others, even if this puts aspects of patient welfare at risk.

### 4. What is safeguarding of vulnerable adults?

Safeguarding identifies vulnerable adults, assesses their needs and works with them and other agencies to protect them from avoidable harms. Vulnerable adults are a diverse group; often elderly, frail, living alone in the community, or without family support in care homes. Some have physical or learning disabilities and mental health needs. In the UK, the *Safeguarding Vulnerable Groups Act 2006* provides legislation and guidance.<sup>1</sup> An audit identified 20 patients out of a potential 700 with safeguarding issues.<sup>2</sup> The consequences of neglect and abuse (institutional, physical, verbal and financial) are of great importance. Most patients wanted protection, but not all wanted to disturb personal care and relationships in spite of abuse.

### 5. Describe the principles of safeguarding.

Safeguarding encompasses six concepts.

**Empowerment** – Autonomy is key. Even if an adult lacks capacity they should be involved in decision-making if feasible.

**Protection** – Support to protect adults should be offered. Where someone is less able to protect their own interests, HCPs should take reasonable measures to ensure protection.

**Prevention** – The primary goal is abuse prevention. Risk reduction, delivering high-quality, holistic, patient-centred, care in a safe environment achieves this.

**Proportionality** – Safeguarding responses should be proportional to the

level of concern. Least restrictive options to the individual should be considered.

**Partnership** – Individuals, HCPs and communities working together to prevent, detect and respond to abuse.

**Transparency and accountability** – Ongoing assessment identifies problem areas and helps improve delivery.

### 6. What factors are important for a care agency working with adults with safeguarding issues?

In the UK, care agencies provide care on the basis of need and prognosis. The agency might require formal capacity assessment. If a patient lacks capacity, a meeting with a close family friend, a family member or an Independent Mental Capacity Advocate, would inform a best-interests decision. Care agencies need to be mindful of potential safeguarding issues. There must be clear communication of concerns to the agency. A designated person co-ordinates a plan of action, training and supervision for staff to enable them to gather information, review feedback and execute interventions.

### 7. What circumstances increase the risk of abuse by a carer?

Mental health problems, drug or alcohol addiction, a history of violence or abuse, previous relationship problems and an acceptance of violence within the family dynamic are recognised factors. Lack of support from family members and HCPs, poor housing conditions and reliance upon the vulnerable person for financial assistance increase the risk. Role-reversal of the relationship and high emotional or physical burden are factors; carers too can be abused by the vulnerable adult ■

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# OPCARE9 – A European perspective on the last days of life

Following completion of the OPCARE9 project, **Massimo Costantini** and **Urska Lunder** provide an overview of end-of-life care provision in Europe, and the process made in OPCARE9 in improving it

The objectives of the OPCARE9 project, conducted over a three-year work programme (from March 2008 to March 2011), included developing innovative ways of addressing the gap in knowledge about care of the dying and of identifying effective interventions able to improve the quality of care at the end of life.

The project is a good example of international collaboration among seven European countries (the UK, the Netherlands, Sweden, Germany, Slovenia, Switzerland and Italy) and two non-European countries (Argentina and New Zealand). Although it was performed by a comparatively limited group,

the consortium is able to present a European perspective in terms of needs, level of demand from the public and professionals, and opportunity for improving the quality of care at the end of life.

## Adjusting to needs

According to the most recent mortality data provided by EUROSTAT, it can be estimated that every year about 4.8 million people die in the 27 Member States of the European Union.<sup>1</sup> This figure has remained stable over the last ten years (see Table 1), but the most likely scenario will be an increase in deaths in the future.<sup>2</sup>

These statistics are not homogeneous in Europe. The analysis of the distribution of the crude death rates (not adjusted for age structure) in European regions shows wide differences in the frequency of deaths. At the regional level, the rates vary between 390 and 2,444 per 100,000 inhabitants.<sup>1</sup>

There is also an obvious strong relationship between the number of deaths and the number of older people, as almost 80% of all deaths occur in people aged 65 years or older. Areas of Europe with a high proportion of older people, such as some regions of Sweden, the UK and Italy, have the highest crude death rates.

Most European citizens die as a result of serious chronic diseases (see Table 1), with similar concerns and palliative care needs.<sup>3</sup> In Europe, neoplasms, neurological diseases and diseases of the circulatory, respiratory and digestive systems account for about 85% of all deaths.<sup>1</sup>

**Almost 80% of all deaths occur in people aged 65 years or older**

## Key points

- OPCARE9 gave the opportunity to present a European perspective in terms of needs, the level of demand from the public and professionals, and opportunity for improving the quality of care at the end of life.
- Dying patients and their families do not receive adequate evaluation and treatment of their suffering. The worldwide experience from hospices suggests that a good death is possible and the demand for that is growing.
- End-of-life pathways such as the LCP have the potential to improve the quality of end-of-life care, and many qualitative and quantitative studies are ongoing across Europe.
- An European perspective should take into account the need for more research in this area.

**Table 1. Yearly absolute number of deaths by causes and period of time in 27 European Union countries**

	2001–03 Number	2004–06 Number	2007–09 Number
Infectious and parasitic diseases	57,069	62,382	69,565
Neoplasms	1,239,468	1,245,745	1,274,792
Circulatory system	2,118,598	1,983,168	1,924,587
Respiratory system	365,818	369,167	380,342
Genitourinary system	71,399	77,853	87,316
Digestive system	225,054	223,422	226,617
Nervous system and sense organs	117,383	129,996	146,021
Others	709,857	695,739	714,533
All causes of death	4,904,646	4,787,472	4,823,773

Note: Estimated as average of the absolute numbers of deaths in the correspondent period of time

EU-27: European Union composed of 27 Member States: Belgium, Bulgaria, Czech Republic, Denmark, Germany, Estonia, Ireland, Greece, Spain, France, Italy, Cyprus, Latvia, Lithuania, Luxembourg, Hungary, Malta, Netherlands, Austria, Poland, Portugal, Romania, Slovenia, Slovakia, Finland, Sweden and the UK

Most of these patients experience a wide range of problems during the trajectory of the disease, including non-appropriate care during their last days and hours of life.

A number of studies carried out in different regions of Europe have shown the poor quality of care at the end of life in all settings of care.<sup>4,5</sup> Dying patients do not receive

adequate evaluation and treatment of physical suffering. Patient and family emotional, spiritual, and communication needs are often unmet.

## A good death is becoming the expectation rather than the exception in all settings

Inappropriate care of the dying may result in the continuation of invasive treatments, with a negative impact on the quality of life of both the patients and the family, and with negative consequences in terms of resource management. The inappropriate disease-directed cancer care in the last weeks and days of life accounts for a high proportion of total cancer care costs.<sup>6</sup>

## A good death is possible

Effective palliative approaches to guarantee a good quality of care for dying people (including guidelines for symptom control, psychosocial support, and bereavement care) have been published.<sup>7</sup>

The worldwide experience from hospices suggests that this approach is feasible with limited resources.

A change is possible, and ensuring a good death should become a major goal not only for healthcare professionals but also for European society.<sup>8</sup>

A number of qualitative studies performed in different countries have tried to conceptualise a good death. During the last decades, a change has occurred in public opinion, and a good death is becoming the expectation rather than the exception in all settings.

## The challenge of performing research on the last days of life

The European OPCARE9 project outputs included the dissemination of key findings and recommendations for further research and development for care in the last days of life.

Several issues are being studied: how to recognise signs and symptoms of approaching death,<sup>9</sup> attitudes towards artificial hydration at the end of life,<sup>10</sup> issues and needs in end-of-life decision-making,<sup>11</sup> complexities in non-pharmacological caregiving activities at the end of life,<sup>12</sup> and spiritual needs assessments and measurements.<sup>13</sup>

Quality indicators for assessing quality of care at the end of life were identified and evaluated.<sup>14</sup>

## Improving the quality of end-of-life care in Europe

Since the latter half of the 1990s, care pathways for dying patients have been developed and implemented in hospitals and in other settings of care.<sup>8</sup>

According to the definition that has been proposed by the European Pathway Association, a care pathway 'is a complex intervention for the mutual decision making



and organisation of care processes for a well-defined group of patients during a well-defined period'.

The general aim of a care pathway is 'to enhance the quality of care across the continuum by improving risk-adjusted patient outcomes, promoting patient safety, increasing patient satisfaction, and optimizing the use of resources'.<sup>15</sup>

The end-of-life care pathways were aimed at improving the professional skills to address the complex needs of dying patients and their families, in an attempt to transfer hospice expertise into a non-specialist context.

The Liverpool Care Pathway for the Dying Patient, which was developed in the UK to transfer the hospice model of care into hospitals and other care settings, is the most structured and is currently in use in over 20 countries.<sup>16</sup>

The Liverpool Care Pathway aims to promote cost-effective healthcare by improving the appropriateness of prescribing and avoiding inappropriate hospital admissions. It focuses on the holistic needs of people who are dying, by incorporating physical, psychological, social, spiritual and religious aspects of care.<sup>17</sup>

The results from qualitative studies<sup>18</sup> and quasi-experimental non-controlled before and after studies<sup>19</sup> suggest that the Liverpool Care Pathway has the potential to improve the quality of end-of-life care delivery in hospitals and other settings of care.

At present, no randomised controlled trials or quasi-experimental controlled before and after studies support the use of the Liverpool Care Pathway.<sup>20</sup> The Italian hospital version of the Liverpool Care Pathway is being tested for effectiveness in a randomised cluster trial in five Italian regions.<sup>21</sup> Other similar studies are planned or ongoing in Belgium, Netherlands and Sweden, making research into the effectiveness of the Liverpool Care Pathway an important area of research in Europe.

## Conclusion

In view of the changing demographics of deaths and the evidence on the care of the dying, better quality of care for dying people should be a realistic objective for Europe. The gap between what is possible and what is really done in all settings of care should be bridged. Quality improvement programmes

such as the Liverpool Care Pathway seem to be effective. A European perspective should take into account the need for more research in this area.<sup>22</sup> Only a small proportion of research funds have been allocated to end-of-life care. A change is possible and the demand for that is growing in all European countries.

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## Declaration of interest

The authors declare that there is no conflict of interest.

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# OPCARE9 – a southern hemisphere perspective

**Jean B Clark** and **Gustavo De Simone** report on the results and outcomes of participation in the OPCARE project as they affected New Zealand and Argentina

Palliative care personnel and organisations in Argentina and New Zealand, two countries significantly distant from Europe, accepted an invitation to join the European collaboration that developed into OPCARE9.<sup>1</sup> Choosing to participate was straightforward as the offer came from international colleagues with whom relationships had been established based on a shared passion for palliative and end-of-life care. In particular, end-of-life care supported by the Liverpool Care Pathway for the Dying Patient (LCP) had created a tangible link around the globe.

The inclusion of two countries outside of Europe in a European project regarding

support and collaboration provided an opportunity to consolidate and further develop networking to ensure wider cultural

## The Palliative Care Council ... provides independent and expert advice

representation, obtain a more international perspective, encourage wider application of outcomes, and influence end-of-life care internationally. The involvement of Argentina and New Zealand via government departments, organisations, services and people evolved over the three years of the project. This article shares a southern hemisphere perspective of OPCARE9.

### New Zealand

New Zealand is a country with a relatively small population of nearly four and a half million<sup>2</sup> inhabitants and a publicly funded National Health Service. The Palliative Care Council, established in 2008 by Cancer Control New Zealand, provides independent and expert advice to the Minister of Health, and reports on New Zealand's performance in providing palliative and end-of-life care. Specialist palliative care services are available in the community (hospice inpatient services

and/or community-based services) and in some hospitals.

Hospice New Zealand is the representative body for member hospices, and while hospice services receive some funding from central government via District Health Boards, they are highly dependent on public donations and support from a large volunteer sector. Specialist palliative care advice in public hospitals may be provided by a team within the hospital in larger centres, or as a visiting service from local hospice services. New Zealand has well-structured specialist palliative care services, a strong volunteer sector, and moderate research capability. Ranked highly in the overall quality of death index,<sup>3</sup> palliative care providers in New Zealand nevertheless acknowledge the need to improve care and evidence for care delivery.

Arohanui Hospice's engagement in OPCARE9 evolved from an established relationship as a collaborative site with the UK

## Key points

- The European Commission's OPCARE9 project to improve the care of cancer patients at the end of life included contributions from non-European countries – Argentina and New Zealand.
- Of the nine OPCARE countries, only New Zealand and the UK recognise palliative medicine as a specialty.
- OPCARE allowed New Zealand professionals to collaborate with, and contribute to, the international palliative care community.
- As a result of working on OPCARE, an Argentinian version of the Liverpool Care Pathway for the Dying Patient is being developed.

LCP Central Team. OPCARE9 provided important opportunities for New Zealand palliative care professionals to contribute internationally to understanding current practice, the identification of gaps in the evidence base and setting priorities to address them.

Establishing a national reference group was central to New Zealand's participation in the five OPCARE9 work packages<sup>1</sup> and provided expert opinion for the Delphi rounds. Reference group members were sought via palliative care forums (such as the Hospice New Zealand Conference, the Hospital Palliative Care New Zealand annual meeting, the New Zealand Chapter of the Australian and New Zealand Society of Palliative Medicine, Palliative Care Nurses New Zealand, and Hospice New Zealand). The reference group included 12 nurses, 12 doctors, eight allied health professionals and nine volunteers. Additional expertise in specific areas regarding spirituality, quality and volunteerism was sought as necessary. Considerable interest and commitment was demonstrated by reference group members in responding to Delphi rounds.

It was an enriching experience to have the opportunity to engage with international colleagues across disciplines from different cultures working in diverse health and palliative care services. We discovered, for example, that of the nine countries, only the UK and New Zealand recognise palliative medicine as a specialty. Volunteerism, which is an essential and integral part of hospice inpatient and community palliative care in New Zealand is not seen this way in Sweden, yet volunteers may be utilised in direct patient care in community settings at the end-of-life care in other countries like Germany. Language was a constant source of interest and intrigue, and finding words to use with meaningful translations into other languages could prove challenging.

The clear structure of the collaborative into work packages with leads, scientific project assistants and other core personnel also supported New Zealand's capacity to be a positive partner in OPCARE9. New Zealand colleagues were enabled to share knowledge, practices and expertise with the international community, and at times provide an external

lens for European partners. A high level of collaboration evolved over the project, resulting in productive work and a growing number of publications.<sup>4,5,6</sup>

Alongside the diversity, many common features in end-of-life care relevant to the global palliative care community have been identified. The chance to contribute adds richness to the findings, and enhances the opportunity for shared learning, dialogue and understanding of the overall need and challenges in end-of-life care. A project outcome of OPCARE9, the COMMEND

study into communication around food and fluids towards the end of life between New Zealand and the Netherlands, is under way.

Geographical distance and time differences were ameliorated, to a large extent, by technology, supportive colleagues and funding to enable a New Zealand lead to travel to one of the two main meetings annually. The model used in OPCARE9 provides a potential template for collaborative working nationally as well as internationally and is worthy of consideration by researchers, institutions and governments looking to advance palliative and end-of-life care.

## Argentina

Argentina is one of the 35 countries that constitute Latin America, with a national population of 40 million people and a high prevalence of chronic disease-related mortality and a clear need for implementation of palliative care.<sup>7</sup> Primary concerns regarding palliative care in the whole region are cultural, socioeconomic and educational: increasing poverty, patients and families receiving inadequate information about their diagnosis or prognosis, drug availability and costs, and insufficient knowledge by healthcare providers are obstacles to palliative care.<sup>8</sup>

Most of these countries fail to provide care for dying patients. However, Argentina is recognised as a leading nation regarding education and provision in palliative and end-of-life care,<sup>9</sup> being positioned at level IV (approaching integration) in the global map of palliative care development.<sup>10</sup> Among the reasons that explain this leadership, it is important to emphasise that there are almost 100 teams in the country working at different cities; a National Association with more than

**Geographical distance and time differences were ameliorated, to a large extent, by technology**



20 years of experience; ongoing programmes of postgraduate training; published norms from the National Health Ministry for implementation of palliative care; increasing recognition from society; a new law that makes palliative care provision mandatory; increasing number of research projects and LCP implementation in different settings.

Nevertheless, these are the main challenges to be tackled to improve accessibility of services: fragmentation of the healthcare system, inequalities in healthcare provision, inadequate implementation of existing regulations and insufficient legal framework in this field with deficient policies regarding drug provision. Clearly, there is still a long way to go to facilitate access to appropriate palliative care and to improve quantitative and qualitative research and teaching activities.

### **OPCARE9 led to active multiprofessional participation in all work packages**

Pallium Latinoamérica is a non-governmental organisation devoted to the relief and prevention of end-of-life suffering with consolidated programmes of assistance, education and research which have a strong impact not only in Buenos Aires but in the whole region. The opportunity for Pallium to be part of OPCARE9 led to active multiprofessional participation in all work packages, with great feedback to and from other country teams and also links and active involvement of local and regional Latin American entities (Pallium and other team leaders; Argentinean and Latin American scientific societies; public and private universities – Universidad de Buenos Aires and Universidad del Salvador; the National Academy of Medicine in Buenos Aires; and city and national health authorities).

We do believe that all OPCARE9 partners – both European and non-European – had a high level of involvement, sharing progress, knowledge and resources, respecting and integrating cultural perspectives and ethical matters, developing and maintaining trust, learning from diversity and promoting an attitude of collaboration more than competition.

In order to summarise the global impact of OPCARE9 in Argentina and Latin America we affirm that after the OPCARE9 project, the PAMPA (Argentinean version of LCP) is now being developed in public/university hospitals in Buenos Aires; it is also a piece of study and

research for the MSc in Palliative Care and is the reference end-of-life project for the Ethical Committee at the National Academy of Medicine. Furthermore, the Ministry of Health – City of Buenos Aires has created a Palliative Care Programme, which includes the PAMPA pathway. More than 25 workshops and lectures in Argentina and beyond, and a plenary session at the Latin American Congress in 2010, were focused on the LCP and main OPCARE9 topics.

The LCP–PAMPA and the OPCARE9 project have really become a new bridge between the port of Liverpool and that of Buenos Aires in South America, contributing to the increasing number of people who can get proper care and relief from end-of-life suffering.

### **Conclusion**

OPCARE9 provided substantial opportunities for support and collaboration. At a national level, professionals and volunteers were able to contribute invaluable to the project. Two southern hemisphere countries had the opportunity to share expertise, learn through a collaborative process and strengthen national and international palliative care links.

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### **Declaration of interest**

The authors declare that there is no conflict of interest.

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# OPCARE9 – future directions for optimising the care of cancer patients in the last days of life

At the conclusion of the OPCARE9 project, **Stephen Mason** and **John Ellershaw** provide information on the International OPCARE Research Collaborative and the Liverpool Declaration that stemmed from the work of OPCARE

**O**PCARE9 was a three-year European Commission Seventh Framework Programme (FP7) Co-ordination and Support Action collaborative project to optimise the care of cancer patients in the last days of life. The project was managed within an international collaborative framework, integrating knowledge from a range of healthcare environments and cultures.

The aim of OPCARE9 was to reach consensus, based on current practice and available research evidence, on the optimum care to be delivered for cancer patients in the last days of life, and to identify gaps in the knowledge base across five primary themes:

- Work package 1 (WP1) – Signs and symptoms of approaching death
- Work package 2 (WP2) – End-of-life decisions
- Work package 3 (WP3) – Complementary comfort care
- Work package 4 (WP4) – Psychological and psychosocial support
- Work package 5 (WP5) – Voluntary service.

Each theme was critically examined, using systematic review and Delphi methodologies, by international, multiprofessional and interdisciplinary teams. Three executive work packages were engaged:

- Work package 6 (WP6) – Management, dissemination and communication
- Work package 7a (WP7a) – Evaluation of collaborative working
- Work package 7b (WP7b) – Liverpool Care Pathway for the Dying Patient<sup>1</sup> International Programme.

The findings and outputs from the work packages have been reported within the current series of articles presented within the *European Journal of Palliative Care* and across other publications.<sup>2</sup>

In brief, the summaries of findings across the work packages suggest that although it is developing, the current knowledge base lacks critical depth. We need co-ordinated, collaborative, high-quality research. Accordingly, the EU FP7 Co-ordination and Support Action funding scheme has, through OPCARE9, provided the basis for local, national and international collaborative research to improve and expedite the equitable delivery of care for cancer patients (and their families) in the last days of life. This article will report on the progress of the work

## Key points

- OPCARE9 was a three-year project to improve the care of cancer patients at the end of life.
- A summit that took place at the end of OPCARE9 led to the Liverpool Declaration, which is a standard against which the provision of palliative care can be judged.
- The International OPCARE Research Collaborative (IORC) has emerged as a structure to put into practice the research protocols from OPCARE9.
- IORC develops research projects – both local and national – that examine the care of the dying, and will support collaborative research that evolves both within and outside the OPCARE groups.

engaged by the OPCARE9 collaborative in pursuit of this aim.

### The Liverpool Declaration

In 2011, at the end of the three-year OPCARE9 programme, an international conference was held in Liverpool to disseminate the findings from the individual work packages and, via an international policy summit, prepare strategies to nurture an environment in which the

### The IORC emerges as a collaborative structure to potentiate the research protocols from

importance of future collaborative research would be realised and championed. The key outcome of the policy summit was the Liverpool Declaration (see Box 1), which

serves as a standard against which the organisation of services can be calibrated.

The Declaration provides an opportunity for national and international health and research communities to examine current service delivery and establish:

- Where standards are being achieved, what, critically, has enabled achievement, and whether transferable models of practice can be developed
- Where standards are lacking, investigation of the reasons why, and what is required to meet them.

### The International OPCARE Research Collaborative

Key aspects of international collaborative working have been learned during the OPCARE9 project, forming the basis for the continued work and development of the group. Working internationally, two aspects were anticipated:

- A collaborative structure only works when the people working in it can own it.
- The structure needs to integrate and synchronise existing leadership from within the beneficiaries, engaging different concepts, styles and contexts.

From continual reflection and evaluation of the collaborative process, two further developments emerged as key in the success of the collaboration. First, in a process of 'invitational facilitation', core members participated in the dynamic sculpting of the organisational structure of OPCARE9. Second, the consolidation of existing collaborative links was crucial in facilitating engagement where the informal rules of collaborative working were already in part established.

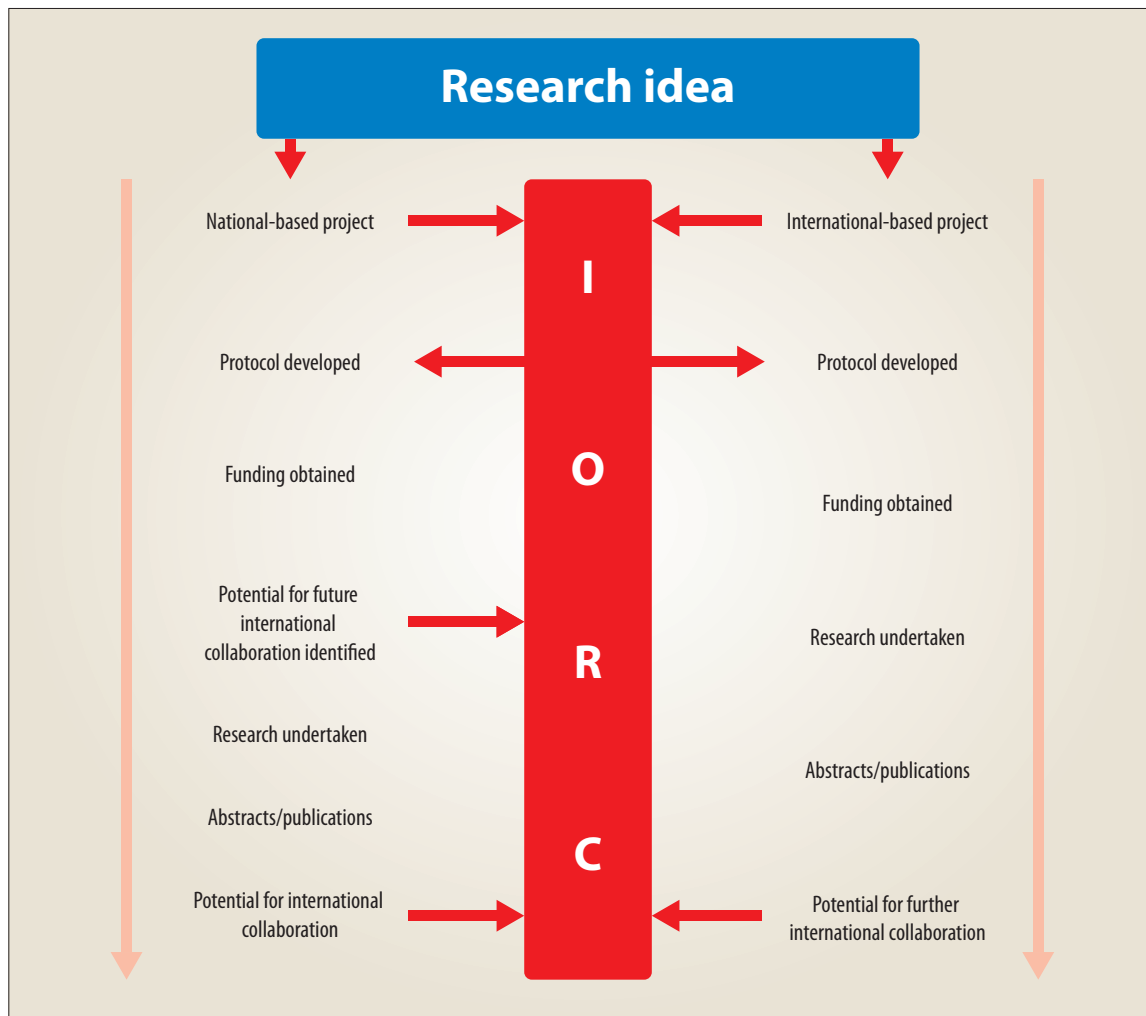
### Box 1. The OPCARE9 Liverpool Declaration

1. Every person has the right to live in societies where death and dying are acknowledged as part of life. We commit ourselves to improving societal and public health approaches to meet this goal.
2. Every person has the right to die receiving optimal care with respect to their wishes. We commit ourselves to improving awareness to meet this goal.
3. Every person has the right to access adequate palliative and hospice care in all settings. We commit ourselves to improving healthcare structures to meet this goal.
4. Every person has the right to this care given by professionals and volunteers who are appropriately trained. We commit ourselves to implementing care of the dying in all curricula for healthcare professionals and volunteers.
5. Every person has the right to continuous improvement of palliative and hospice care through transfer of research results into practice. We commit ourselves to improving conditions for research for care of the dying and implementation of research results.
6. Every person has the right to equitable access to high quality end of life care across all countries. We commit ourselves to the setting of international standards and evaluating their ongoing implementation.

These organisational aspects enabled the OPCARE9 group to deliver on the project objectives and evolve as a cohesive group. What has subsequently developed is a strong collaborative and co-ordinated network of research-active clinical and educational groups, all with a key aim of generating evidence which will inform practice and improve the care of dying patients across the partner countries and beyond – the International OPCARE Research Collaborative (IORC).

The IORC emerges as a collaborative structure to potentiate the research protocols from OPCARE9; developing local and national research projects examining care of the dying and serving as a platform to elevate suitable studies for international collaboration (Figure 1). Further, the IORC will look to support the collaborative working that develops from the established networks both within and beyond the OPCARE9 project. In addition, an IORC-Steering Group will play a facilitative role in linking developments with the newly developed Liverpool Care Pathway for the Dying Patient (LCP) International





■ **Figure 1.**  
International OPCARE  
Research Collaborative  
(IORC) – Potentiating  
collaborative research

Reference Group, making sure that engaged research will produce appropriate outcomes to improve practice, and reciprocally that the research agenda is driven by appropriate need.

### **The Liverpool Care Pathway for the Dying Patient (LCP) International Reference Group**

The aim of the LCP continuous quality improvement programme is to translate the excellent model of hospice care for the dying into other healthcare settings, and to develop outcome measures using an integrated care pathway (ICP) for the last hours or days of life. Since 2000, the LCP Central Team at the Marie Curie Palliative Care Institute Liverpool has been working alongside palliative care and oncology leads across ten countries around the world regarding development, implementation and dissemination of the LCP programme. The LCP core document is now used in more than 20 countries, within very different cultural contexts.

International LCP meetings have attracted a multiprofessional audience since 2004 as an

opportunity for shared learning, networking and the potential for service innovation. The OPCARE9 programme incorporated a work package to develop a more robust innovation and research agenda across the international LCP community and led to the inaugural LCP International Reference Group meeting held in London in December 2011.

The international programme now developing, driven by the reference group, will enable the collaborative progress of emerging research methodologies related to the LCP that respond to and inform the IORC agenda.

### **Generating the evidence base**

The aim of OCPARE9 was to reach consensus, based on current practice and available research evidence, on the optimum care to be delivered in the last days of life and to identify gaps in the knowledge base across the five primary themes. Evaluation of the evidence base and commentary on issues for practice is emerging from the systematic and structured reviews that have been published.<sup>2</sup> Further, a number of the research protocols

**Table 1. Funded projects developed from OPCARE9**

Project	Funding
COMMunication regarding foods and fluids towards the END-of-life. A qualitative approach (COMMEND Study)	<ul style="list-style-type: none"> <li>• Genesis Oncology, New Zealand</li> <li>• Dutch Cancer Society</li> <li>• Erasmus Trustfund Rotterdam, Netherlands</li> </ul>
Medication, diagnostic and interventional procedures in the dying cancer patients. Developing indicators for measuring the quality of care at the end of life	<ul style="list-style-type: none"> <li>• Lefebvre D'Ovidio Foundation-Onlus, Rome</li> </ul>
Development, implementation and assessment of the LCP Programme in community. A phase 0-1 study according to the MRC Framework	<ul style="list-style-type: none"> <li>• LUVI Foundation, Milan, Italy</li> </ul>
Diagnosing dying – development of a tool for identifying the last days of life (LDOL)	<ul style="list-style-type: none"> <li>• Swiss Cancer League</li> <li>• Foundation for Cancer Research, Switzerland</li> </ul>
Randomised clinical trial comparing oncological therapy with palliative interventions versus oncological therapy plus early and continuous palliative care on advanced digestive tract cancer patients	<ul style="list-style-type: none"> <li>• National Cancer Institute in Argentina</li> </ul>
Practice of responding to desires for hastened death in specialist palliative care in Germany	<ul style="list-style-type: none"> <li>• Köln Fortune Program of the Medical Faculty, University of Cologne, Germany</li> </ul>
Implementation of LCP-Liverpool Care Pathway (local version PAMPA) for the quality care of cancer patients in last days of life	<ul style="list-style-type: none"> <li>• National Cancer Institute in Argentina</li> </ul>
A Living Community Presence: an innovative approach for volunteers to support the care of patients and their families in the last hours and days of life	<ul style="list-style-type: none"> <li>• Dimpleby Cancer Care, UK</li> <li>• Marie Curie Cancer Care, UK</li> </ul>
Designing sensory experience in end-of-life patient care: transdisciplinary interventions	<ul style="list-style-type: none"> <li>• PICK-UP (ALF), Sweden</li> </ul>

that were developed to address identified gaps in the evidence base have now received funding and are currently being undertaken (see Table 1).

In addition to the projects that have secured funding, further submissions are expected to secure resources and generate data that will contribute towards improving the care of cancer patients in the last days of life.

## Conclusion

Cicely Saunders said that, 'A society which shuns the dying must have an incomplete philosophy'.<sup>3</sup> However, as highlighted in the series of articles that summarise the findings from OPCARE9, little attention is given to the care of the dying throughout international health care systems. Crucially, the changing profile of our ageing population and the projected increase in the number of people requiring appropriate palliative care, highlight that care of the dying must become a key issue for all clinicians and politicians, and for society.<sup>4,5</sup> The International OPCARE Research Collaborative is positioned to engage with these challenges, sustain the political debate and pursue collaborative research to generate evidence that will make a difference to the care of dying patients in Europe and beyond.

## Further information

Further information on OPCARE9, its members, work packages, outputs and contact details, can be found online (at [www.opcare9.eu](http://www.opcare9.eu)).

### Acknowledgement

OPCARE9 is funded by the European Commission's Seventh Framework Programme (contract number: HEALTH-F2-2008-202112) with the aim of improving care in the last days of life by systematically identifying existing knowledge as well as knowledge gaps. The project aims to do this collaboratively across Europe and beyond to integrate knowledge from a range of healthcare environments and cultures and to avoid duplication of resource and effort. Project outputs include the dissemination of key findings and recommendations for further research and development for care in the last days of life.

### Additional contributors

All WP members, PSG and SPAG if not included in the main author list.

### Declaration of interest

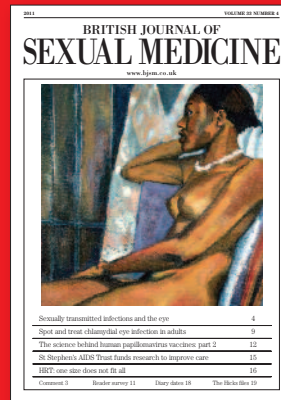
The authors declare that there is no conflict of interest

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■ Clinical practice generates too much information for individual clinicians to assimilate into structured evidence

# The importance of publishing studies with negative results in palliative care

TACO MEERUWSEN/GETTY

Palliative care research is still a minority interest area. **David C Currow** and **Amy P Abernethy** explain why it is important to aim for publication of palliative care studies – even those with negative outcomes

**T**he minimisation of bias is the underpinning of rigorous research; the goal is to most closely approximate ‘truth’ in a reliable and reproducible way while simultaneously optimising the resources needed to reach the conclusion.

Bias can be generated in: selection of methodologies, potential participants and interventions; conducting interventions; recruitment and retention; study procedures; analysis; results interpretation; and dissemination. The extent and types of biases present or addressed in any individual study are unlikely to be defined in a cursory review

of the study, since no single methodology eliminates every type of bias.<sup>1</sup>

## Publishing in 2012

Publication in peer-reviewed journals is difficult and time-consuming to achieve. To publish in a particular journal, the article has to align the readership’s interests and journal’s expectation of study design and reporting quality. The rate of rejection is higher than 95% for some very high-impact journals, and although most rejected papers are submitted elsewhere, the findings from many studies are ultimately not published. Publication of

negative studies can be particularly challenging; the results are less likely to engender excitement (unless they oppose current clinical practice or expert opinion) and sponsors are much less likely to push for publication. The studies that are published tend to be published in lower-impact journals, and papers in lower-impact journals carry less academic currency. The summary result is that negative studies are much less likely to be published than positive studies on the same topic – especially in the peer-reviewed, searchable literature.<sup>2,3</sup> This has direct implications for practice and policy across all fields of clinical practice.

### Definition of negative studies

Not all ‘negative trials’ are the same. A hypothetical categorisation of negative studies and their likelihood to be published balances methodological quality and statistical power, tempered by other motivations such as sponsorship goals and academic currency. Categories include:

- Well-designed, rigorously conducted and adequately powered studies that demonstrate a negative result after recruiting the full sample. Such trials are more likely to be published, and the impact of the journal they may be published in is determined by the importance of the result within the context of current clinical beliefs and practices
  - The result is in conflict with current clinical practice or expert opinion – most likely to be published, and likely in a high- or mid-tier journal
  - The result is consistent with current clinical practice or expert opinion – generally will be published, although not all will; if published, likely to be in a mid- or low-tier journal
- Well-designed, rigorously conducted but underpowered studies that demonstrate a negative result in the context of being unable to accrue the full study sample needed to be powered for a confident result. These studies may be called ‘pilot’ or ‘preliminary’ data by some investigators, even though the original intention was to complete the definitive trial
  - Result is in conflict with current clinical practice or expert opinion – reduced likelihood of publication and, if published, in a mid- or low-tier journal.

– Result is consistent with current clinical practice or expert opinion – may be published or not, and, if so, likely to be in a low-tier journal

- Poorly designed and/or poorly conducted studies that demonstrate a negative result; these may or may not have accrued the target study sample. These studies may be also called ‘pilot’ or ‘preliminary’ data by some investigators, especially if a more methodologically rigorous study or improved study procedures are generated in response to lessons learned. These studies are often not published in peer-reviewed literature, and, when they are, manuscripts are generally submitted to very low-tier journals. These lowest-tier journals are often not searchable within the standard electronic search engines. The other place they will be found will be in the ‘grey’ literature – that is, unpublished works or government reports, for example.<sup>4</sup>

Hospice and palliative care practice has some specific considerations regarding the publication of negative studies that, although not unique, amplify some of the key issues seen in the omission of negative studies. Methodological quality and innovations in conducting adequately powered trials are maturing, but many studies are still poorly conceived and/or conducted. Recruitment is notoriously difficult. Few study sponsors have financial motivations to urge publication. The competing urgent demand of clinical palliative care is argued by many to reduce the academic urgency to publish. As a result, negative hospice and palliative care studies – and the systematic reviews of the literature

### Key points

- It can be difficult to secure publication in peer-reviewed journals, particularly for studies with negative outcomes.
- The broad omission of negative studies from publication is termed ‘publication bias’ and can arise from researchers (choosing not to submit their articles), journal editors and peer reviewers.
- Public registration of a trial allows researchers to view the trial’s progress and makes it more accessible to literature reviews and meta-analyses.
- By nature, palliative care trials are often small or underpowered, but this does not mean their results should not be publicised, as their data can still be used to make meta-analyses more complete.

intended to inform clinical practice – are at even higher risk of (negative) publication bias.

## Publication bias

### Definition

The omission of negative studies from the peer-reviewed literature is termed ‘publication bias’. There are at least three groups of people who can contribute to this process: researchers (deciding whether or not to submit the results of a study); journal editors (deciding on whether to seek further review of a submitted paper); and peer reviewers for that journal.<sup>2</sup>

For more than a quarter of a century, the impact of publication bias has not only been recognised, but quantified.<sup>3,5</sup>

Publication bias, largely, has been attributed to negative trials, but other issues are at play – the

language in which the paper is published, funding sources, and type of intervention being evaluated. For example, positive industry-sponsored studies are more likely to be published, and to be published rapidly in more prominent journals. Meanwhile, studies of non-pharmacological interventions are less likely to be published. Inherently, this bias is non-random in nature.<sup>2,6</sup>

### Impact

There are two ways in which publication bias has the likelihood of impacting negatively on the greater body of knowledge. First, a complete record of knowledge is needed if work in a particular line of inquiry is to be progressed as rapidly as possible. Second, if data are to be combined into a meta-analysis, all data of sufficient quality must be available readily for inclusion.<sup>2</sup>

### Managing publication bias

Publication bias can be reduced or better assessed using a systematic approach. Before a study commences, the study can be publically registered so that researchers can follow its progress. Systematic reviews should search the grey literature as well as the various clinical trials registries to identify all data sources.

When conducting systematic reviews and meta-analyses of existing literature, the extent of publication bias needs to be assessed.<sup>7</sup> Funnel plot graphs are the most widely used way to assess the presence of publication bias.

The expected outcome for plotting the clinical effect against study size would be a normally distributed range of findings. If the outcome is not symmetrically distributed, this raises the possibility of publication bias.<sup>6</sup>

At the broadest policy level, to aid the ability of researchers assembling systematic reviews and conducting meta-analyses, the World Health Organization (WHO) has authorised clinical trial registration on sites such as [www.clinicaltrials.gov](http://www.clinicaltrials.gov) and the International Standard Randomised Controlled Trial Number Register ([www.controlled-trials.com/isrctn/](http://www.controlled-trials.com/isrctn/)). Clinical trials are not the only studies where there is publication bias, and there have been calls for registration beyond Phase III clinical trials to ensure that all study data are available and that there is the widest possible dissemination of knowledge.<sup>2</sup>

Such trial registration sites link researchers with current work in their area of endeavour to inform their own study design, and help to inform researchers conducting meta-analyses and systematic reviews. As a consequence of this, and to systematically reduce publication bias to positive studies, the International Committee for Medical Journal Editors has now made it a uniform requirement that there is public registration of all clinical trials before they can be published in their journals. Similarly, the US Food and Drug Administration (FDA) requires clinical trial registration for all intervention studies that contribute to FDA submissions. Although this does not address the issue of researchers who do not register their clinical trials and do not publish, it is a way of encouraging researchers and study sponsors to have more public accountability.

At the same time, there has been a shift by the pharmaceutical industry, particularly by big companies, to commit to publishing their studies whether they are positive or negative, although the net impact of such moves has not been fully realised yet. An area of bias in preparing for publication has been companies’ desire not to make public adequately powered negative studies when they demonstrate that a particular medication under patent is not delivering the hoped-for benefit. This has led, on occasion, to the continued use of medications where companies have explicitly known that the purported benefit was not achievable and was not being delivered across the population.

## When conducting systematic reviews and meta-analyses ... the extent of publication bias needs to be assessed



## Clinical relevance

For clinicians in all disciplines, the net clinical effect is made up of both the positive effects and the toxicities of any particular intervention. To that end, relevant clinical negatives are a crucial part of understanding the net effect of an intervention. This means that there needs to be consideration of the publication of all relevant data. Hence, even some small underpowered studies not in the peer-reviewed literature may contribute meaningfully when making policy and practice decisions.

The publication of all relevant data means not only that meta-analyses can be performed adequately, but also that studies with contradictory findings can be explored in detail. The aim of such a process would be to resolve any methodological differences that may explain differing outcomes. Ultimately for clinicians, policy-makers and funders, best evidence needs to be based on the widest possible available data that have been collected in relevant settings.

## Implications of not publishing

What are the implications for non-publication of negative findings in palliative care? As noted above, the decision to attempt to publish rests with the investigators. Hospice and palliative care researchers have a poorer track record for publishing in searchable, peer-reviewed literature than other disciplines; for example, it has been documented that the rate of converting conference abstracts relevant to hospice and palliative care to peer-reviewed papers in journals is much lower than other clinical disciplines.<sup>8</sup>

Hospice and palliative care studies are often underpowered, either because a power calculation has not been done or because of difficulty recruiting to the study. The latter is magnified because of the large number of single site studies that continue to be done. Multisite research is absolutely key to completing studies in a timely way.<sup>9</sup>

Given the relatively small number of patented medications used in hospice and palliative care and the few new industry-sponsored medications coming into the domain, specific positive bias to publish positive results or to delay publication of negative results is unlikely to have a huge impact at this time. With the ability to apply emerging technology and personalised

medicine in the supportive and palliative care setting in years to come, this may not always be the case.

There is a key ethical imperative for people to have their data made available when they have participated in a clinical trial in hospice and palliative care. Hospice and palliative care patients and their caregivers are highly committed to improving the care for others by participating in studies that will help to improve systematically the care offered.<sup>10</sup> The generosity of people to give time and energy at the ends of their lives by participating in clinical studies deserves a real commitment from researchers to make such data available as widely as possible.

In palliative care, given the apparent reticence to conduct multisite studies, the literature is replete with studies that have either not had a full power calculation or have not reached their proposed recruitment targets. Ensuring that other researchers know about such studies is crucial in order to ensure that meta-analyses are as complete as possible and use as much data as possible to improve their power to determine net clinical benefit. Also, it is crucial that prior experiences with conducting clinical trials are published for other researchers to access, so that the same difficulties and mistakes are not repeated over and over.

It is easy to underestimate the number of potential participants with a particular symptom, and hence the feasibility of hospice and palliative care studies.<sup>11</sup> There will be smaller populations in terms of both eligibility and recruitment than simply the number of those who present with a symptom.

## Underpowered studies

The relevance of an underpowered (and hence one type of negative) study being available is highlighted well in the hospice and palliative care literature. The meta-analysis conducted by Jennings *et al* exploring the patient-defined benefits of opioids for refractory breathlessness brought together nine underpowered studies with 116 participants in total.<sup>12</sup> The resultant findings showed that opioids were likely to be of clinical benefit.

This was borne out almost simultaneously with an adequately powered, double-blind, randomised, placebo controlled cross-over study in 48 participants (approximately the

**The decision to attempt to publish rests with the investigators**

equivalent of 96 participants) of once-daily sustained-release opioids where the net benefits seen were of the same order of magnitude and direction as the meta-analysis.<sup>13</sup> Not only does the science demonstrate consistency here, but highlights the necessity of having access to all relevant data to confirm the validity of findings.

There is a perception that negative studies cannot be published and, if they are, it will not be in journals with any sort of impact factor. This is not the case. An adequately powered, international multisite, double-blind, parallel arm block randomised and stratified controlled trial in a palliative care population was published in the *Lancet* in 2010.<sup>14</sup> The study compared the use of two litres per minute of 15 hours per day oxygen versus

medical air for one week in people with refractory breathlessness who did not qualify for long-term domiciliary oxygen using international criteria. This

study did not demonstrate any difference between medical air and oxygen and, as such, supported the use of medical air or the more rigorous evaluation of therapies such as fans in the setting of refractory breathlessness. Negative studies that are well designed and well conducted can and should be published.

There is an imperative for all palliative care trials to be registered publically in order to more rapidly build the evidence base, link researchers working in similar areas, help researchers to refine their research more rapidly given an ethical imperative not to replicate work that is already being done (especially because of the waste of time this is for participants), and to ensure that reviews of all relevant data can be carried out quickly and effectively.

We must devise more efficient ways to integrate various study designs (such as experimental randomised trials and observational cohort studies) to make sense of all of the information available to us. Also, we must ensure that all of our evidence sources are searchable. As our discipline pushes to publish more of our available research – including negative studies – the growing number of small, non-searchable hospice and palliative care journals will house this information; we must ensure that these journals are searchable too.<sup>8</sup>

We need to monitor ourselves. First, set the baseline. Develop an understanding of what proportion of our literature is currently visible in the published-searchable, published-non-searchable, grey, and non-published spaces.<sup>8</sup> Then, regularly update the report and monitor to see that it is improving.

Ultimately, in practice there is too much information being generated for individual clinicians to assimilate into structured evidence. There is a need for rapid learning systems that use real-time data in conjunction with systematic reviews that are constantly updated in order to manage the tsunami of new information becoming available.<sup>15</sup> This can only happen effectively if all researchers respect basic tenets of ensuring that their data are as visible as possible to fellow researchers, clinicians, policy-makers and funders.

#### Declaration of interest

The authors declare that there is no conflict of interest.

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# Implementing spiritual care at the end of life: the Netherlands

The development and implementation of spiritual care in palliative care is developing rapidly in many countries. In this occasional series, members of the European Association for Palliative Care Taskforce spiritual care report on national developments across in order to share ideas and stimulate the implementation of spiritual care. Here, **Carlo Leget** discusses the recent progress in the Netherlands

**T**raditionally a country where the Roman Catholic tradition was widespread in the southern and eastern parts, and Protestantism in the northern and western regions, after World War II Dutch society has changed into a culturally diverse and strongly secularised landscape where Roman Catholic (27%), Protestant (16.6%), Muslim (5.7%), Hindu (1.3%), Buddhist (1%) and people with no faith system (48.4%, of whom humanist organisations claim to represent 9.4%) live together.<sup>1</sup>

Since 1996, spiritual care in healthcare institutions has been provided by chaplains, who are organised in a professional body that comprises all religious and non-religious denominations.<sup>2</sup> These chaplains (some sent by a church) work as spiritual caregivers who can work with patients whatever their religious (or non-religious) background.

Patients who are cared for at home are the most problematic group from the viewpoint of spiritual care. Most of them are no longer connected to local churches and are not being cared for by the chaplains working in institutions. In the last decade, developments have taken place that contribute to the implementation of spiritual care in both institutional and home-care settings.

## Recent developments

First, a process of developing a national consensus-based guideline on spiritual care for physicians and nurses has contributed to finding a common language and point of reference for people coming from various

traditions. The result of a long process in which professionals from various disciplines were invited to comment and contribute, the guideline has provided those who were motivated to implement spiritual care with an authoritative text that helped them to address their managers, directors and boards.<sup>3</sup>

Second, focusing more closely on content, the guideline has helped to orient and promote the education of healthcare professionals and volunteers. In the past five years, more attention has been paid to spiritual care in the advanced palliative care education of physicians and nurses. In some regions, the same development has been seen in the primary education of nurses.

Third, from 2007 onwards, chaplains working in palliative care have been trained in small groups (master classes) to understand

## Key points

- The Netherlands is a majority secular country; the largest faith communities are Catholics and Protestants.
- Since 1996, spiritual care at the end of life has been provided by chaplains, who can be of any religion.
- Providing spiritual care for those being cared for at home is more problematic than for those in an institutional setting.
- Launched in 2010, a national spiritual care guideline has provided education and direction for healthcare professionals. It gives guidance on raising the issue of spiritual care with health boards, and has led to greater attention being paid to spiritual care provision in the training of healthcare professionals.



the chances and possibilities of their position in stimulating the implementation of spiritual care. Often, chaplains were not aware of how palliative care in the Netherlands is organised (66 regional networks in which healthcare organisations work together). Becoming aware of their key position, they were stimulated to reach out to other disciplines and settings. From 2012, chaplains' training is being developed in a multidisciplinary fashion, in which professionals of different disciplines become aware of their specific opportunities in this area. The co-ordinators of the regional palliative care networks have constantly been informed about the development of the spiritual care guideline in national conferences. Multidisciplinary groups on spiritual care were founded; these organised education of professionals and volunteers, training of consultation teams, and better structures for spiritual care at home. Recently, a promising new initiative was developed: a healthcare insurance company was prepared to pay over a period of three years for spiritual care at home provided by chaplains from healthcare institutions organised in a pool of professional volunteers.<sup>4</sup>

## Conclusion

The implementation of spiritual care is a process intrinsically linked with, and based on, ongoing research and education. In a rapidly changing and multicultural society, such as that of the Netherlands, the process of working from a common point of reference, the national guideline, has proved to be successful. From the perspective of implementation, however, this is only a first step. Only when attention to spiritual care is a normal part of the primary education of healthcare professionals, and all patients are reached, can one really conclude that the process of implementation is accomplished.

### Declaration of interest

The author declares that there is no conflict of interest.

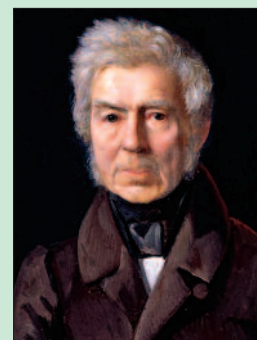
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## In the next issue ...

■ **Nadia Khan** and **Dan Munday** provide an overview of the palliative care implications of using non-invasive ventilation for end-stage COPD.



■ **Jenny Baulkwill, Andrea Dechamps, Julia Manning, Ninon van der Kroft** and **Malcom Payne** report on an evaluation of support groups for young people who are providing palliative care in the home.

■ **Piotr Krakowiak, Agnieszka Paczkowska** and **Robert Witkowski** provide details of an innovative Polish project using prisoners to volunteer in palliative care services.

■ Making decisions about artificial nutrition in end-of-life care is complicated. **Nicholas Herodotou** presents a decision-making pathway to help.

■ As part of the ongoing 'A day in the life' series, **David Glenister** provides insight into his work as a visual artist and pastoral care practitioner in Australia.

■ The occasional series of articles on spirituality in the European palliative care setting continues with **Laura Campanello, Cinzia Martin** and **Filippo Laurenti** discussing Italy, and **Bella Vivat** covering the UK.

■ **Giampiero Porzio, Federica Aielli, Marco Valenti, Lucilla Verna, Enrico Ricevuto, Katia Cannita, Paolo Aloisi** and **Corrado Ficarella** look at the prevalence of symptoms in end-stage cancer.

■ **Usama Hasan** discusses the understanding of life, death and illness in Islam.

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# Where's the humanity? Assisted dying is not the solution to providing dignity

In a personal response to the findings of Lord Falconer's Commission on Assisted Dying, **Dimity Grant-Frost** argues that legalising assisted dying is not the answer to the issue of dignity at the end of life

I can clearly remember sitting at the bedside of a middle-aged Jamaican man with cancer who I had been caring for during his admission with spinal cord compression. He had struggled desperately to come to terms with the weakness in his legs but had remained low in mood throughout his hospital stay. As we spoke that day, large tears spilled down his cheeks while he recounted his first experience of faecal incontinence, which had occurred as he lay in bed during the early hours of that morning.

Thinking I grasped his horror at what had happened, I reassured him that incontinence was normal given the circumstances, and that we would work hard to ensure we minimised his distress should it happen again in the future. Though he continued to weep, he smiled broadly and said, 'You don't understand ... I'm not crying because of the mess. I'm crying because the nurse who cleaned me up was so lovely. She made me feel that I was no trouble to her at all'.

The 'loss' of human dignity has been cited throughout the debates of the last few years as a key motive for changing legislation to allow physician-assisted suicide. There were those who were part of Lord Falconer's Commission on Assisted Dying earlier this year who encouraged us to believe that so-called 'assisted dying' would provide 'a more dignified death'.<sup>1</sup>

Frustratingly, there were also those on the commission's panel who felt there was cause to suggest that medical professionals 'exclude the terminally ill' from a duty of care in not supporting a change in the law to this end.<sup>2</sup>

Human dignity is, however, not something granted, gained or lost on the grounds of health, wealth, independence, ability, mental

capacity or youth. Human lives are dignified because they are just that: human. There is something inherently and mysteriously precious and beautiful about a human life, and these qualities are not invisible in the one who is permanently or terminally ill, who is suffering mental or physical disease, who is old or weak or poor.

The one whose quality of life is, even for a period, dependent on the time, finances, patience and energy of others has not, fundamentally, lost their dignity. At vulnerable moments, of course, we may feel that our dignity has abandoned us. There are, to be sure, several examples of human experience that are deeply unpleasant, unattractive, tumultuous and painful – the groaning, tearing, bloody mess of childbirth being one poignant example outside of chronic or terminal illness. And yet the times where dignity and control seem lacking, as is obvious with but by no means exclusive to childbirth, can give rise, even through pain, to great personal growth for those who experience or are witness to them.

Age, illness or disability may rob us of control, but dignity itself is not a dependent

## Key points

- The findings of the Commission on Assisted Dying suggested that, in some cases, providing assisted dying would allow a more dignified death.
- Dimity Grant-Frost argues that dignity is not lost through illness or incapacity, and that humans have inherent dignity.
- Palliative care should seek to remind and reassure patients of their own dignity.

variable. The problem (highlighted by reports on standards of care and compassion in UK healthcare facilities)<sup>3</sup> arises when we fail to care for people with the dignity that is manifestly theirs. Surely the job of the strong, the resourced and the powerful (all, I might add, temporary conditions themselves) is to pour love, support and hope in vast quantities into those who are weak, vulnerable, suffering and broken. It cannot be best to reinforce for them the gnawing fears that plague them as they face life's greatest difficulties. A society, and indeed a body of healthcare professionals, willing to confirm that suffering and death are relentlessly traumatic and beyond redemption and that human dignity and value fluctuate depending upon the perception of the individual or society has surely lost its way.

Beyond the pro-euthanasia lobby's perceived or rectifiable inadequacies of palliative care and the offensive intimation that a failure to support a change in the law constitutes the healthcare professions' neglect of their duty of care – even beyond the assurances of 'strict safeguards', 'monitoring commissions' and 'public support' – lies a greater problem. We are failing to behave in the way that our human dignity calls us to. We ought to respect, value and protect the flesh and blood of which we have been made, even when it is failing us or others. We must persevere relentlessly in the pursuit of excellent medical, nursing and social care.

We need, gently and respectfully, to assure those who feel their lives lack value, meaning and dignity, that – simply because they are human beings – they are mistaken. We must resolve, in whatever capacity, to care sacrificially for all who suffer. We must not confuse these actions with treating people 'as if they had' dignity. We are not playing pretend. Human lives have great dignity. They ought to be treated accordingly. In so doing we may take some of the sting even from the pain of death itself.

### Declaration of interest

The author declares that there is no conflict of interest.

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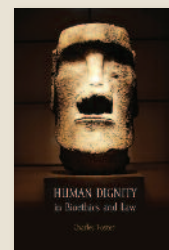
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### Human Dignity in Bioethics and Law

*Foster C. Oxford and Portland, Oregon:  
Hart publishing, 2011; 218 pages, £30*

**In palliative medicine, ethical decisions are frequently based on either patient autonomy or best interests. Autonomy, however, relies on someone being able to convey their wishes and what is deemed acceptable.**



**Best interests reflect known wishes, but this is often not enough in complex decision-making and we seek help from others to decide on what is 'best'. This book, academic though it is, takes these processes to a whole new level and is empowering as a result.**

The first half of the book unpicks the often nebulous concept of 'dignity'. Foster argues that dignity is the maximisation of human thriving and should underpin any ethical or legal decision made.

Foster utilises a vast array of philosophical, religious and legal references, internationally sought, to allow the reader to informatively consider his argument.

The engaging case examples include one of a dwarf prohibited from being tossed onto a Velcro wall for money, on the grounds of 'public order' – dispensing with autonomy – and the book goes on to chapters that include debates on cloning, abortion, euthanasia and body parts.

Foster prompted me to ask some difficult questions:

- Can dignity be found in the death of Jesus who supposedly hung on a cross to die?
- If autonomy is an absolute right, why should informed, advanced decisions to refuse treatment still get overturned?
- If suicide is legal, is it justifiable for it to be illegal in someone who is physically unable to perform the act themselves, thus requiring assistance?

The end-of-life chapter only incorporated eight pages and, somewhat selfishly, I wanted more. Nevertheless, I agreed with Foster; the word dignity is often used as an ethical antiseptic and is poorly defined. His proposed transactional model analysis has equipped me to better manage my next ethical dilemma ■

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# Hospice volunteering: work, socially useful leisure or just filling in time?

Hospices have long relied on volunteers. **Jacqueline H Watts** looks at the differing motivations that hospice volunteers may have for the work they do, and the importance of providing them with employment support

**W**ork as paid employment is economic in character and is undertaken across the life course usually as a means of sustaining self and dependents. Orientations to work, however, are complex and are shaped by education, cultural values and family practices that influence the choice of career or occupation.<sup>1</sup> The choices and decisions people make about their work are also shaped by the structure of the labour market, which operates to economically 'value' some forms of work more than others (as well as some types of worker over others), and there now exists a wide body of literature that debates the experience and meaning of work in contemporary society.

An emerging theme in recent years has been a blurring of boundaries between paid and unpaid work that challenges the preoccupation of policy-makers with employment as the only work of value such that those outside or excluded from employment are not recognised as 'working'. Indeed, recent debates about the centrality of paid work to living a useful life have been increasingly tied to the credentials for citizenship that Lister argues are an essentially contested concept.<sup>2</sup> This notwithstanding, there is growing acknowledgement by commentators of the significance of the voluntary sector in the provision of a range of services, particularly in the field of health- and social care, giving rise to new understandings of work.

The importance of voluntary work (unpaid work outside the home) is central to these new understandings, and is now the subject of considerable government interest in its attempts to stimulate social engagement in a plethora of community programmes. For the

hospice sector, however, volunteering has long been embedded within its operational ethos; Howlett argues that many hospices could not continue to offer a range of services without the commitment of their volunteer workforce.<sup>3</sup> Recruiting and retaining volunteers to work in different parts of the hospice is thus an important priority for hospice managers, and this article considers some of the factors that influence the experience of both becoming and being a hospice volunteer.

## Why do people become a hospice volunteer?

The organisational and management literature has focused attention on why people take up voluntary work, noting that motivations to volunteer are varied, with a number of broad themes emerging. These are helping others, having time on their hands, being asked by friends or relatives and having links with a particular organisation.<sup>4</sup> In relation to hospices, similar motivations are in evidence, and can be understood through instrumental and altruistic categories. The opportunity that volunteering affords to help

## Key points

- Motivations for volunteering in a hospice include altruism, and the potential for gaining experience as a route to paid work.
- Some volunteers may view volunteering as a way of managing their own grief or converting others to their religion, and volunteers should be scrutinised carefully.
- Volunteers need proper training and support to ensure they can fulfil their roles confidently and according to standards.

organise time and give structure to weekly routines (particularly for retired persons) is an example of an instrumental motivation that accords with the 'having time on their hands' phenomenon noted above. Many older people find themselves living alone following the death of a spouse and the social dimension of working with others in a voluntary setting should not be underestimated in terms of its motivating force. The extent to which the social contact sustains motivation rather than initiates it is difficult to judge, but as Howlett notes, volunteer motivations do change over time, making it difficult for voluntary service managers to identify and respond to motives as part of their recruitment activities.<sup>3</sup>

### **The social dimension of working with others in a voluntary setting should not be underestimated**

Hospice volunteers come from a variety of backgrounds, and some are, or have been, employed in demanding professional/occupational roles where they have been able to develop and use a range of skills in fulfilling ways. The work of a hospice can provide opportunities for people to continue using skills from their professional work, providing 'bridging' between paid and non-paid work, and continuity in being valued. An example of this might be a volunteer working in day care who has had a career in social work and has developed the skills of listening and supporting, particularly in the context of loss. Another example would be a trained counsellor who contributes to the work of the bereavement care team. Again, listening and empathy skills are important in this role. Being a paid worker has been found to confer status, identity and enhance personal self-esteem,<sup>5</sup> and being part of an organisational team as a volunteer worker can be experienced as significant by some in helping to re-enforce a sense of self-worth post retirement.

Increasingly, the route into paid work may involve periods spent working in an unpaid voluntary capacity where a prospective employer assesses a person's aptitude and skill for a particular role. Internships are commonplace and are one example of this and, though they may sometimes lead to an offer of a paid job, some commentators regard these arrangements as exploitative and unsustainable. Although not operating in the commercial sector, hospices can be of

instrumental value to some groups of volunteers providing 'mini-internships'. For example, during a recent visit to one hospice I met a woman volunteering in day care specifically to gain experience in support of an application to enrol on a social work degree programme. In talking to her about her experience at the hospice, she made it clear that she enjoyed her work there but that it would be time-limited in relation to her goal of training as a social worker.

The second motivation category is that of altruism, summed up as 'wanting to give something back' that Noon and Blyton term as a form of 'gift work'.<sup>6</sup> Hospice volunteers often initially come into contact with the hospice because of the terminal illness of a friend or family member and want to commit effort to the work of hospice as a material way of saying 'thank you'. While selfless altruism remains ideologically dominant in the culture of volunteering, this is gradually changing and Howlett argues that the area of volunteer motivations is complex with an increasing emphasis on voluntary work as a reciprocal relationship.<sup>3</sup>

Although the two types of motivation discussed above are clearly significant in hospices continuing to recruit volunteers to their workforce, it is important to emphasise that sometimes those who apply to join hospices in a voluntary capacity may not have a particular motive or aim but do so out of curiosity and good, if not clearly defined, intention.<sup>7</sup> Others may want to undertake this work as part of their own recovery from bereavement or with the goal of converting others to a faith before they die.<sup>8</sup> This raises the important issue of suitability for this role and the need for careful scrutiny of applicants by voluntary service managers.

### **Support and training**

Once recruited, volunteers need to be trained and supported<sup>1</sup> so that they can perform their role with confidence and according to the codes and standards prescribed by the hospice. As in other sectors, voluntary work in the hospice setting has become characterised by more standardised working practices<sup>3</sup> and this is gradually changing the experience of volunteering because, as Morrison argues, 'there is a particular and very significant tension between a professionalised managerial approach and a more traditional volunteering

ethos'.<sup>9</sup> Operating within the 'professional' discourse of quality, accountability and regulated practice, some voluntary work has been made closer to the experience of paid work and Howlett notes that hospice volunteers are expected to operate as quasi-professionals.<sup>3</sup> It is not surprising then that there has developed an increased focus on training and support for volunteers. This is generally welcomed but may have added to the 'formality' of voluntary work in this setting.

Different forms of training and support are to be found in each hospice, with many having an education centre that runs training and education for volunteers, carers and health and social care professionals. For new volunteers, Connor identifies a series of topics that he calls the 'basics' – death education, personal death awareness, principles of palliative care, social and psychological reactions to death, grief and loss and working as a member of the multidisciplinary team.<sup>8</sup> In the UK context, education in cultural awareness and diversity is also seen as important, as is a stronger focus on understanding spirituality.<sup>10</sup> This work can be emotionally demanding<sup>11</sup> and the need for ongoing support of volunteers by having debriefing sessions, clear reporting lines and the opportunity to informally talk through issues is well recognised and, in my experience, appreciated by the volunteer community.

Taylor<sup>1</sup> notes that much of the policy literature on volunteering rests on the assumption that volunteering is by definition a positive activity, 'beneficial' for the volunteer, those they help and society at large. Marginalised groups, such as disabled people and black and minority ethnic communities, who are under-represented in volunteer roles, are deemed to be 'missing out'. However, being a hospice volunteer can be demanding and stressful on a number of levels, and may not always be experienced as 'beneficial', due to the distress caused by witnessing 'untimely', 'bad' (or at least less than 'good') deaths, however we may want to define these. Furthermore, with greater accountability expected of volunteers comes greater responsibility on the part of hospice management to ensure that volunteers are fully supported in their roles.

## Conclusion

Motivations to take up hospice volunteering are varied, shaped by both instrumental gain and altruistic intent. Understanding why people choose to spend time as a hospice volunteer rather than on hobbies or other leisure pursuits involves giving attention to the circumstances and life histories of which these motives are a product. The 'self' of the past is the underpinning of the 'self' of the present. Because a 'busy ethic' may serve as a replacement for an earlier 'work ethic' (that may include family as well as paid work),

volunteering may be activity to stave off boredom and social isolation. Not all hospice volunteers are of retirement age but many are. Growing older requires both

men and women to (re)negotiate identities that, in part, may be shaped by 'free' time use.<sup>12</sup> The potential for leisure to be socially useful is captured in the commitment shown by many volunteers to the hospice movement. In this, we are reminded that the management of emotional labour does not stop when one leaves the employed workplace, and issues of competence and the maintenance of personal credibility continue as an ongoing project across the life-course.

## Declaration of interest

The author declares that there is no conflict of interest.

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# A day in the life of ...

## Natalie Davies, Speech and Language Therapist

■ Patients present with a wide range of swallowing and communication disorders

The palliative care team is made up of many people, doing different jobs. Meet them in this occasional series, in which the *European Journal of Palliative Care* invites those involved in palliative care to describe their typical day. Here, **Natalie Davies** describes her role when she worked as a highly specialist speech and language therapist at Meadow House Hospice

The multidisciplinary team based at Meadow House Hospice sees patients in the community as well as inpatients at the hospice itself. When my day starts at 9 am I never know what is ahead, which keeps me on my toes and always presents a challenge.

### Meadow House

The Meadow House team is composed of doctors, nurses, occupational therapists, physiotherapists, a dietitian, social workers, a complementary therapist, chaplaincy, counsellors, volunteers and our administration team.

A team meeting is held once a week to discuss current inpatients. Working as part of a team allows me to share information with my colleagues to ensure that we are meeting our patients' needs and addressing issues as they arise.

I see patients who present with communication and/or swallowing disorders as a result of a wide range of conditions, including cancer and neurological disorders.

My role focuses on assessment, diagnosis and management of communication and swallowing difficulties, with the aim of maximising their potential and quality of life. I go through my caseload and prioritise my day by booking appointments to see patients at home and liaising with ward staff on the inpatient unit to see if any inpatients require input.

### David

My first patient is David,\* who is a 31-year-old man who has a grade IV glioblastoma. He recently underwent neurosurgery, which has left him with a severe verbal apraxia, affecting the brain's ability to plan the necessary motor movements for purposeful speech. As a result, his speech output is significantly limited and variable, and this is incredibly frustrating for him.

He has recently married his long-term girlfriend and they now live

BERNARD ELLIS/GETTY

together in a local nursing home while looking for private accommodation to move to. He also has some cognitive difficulties as a result of the brain tumour and its location; this has affected his insight and ability to take on board and process more complex information. I have been seeing David for a few weeks now, and have assessed the extent of his speech disorder and discussed appropriate therapy options. His wife is keen to be involved, which always helps when considering support options for patients who may need assistance in completion of therapy tasks outside of my sessions.

David is keen to work on improving his speech; however, given the nature and prognosis of his brain tumour and the severity of his speech disorder, impairment-based therapy has limited success in significantly improving speech.

Often, my role is based around providing strategies and alternative communication methods to support patients and their conversation partners. This can be a hard concept for patients to comprehend, as it involves a journey of acceptance that the presenting speech disorder may not improve and that it may be something they have to learn to adapt to.

One way of helping patients to get the most out of therapy is to set goals at the beginning of our intervention. Patient-centred goals assist in directing the patient towards what they would like to realistically achieve during their block of therapy. It is also an effective way of measuring progress and helping patients to evaluate their successes, and provides a way of demonstrating when goals are not being met, allowing for discussion as to why this may be.

I find that when you are working with progressive conditions, such as motor neurone disease or dementia, the goals are often centred on maximising the strengths that patients



■ **Natalie Davies:** 'It always amazes me how the smallest pieces of advice can make a huge difference'

## I never know what is ahead, which keeps me on my toes

have and maintaining skills, rather than taking a curative approach. This approach is invaluable with David, as it gives him a greater understanding of what is realistically achievable. David's goals are focused on being able to socialise with his wife, family and friends.

David gets incredibly frustrated with his limited speech and the effect it has on his ability to participate with others. Loss of communication when working in palliative care is always an emotive issue for both patients and their families. Communication can define a person's identity, and is a means of expressing thoughts and emotions to others. To lose that ability when you are nearing the end of your life and there is so much to say to others must be heartbreaking, and I feel strongly that our role as speech and language therapists is to make sure that we optimise and utilise all means of communication for our patients.

For David, we experimented with using a communication chart – a pictorial board of different words and photos that he can point to when he cannot express himself verbally. This can be added to over time with words, phrases, pictures and photos that David feels are relevant to him when interacting with others. However, after a period of time trialling this, he feels it is not for him. He is adamant that he wants to work on increasing his speech output and that alternative and augmentative communication strategies are not enough.

We compromise by providing David with a range of impairment-based speech exercises that he can carry out in his own time. I am mindful, though, to remind him of the potential limitations of this approach, but he is willing to accept it. I continue to support him and his family by revisiting over time the alternative communication options. For many people, it is time that is needed to come to terms with such a great loss.

### Rosa

My second patient of the day is Rosa, an elderly lady with advanced dementia who lives in a nursing home. There have been recent concerns over her ability to eat and drink safely. She has been developing recurrent chest infections and the concern is over whether or not her potentially impaired swallow function is putting her at risk from aspiration.

Aspiration is where fluids and foods are directed into the trachea rather than into the oesophagus, which over time can lead to recurrent chest infections, dehydration and malnutrition, and can also have an impact on quality of life. Dysphagia (disorder of swallowing) can significantly change how a person eats and drinks.

The social impact of this can be huge, given that many of our social interactions are centred on food and drink. Speech and language therapists

have highly developed specialist skills in the assessment, diagnosis and treatment of swallowing disorders. These difficulties may stem from neurological disease, malignancy and a wide range of general medical and surgical causes, including respiratory conditions such as chronic obstructive pulmonary disease.

In Rosa's case, the advancement of her dementia has begun to affect her swallow function. The cognitive impairment can have a significant effect on eating and drinking, often by reducing a person's awareness of food and drink in front of them and also their sensory awareness once they start to eat and drink. It is common to see people hold food and drink in their mouths for prolonged periods and have difficulty in initiating a swallow. In very severe cases, meeting nutritional requirements becomes problematic. Increased aspiration risk is another complication of dementia, and significant factors pointing to the development of aspiration pneumonia include the dependence on others for feeding, becoming bed bound and poor oral hygiene.

One of the clinical nurse specialists from the hospice has requested a joint session with me to assess Rosa's swallowing. There are concerns that after eating and drinking she is coughing, which is a sign of aspiration. Her oral intake is also very poor and, coupled with a recent chest infection, it is likely that her swallow function has deteriorated. We visit her at the nursing home together. I assess Rosa using different consistencies of fluids, as staff at the home have reported that it is after fluids when she appears to cough.

Positioning is important, so the nurse and I make sure she is in an optimal position to lessen any risk of oral intake being aspirated. Indeed, after assessment it is clear that she is coughing on thin fluids. Thicker fluids (using a starch-based powder to thicken to a syrupy consistency) appear to reduce the risk of

aspiration. This works by allowing fluid to travel more slowly – as it is thicker – thus giving Rosa more time to initiate a swallow.

An important part of my job is to liaise with the other members of the multidisciplinary team to ensure the care of every individual is optimised. Clear and concise communication is fundamental to my job, so with all patient contacts I document in individual medical records what I have done, and hand over any communication and/or swallowing guidelines to nursing staff and the medical team in person.

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## Clear and concise communication is fundamental to my job

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Attendance at multidisciplinary team and family meetings may also be required. It is imperative that the patient is also involved with decision-making as much as possible. Even when cognitive and communication difficulties are present, it is vital that every effort is made to facilitate a patient's communication abilities to support their understanding of complex situations and to support them in conveying their thoughts and decisions. The speech and language therapist is pivotal to this process, through alternative and augmentative communication strategies, such as pictorial support or more hi-tech equipment, including switches and computer-assisted technology.

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## Would you like to contribute to this series?

If you are working in palliative care and are keen to share your experience with others, the *European Journal of Palliative Care* would like to hear from you.

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## Roger

My last patient of the day is Roger, who is a 50-year-old man and a current inpatient at the hospice; he has end-stage lung cancer. As a result, he is struggling to produce a voice due to lack of respiratory support, and this is distressing to both him and his wife. He is short of breath at rest and can only produce a few words at a time.

His voice is low in volume and has a breathy, rough quality to it, which makes it difficult for others to understand him when he is speaking. Roger is also incredibly tired and fatigues quickly, another factor that affects his voice. We go through some voice conservation strategies and some tips for increasing volume of voice.

A lot of the session focuses on helping Roger and his family come to terms with why his voice is affected. I am honest and open with my answers and feel it is important to be realistic about prognosis. Roger is aware and obviously upset that his voice will not recover but with some simple strategies in place for both him and those around him, he can regain some control over conversations and be able to put into words those essential messages to his loved ones in his last few days.

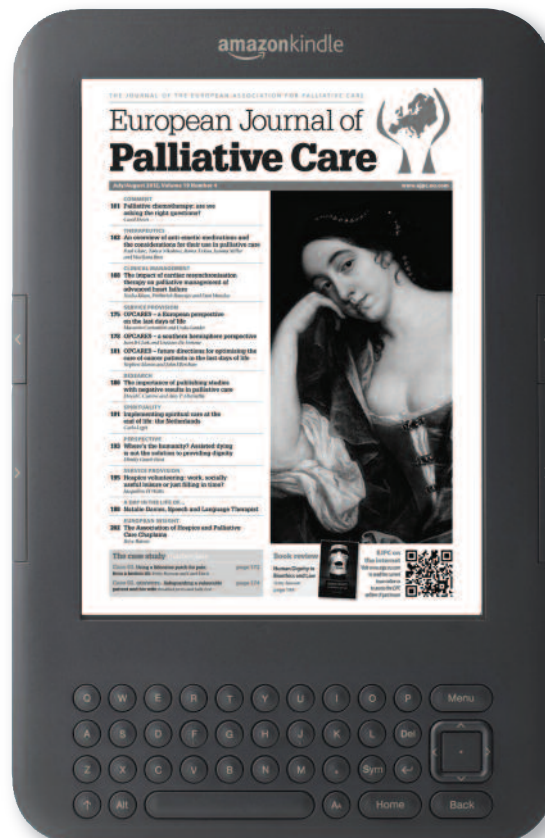
## Final conversations

One of the reasons I enjoy my work is because no person is the same. You can be presented with similar problems but the variation in people leads you to deal with these issues in many different ways. It also always amazes me how the smallest pieces of advice can make a huge difference to a person and their loved ones.

When a person is dying, time is of the essence and the thought of not being able to communicate to those around you is unimaginable.

I believe the speech and language therapist can help people to have those final conversations and to feel that they are being listened to at a time when you only have one opportunity to get it right ■





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*What can we do for you?*



In this section, European palliative care organisations are invited to explain their goals, express their hopes and voice their concerns

## The Association of Hospice and Palliative Care Chaplains

The Association of Hospice and Palliative Care Chaplains (AHPCC) is a community of palliative care chaplains in the UK who gather regionally and nationally for mutual support and encouragement. Is its characteristic informality about to change?

Steve Barnes muses over spiritual care and the evolving role of the AHPCC.



**Steve Barnes**, Chaplain, Willen Hospice, Milton Keynes, UK; President, AHPCC

Since the very beginnings of the modern hospice movement, spiritual care has been at its heart. Cicely Saunders, the pioneer of hospice care, understood the importance of the patient's own story and adopted the term 'total pain',<sup>1</sup> referring to the physical, psychological, social, emotional and spiritual components to distress and suffering in terminally ill cancer patients. Thus, addressing spiritual issues has always been a core element of good palliative care.

When people face incurable disease, some of life's big questions suddenly demand careful and considered acknowledgement, attention and, if at all possible, resolution – 'Why is this happening to me?', 'What have I done to deserve this?', 'What has my life been about?'. Questions of this kind may lead to all sorts of consequences – regret over smoking those 40 cigarettes a day, a tussle about the purpose of life, a readiness to write one's will and prepare a funeral, or a need to be quiet and face the sadness.

Often, words are not enough; sometimes a simple ritual reaches far deeper than hours of academic discourse, and a smile can do more to maintain a patient's dignity than reams of policy documents.

**Addressing spiritual issues has always been a core element of good palliative care**

Everyone working in palliative care has some influence over the spiritual well-being of patients and their families.

The chaplain is one member of the team providing that care. Long ago, he (and it was 'he') might have been a Christian cleric – and Church of England at that (in England at least) – called upon whenever prayers were needed, but the role is ever broadening. Today, hospice chaplains are male, female, ordained and lay, derived from any Christian denomination and, indeed, from many different faith traditions. They may be full or part

time, paid or voluntary, dedicated to the organisation, or on call from the local community. The title 'chaplain' has a Christian origin, so many are now called the neutral 'spiritual care co-

ordinator', or something similar, but 'chaplain' still seems the most universally understood among patients and visitors, and is accepted by a large number of faiths.

### AHPCC – a brief history

In the early days of palliative care, hospice chaplains worked largely in isolation from each other until, in 1987, the first suggestion was made

for an Association of Hospice Chaplains (AHC) to be formed for mutual support and exchange of ideas.

A letter was sent to those in full-time hospice chaplaincy to allow them to indicate interest in joining a group whose aims and objectives were to:

- Provide support and fellowship for chaplains caring for the terminally ill and their relatives
- Encourage theological discussion and training
- Provide liaison with the church at large and allied organisations at local and national level
- Seek to maintain and improve standards, pay and conditions for all in hospice chaplaincy.

An inaugural meeting was held in 1988, attended by eight chaplains, and the Association was born.

The following year, the first residential annual conference was held, and a year after that, the membership had already reached 108. To this day, the annual conference is a significant time of support, networking, discussion and training. Attendance averages 75, about half of today's total membership.

In 2002, the AHC's name was expanded to AHPCC to acknowledge that hospices are not the only places where palliative care chaplains work. The Association's objectives, nonetheless, remain much the same.

For a long time, the Association kept in touch with members via a quarterly newsletter which, in recent years, has been superseded by our website.<sup>2</sup> This is regularly updated and is rapidly developing into a valuable resource in a number of ways: a deposit of Association publications and chaplains' own liturgies and work; links to useful articles, publications and kindred organisations; news of forthcoming courses and conferences; and information necessary for the recruitment of chaplains.

In the very near future, a members-only message board will greatly enhance communication and professional support between individuals, but that one section aside, we are glad to make the site as widely available as possible.

As long ago as 1997, members were encouraged to think about the chaplain's identity in the workplace, where we work with other professionals who have clearly defined roles. At the same time, concerns about data protection led some NHS hospitals to restrict chaplains' access to patient notes. Chaplains were not regarded as genuine healthcare professionals. Thus began two serious strands of development: standards and registration.

## Standards

A great deal of concentrated work led to the publication, in 2003, of the AHPCC Standards for Hospice and Palliative Care Chaplaincy,<sup>3</sup> revised in 2006. Its seven main strands are:

- Access to chaplaincy services
- Spiritual and religious care
- Multidisciplinary team working
- Staff support
- Education and training
- Resources
- Chaplaincy to the institution.

This document also contains its own self-assessment tool, invaluable in appraisal and audit processes.

We are encouraged that its format and content have formed the basis of the NHS Scotland Standards and were also adopted by the European Network of Healthcare Chaplains (ENHC) at their conference in Lisbon in 2006.

Also, in 2003 the AHPCC-endorsed Spiritual Care Competencies<sup>4</sup> were published

by Marie Curie Cancer Care. This document promotes four levels of spiritual care competency, from the basic awareness of patient vulnerability needed by every member of hospice staff, to the specialist skills required to resolve complex spiritual care needs.

## Registration

From the early 2000s, the AHPCC and its three sister professional organisations – the Northern Ireland Healthcare Chaplains Association,<sup>5</sup> the Scottish Association of Chaplains in Healthcare,<sup>6</sup> and College of Healthcare Chaplains<sup>7</sup> – worked together to co-ordinate training and academic requirements for chaplains. From this collaboration was born, in 2008, the UK Board of Healthcare Chaplaincy (UKBHC),<sup>8</sup> with a broader remit to consider qualifications, membership, authorisation, discipline, continuing professional development (CPD) and many other issues related to becoming a registered healthcare profession.

One of those issues concerns the authority to practice, usually granted by a mainstream faith community. The Multi-Faith Group for Healthcare Chaplaincy, MFGHC,<sup>9</sup> is seeking to establish authorisation processes common to all the major faiths. This becomes yet more complicated as we take seriously such questions as, 'Can Humanists be chaplains?'

**Hospices are not  
the only places  
where palliative care  
chaplains work**



There are many issues still to be debated that must seem strange to many of our European colleagues – because such concerns were dealt with years ago, or chaplaincy is fully integrated into all healthcare, or chaplaincy is the unchallenged remit of a particular religious denomination. The UK is truly a multicultural society and matters are further complicated by the fact that England, Wales, Northern Ireland and Scotland each have different laws and healthcare policies.

## Research

Chaplains are not renowned for being proactive about research. The chief difficulty is how to draw statistical and objective conclusions from evidence that is usually subjective and anecdotal.

### In the UK, the word 'spiritual' continues to puzzle and frighten in equal measure

In our 'evidence-based' age, chaplaincy has to find ways of conducting research, and the Association offers support to its members who do so. The number of projects is slowly increasing

and a few members have committed their experience to print.<sup>10</sup> Ongoing challenges include determining how current research might be monitored and how future initiatives may be co-ordinated.

## Recent developments

Palliative care has become a respectable medical discipline in recent decades and even more prominent with the introduction of two particular initiatives – the Liverpool Care Pathway for the Dying Patient (LCP), introduced in many health authorities to raise the quality of end-of-life care in different healthcare settings (such as hospital, nursing home and so forth) nearer to the level expected in a specialist unit; and the End of Life Care Strategy, launched by the government in 2007 and culminating in the publication of the NICE Quality Standard in November 2011.<sup>11</sup>

Both initiatives give due emphasis to spiritual and religious care and during the consultation periods, and by participating in workshops and pilots, AHPCC members played some small part in their development.

General interest in spiritual care is considerable, and AHPCC members have many opportunities to be involved in education at local and national events and conferences. Hospices are also keen to make positive and successful appointments, and we are pleased to be consulted in that process.<sup>12</sup> In the UK, there is a vigorous campaign to legalise

assisted dying, and palliative care professionals including chaplains are engaged in the debate.

The AHPCC has made submissions to Parliament<sup>13</sup> and responded to a 2010 commission on the subject, though it should be noted that there is a range of opinions among chaplains on this difficult issue.

## Further challenges and opportunities

One of chaplaincy's continuing challenges is explaining our role. It is partly a matter of language;<sup>14</sup> in the UK, the word 'spiritual' continues to puzzle and frighten in equal measure. Many equate it with 'religious', but religion is just a part of the story and only for some people. 'Emotional', 'psychological' and 'social', similarly, are all parts of the jigsaw, but not the whole of it. 'What makes you tick?' is pretty close.

The difficulty of defining spirituality makes chaplaincy a soft target when economies are being made in staffing levels. The AHPCC is active in the promotion of its profession at the same time as it supports members when their hours are reduced or their posts axed.

The AHPCC receives many enquiries from overseas chaplains. For practical reasons, membership is open only to those residing in the UK. A prime function of the Association is facilitating local support and networking – not so easy with members in different countries. Also, aligning membership with professional registration is a considerable task within the UK context alone; the inclusion of more jurisdictions would be very complicated indeed.

However, we do welcome correspondence with chaplains around the world. Our website is open to all, along with its resources (an acknowledgement would be appreciated if you use them), and our annual conference is open to non-members. With humility, we offer our experience and support and, in return, are delighted to receive your information and news ■

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**email:** info@alcc.net.au

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**website:** www.worldcancercongress.org

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**email:** anzspm@willorganise.com.au

**website:** www.willorganise.com.au/anzspm2012/#info

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**Tel:** +65 660 11131.

**email:** seemieng.tan@duke-nus.edu.sg

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**Contact:** 19th International Congress on Palliative Care, c/o O'Donoghue & Associates Event Management, 75 Chemin Mountain, Mansonville, Québec, Canada.

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**Fax:** +1 450 292 3453.

**email:** secretariat@pal2012.com

**website:** www.palliativecare.ca/en/index.html

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**email:** m.hay@highlandhospice.org.uk

**website:** http://highlandhospice.org/education/the-space-between

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**email:** secretariat@imfpc.org

**website:** www.imfpc.org/

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