



## Voluntary hospices in England: A viable business model?

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### ABSTRACT

This article is concerned with how the UK Government's End of Life Care Strategy seeks to draw upon the capacity and additional choice provided by voluntary charitable hospices in England. Constructing a hospice financial business model we consider the extent to which the policy intersection outlined in the Governments End of Life Care Strategy between Primary Care Trust (PCT) commissioning and the contribution of voluntary hospices is now robust or fragile going forward. Analysis in this paper reveals how charitable income streams donated to voluntary hospices are significant relative to government funding but that this income is uncertain and volatile. Hospices trustees thus maintain balance sheet reserves and invest in capital markets to secure additional financial leverage. In this paper we argue that this serves to recycle and amplify financial uncertainty at a time when the demand for palliative care will increase. The UK population is ageing and hospices are under pressure to provide increased scope for end of life care. Government policy must address the contradictory forces that operate within the hospice business model to secure the capacity to deliver palliative care and patient choice going forward.

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### 1. Introduction

This article is concerned with the provision of palliative care services in England by voluntary charitable hospices. The literature on voluntary hospices is fragmented and scattered within academic and practitioner discourses but collectively this reveals the challenges facing this sector. Specifically, how the provision of hospice palliative care has changed over time in response to patient needs and regulatory requirements especially when 80% of specialist in patient palliative care capacity in England is located in voluntary hospices (McDermott, 2005).

Hospices have responded to the increased demand for their services (in stay and hospice at home visits, and broader holistic care) by developing and consolidating a range of income to maintain service capacity and meet regulatory demands. However, hospice income is uncertain and often volatile as it arises from charity shops, legacies, lotteries, fundraising and financial market holding gains. Hospices' trustees, following appropriate governance within this sector, operate with significant balance sheet reserves not only as a hedge against uncertain income but also leveraging additional financial return on invested assets. Reserves are subject to "mark to market" accounting in compliance with Accounting and Reporting by Charities (Statement of Recommended Practice, SORP<sup>1</sup>). The global credit crunch has negatively affected hospices in terms

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<sup>1</sup> The Statement of Recommended Practice (commonly referred to as the SORP) is issued by the Charity Commission and the Office of the Scottish Charity Regulator (OSCR) and basically gives instructions as to how charities are expected to report their activities, income and expenditure and financial position in their annual report and accounts. <http://www.oscr.org.uk/SORPCommittee.stm>. For the purpose of this paper we are employing SORP 2005 updated July 2008.

of sustaining donations, predicting the value of legacies and extracting “mark to market” holding gains that, in recent years, all served to inflate reserves held for revenue contingency and longer term capital projects.

Voluntary charitable hospices make a significant contribution to end of life care and increase choice for patients either as an in stay patient or through the hospice at home network and this is recognised in the Government’s End of Life care Strategy. (Department of Health, 2008, 2009).

In July 2008, following consultation over two years, the Department of Health published its *End of Life Care Strategy* (the Strategy) which aims to improve the provision of care for all adults approaching the end of their life, including support for their families and carers. The Strategy centres on:

Developing specialist palliative care outreach services by encouraging PCTs and hospices to work together to provide appropriate support to all adults in the community, regardless of their condition. (National Audit Office, 2008a, p. 5)

This paper considers whether the policy intersection between Primary Care Trust (PCT) commissioning and contribution of voluntary hospices as outlined in the Government’s ‘End of Life Care Strategy’ is founded upon a robust or fragile business model.

## 2. Hospices delivering and extending palliative care provision

The modern hospice movement arises out of the work of Dr Cicely Saunders who established St. Christopher’s Hospice in London in 1967 promoting primarily a philosophy of care (Denice & Walter, 1996; Milicevic, 2002; Saunders, 1993). Hospices, for the first time, provided a holistic approach to care, which aimed to transform the clinical management of patients suffering pain from advanced cancer (Clark, 1998; Saunders, 2000; Seymour, Clark, & Winslow, 2005; Twycross, 2006). Initially, the emphasis was on caring for adult, terminally ill, cancer patients during the final stage of their lives. However, the provision of palliative care services has progressively extended to cover more patient groups in need of longer periods of care including, children, HIV, and patients with neurological disease. In turn, this broader demand for palliative care changed the nature of and cost of the service provided by hospices (Finlay, 2001; WHO, 2002).

Patients with motor neuron disease (MND) often require long-term provision of palliative care services instead of just terminal care (Hicks & Corcoran, 1993; Oliver & Webb, 2000). The demand for palliative care from patients suffering from acquired immunodeficiency syndrome (AIDS) has also increased and Saunders (2001) notes that the focus on cancer delayed the development of hospice provision to other areas of need. The introduction of highly active antiretroviral therapy (HAART) transformed HIV/AIDS into a chronic rather than a uniformly fatal illness influencing both the type and duration of required palliative care services. As a result, the need for developing AIDS specific hospice services, as well as the need for staff experienced in the management of AIDS related problems has increased (Easterbrook & Meadway, 2001; Foley & Flannery, 1995; Stephenson, Woods, Scott, & Meadway, 2000).

Likewise palliative care provision to children differs from care provided to adults both in the nature of needs and the time-period that care is required (Goldman, 1994). The aim of a children’s hospice is not just to provide terminal care. Relief care to the patient and practical support to parents must be provided after diagnosis and continue even after the child’s death in the form of bereavement care for the family (Dominica, 1987; Worswick, 1995). In contrast to adult hospices, children’s hospices care for children with many different conditions such as complex disorders of which many are neurological in nature, progressive and degenerative leading to a premature death (Farrell, 1996). The nature of support and care provided requires the services of multidisciplinary care teams, able to anticipate both the practical care provided to the child as well as the psychosocial implications and the financial hardship for family members (Emond & Eaton, 2004; Goldman, 1994; Thomas, 1994; Trapp, 1994).

Apart from issues related to the widening patient base in need of palliative care services, demographic factors are imposing additional challenges on the voluntary hospice sector. The population of the UK is ageing such that over the last 25 years the percentage of the population aged 65 and over increased from 15% in 1983 to 16% in 2008, an increase of 1.5 million people in this age group.<sup>2</sup> Given that cancer is a disease of the elderly<sup>3</sup> changes in population demographics will add to the pressure for palliative care.

Although Government funding is, on average, one-third of their income hospices integrate into the complex structure of the National Health Service (NHS) and are subject to government policy and regulatory initiatives. Hospices contribute to the provision of patient choice and capacity for palliative care provision and help to ease pressure on acute hospitals.

In 2006–07, hospices provided inpatient services to over 38,000 people and supported over 112,000 people in the community, yet current contractual arrangements with PCTs limit their ability to plan and develop services (National Audit Office, 2008a, p. 7)

Analysis of the 2005/06 Hospital Episodes Statistics (HES) indicate that 5% of patients account for 49% of all inpatient bed days. This burden is expected to increase substantially in the future. There will be 18 million people in England by 2020 who will have at least one long-term condition (National Audit Office, 2008b, p. 1)

<sup>2</sup> <http://www.statistics.gov.uk/cci/nugget.asp?ID=949>.

<sup>3</sup> <http://www.statistics.gov.uk/CCI/nugget.asp?ID=1332andPos=1andColRank=1andRank=310>.

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