



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

Help the Hospices: the charity for hospice care in the UK

With the aim of helping UK hospices to respond to the changing needs of the communities they serve, Help the Hospices has established its Commission into the Future of Hospice Care. The charity is calling for transformation of end-of-life care in the UK.

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The UK hospice sector faces uncertain and challenging times. In response, Help the Hospices, the charity for hospice care in the UK, has established the Commission into the Future of Hospice Care. Its aim: to help hospices adapt and innovate so they can meet the ever-changing needs of the communities they serve. In 2010, Help the Hospices commissioned a report by the thinktank Demos. The report, *Dying for Change*, called for a radical transformation in the way that people who are dying are cared for in the UK.¹ This is the commission's starting point.

The challenges

The challenges arising from demographic, epidemiological and health service change are stark. Hospices face the twin difficulties of change in the way services are commissioned by the NHS and the prospect of reduced statutory and charitable income.^{2,3} In the longer term, changes in the demography and epidemiology, alongside the desire to meet the preferences of people nearing the end of life, mean ever-increasing and complex demands on end-of-life care providers.^{4,5}

Many hospices are uncertain of what role they should play in the increasingly complex network of care needed to provide high-quality palliative care.

How should they seek to shape their future services? What new partnerships might they forge to deliver the best hospice care? How can they offer leadership to enable the wider system to give individual, empathic and high-quality care to all those who are dying? How do they complement care provided by others to ensure seamless provision to those who need their support?

The commission

The commission is an independent group of thinkers, researchers and practitioners from within and beyond the UK hospice sector. Their job will be to provide the strategic thinking necessary to help hospices and hospice care adapt to the challenges of the next 15 years – whenever possible, sharing their thinking and encouraging debate.

Chaired by Dame Clare Tickell, Chief Executive of Action for Children, the commission has two years to do its work and will take an approach that is participative, provocative and practical. It will ask hospice teams chosen to reflect the diversity of hospice services across the UK to help explore emerging findings, and test the acceptability and value of its thinking.

It will not shy away from questions about the value and cost-effectiveness of, and need for,

hospice care. The health service is committed to shaping more integrated systems of evidence-based care for all those at the end of their lives, regardless of their illness. How should hospices adjust to meet these needs? How could provision be encompassed within the ethos of the hospice movement? How might hospices and the services they provide be better integrated into the web of health- and social care services needed by people living with chronic and progressive disease?

The commission is determined to generate practical outputs and outcomes; these will come from an unremitting focus on securing greater access to the high-quality individual care that is synonymous with the UK hospice movement. Central to its aims is the desire to be relevant, useful and helpful to individual hospices, working to provide them with tools to apply national evidence and strategic thinking to their own planning and service development.

Understanding possibilities

The commission wishes to identify the strategic options open to hospices, seeking out the roles that might populate such a map of possibilities. It will explore how some hospices are developing services to provide social and domiciliary care. It will consider how others are adapting care to meet the needs of patients with dementia, or heart or renal failure. It will look at how hospices are working across emerging networks, creating partnerships with other voluntary, NHS or private sector providers to deliver care across their 'patch'. It will work to understand how hospices support families and communities to provide care.

Having identified the range of opportunities currently being taken across the hospice sector, the commission wants to understand the local needs and organisational capacity that enables such change. Why might it make sense for a specific hospice to work in a particular way? What would make such an innovation a clear and sensible choice for another hospice? And how do these choices reshape and redefine the ethos and approach of UK hospice care?

We anticipate that there will be some common journeys and established paths that some hospices anticipate following, although the local terrain and the readiness for the task may differ. The commission sees its job as identifying the dilemmas, the decisions and the changes necessary to build a readiness to work in any particular new role as the health service and the needs of the population change.

In addition to helping hospices consider their future position, the commission will help hospices identify what sort of care they might provide in the future by undertaking five distinctive and interconnected tasks. These are: understanding the drivers for change; identifying innovation; exploring the consequences of change; pooling existing expertise; and refining practical options for the future.

Understanding drivers for change

The commission will work with hospices to identify, share and publish an understanding of the strategic drivers for change.

The drive to improve and extend care at the end of life raises questions about how to articulate the purpose and aspiration of hospice care for all those living with progressive and terminal chronic illnesses, often of unpredictable course. Hospices will need to understand the changing scale and nature of needs for care, as well as the practical implications of new funding and commissioning mechanisms and intentions. Many are considering the need to play more active roles in clinical networks that encompass a broader range of services that might constitute a more integrated and coherent system of care.

Identifying innovative practice

Central to the work of the commission is engagement with a hospice movement that is characterised by its instinct to innovate. The commission aims to be a catalyst, and to encourage hospices to consider challenging and reshaping care in ways that alter, rather than just add to, existing services.

We believe that hospices and their workforce can be ambassadors for change, mediating between a steady focus on individual needs and the imperative to develop systems that ensure high quality and safe care for large numbers of people. Where there are failings in the system, hospices can and should challenge the way services are currently organised.

In meeting future challenges, hospices will need to consider developing new services or new ways of providing care. The commission will explore current innovation – for example, looking at opportunities for enabling volunteers to deliver more, and considering new configurations of care to deliver community-based services. The commission will also explore the potential for

hospices to initiate new social enterprises to develop services with others, as well as considering the potential arising from care-based research and technological and social change.

Exploring strategic consequences

To achieve positive and sustainable change, hospices need a coherent view of how their services will work with the systems around them; being clear about their relationships with wider health and social care providers. Hospices will need to make choices about how to work with, or work to transform, those partnerships, and ensure the availability of the wider spectrum of care needed by people living with life-shortening illness. To do this will require a coherent view of how new services or new partnerships fit into a sustainable and clear sense of the future identity of the hospice and the hospice movement.

The commission will aim to consider the strategic consequences of potential change, to consider how choices about the nature and role of hospice services can be made in a way that creates sustainable future income or robust partnerships with sufficient resilience to endure future change.

The commission wants to understand and present an analysis of the impact of change, addressing, for example, the consequences for the future hospice workforce of an approach that better shares care between multiprofessional and non-professional teams across the health- and social care system.

Making the most of expertise

To shape an achievable future, the commission must pool the experience of those who provide and receive care. The best ideas are already in gestation. The wisdom needed to find and deliver the new services that will make a difference already exists. The challenge is to bring together the knowledge that is dispersed among families, carers, patients, clinicians and organisations.

These are vital data sources, within which are opportunities for improvement and even transformation. In short, these data hold the blueprint for future care that can fit new populations of people with emerging needs, different expectations and changing preferences for how they live with life-shortening illness. The commission will call for this evidence – using existing data as well as generating new evidence to allow for a greater understanding of both the lived

experiences of patients and those close to them. The commission will also want to hear from the front line of care, particularly in relation to how best to meet the needs of the diverse communities that many hospices serve.

The commission will seek to collate new data, capturing the full scope of one day of care across the UK hospice sector, granting an understanding of the scale and complexity of care, as well as the reach of the hospice movement. The commission will also take evidence from individuals and organisations who wish to contribute to our thinking.

Refining options for change

Our aim is for each stream of work to help us refine and update an analysis of the strategic options for hospices and contribute to a practical toolkit that can help promote appropriate innovation and build hospice readiness and resilience. After 18 months, we intend to embark on a period of testing our analysis, ideas and practical tools to ensure relevance to the hospice community.

Our commitment is to ensure our thinking is clear, evidence-based and tested, our strategic analysis helpful, and our toolkit of innovation usable and adaptable as well as widely and freely available.

The commission is an ambitious and important piece of work undertaken by Help the Hospices on behalf of its members to ensure an effective role for hospices in the future. Its nature is such that reflections, comments and ideas about how its aims are best met are welcome from any of its stakeholders.

To do this, readers are invited to make contact with the authors of this article (at commission@helpthehospices.org.uk) ■

Declaration of interest

The authors declare that there is no conflict of interest.

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