

## Rehabilitative Palliative Care: enabling people to live fully until they die

On behalf of the authors, the many professionals and the individuals with whom they work, Hospice UK would like to thank the Burdett Trust for Nursing for its foresight in supporting this timely work which we anticipate having a significant impact on the future scope of hospice care – for wellbeing and day services as well as for inpatient and community teams.

The report which follows outlines the background to the work and its various components. It includes a selection of feedback from people who attended the 3 July conference at which the publication 'Rehabilitative Palliative Care' was launched.

### Background

The Burdett Trust for Nursing awarded Hospice UK a grant in September 2014 with the aim of producing 'a high quality evidence-based publication on rehabilitation in hospice and palliative care to support hospice nurses and other care professionals to explore how they can develop effective and sensitive models of rehabilitative care; and to enable them to take a proactive approach to supporting more people with progressive and life limiting conditions, including those that are long term in nature, and their carers'.

As well as producing the publication, Hospice UK undertook to incorporate learning events for hospice staff - in both the development and dissemination stage of the publication, and to design a means of measuring the outcomes of the work.

### The publication

Two copies of the publication were sent to the Burdett Trust for Nursing on 6 July 2015 and further copies are included with this report. In what is a comprehensive and practical document written by a specialist physiotherapist (Rebecca Tiberini, Therapies Services Manager at St Joseph's Hospice) and a nurse (Heather Richardson, Joint Chief Executive at St Christopher's) the publication advocates an approach that responds to many of the challenges identified in the final recommendations of the Commission into the Future of Hospice Care.

The publication defines and describes the Rehabilitative Palliative Care approach which differs from 'palliative rehabilitation' in scope, makes the case for change, helps hospices to consider what this may look like in terms of a multidisciplinary approach to practice and provides guidance about how best to achieve it. More specifically, it contains:

- an evidence-based rationale for the approach, and checklists for best practice
- 'perspectives' on the approach from a range of health care professionals

- case studies from hospice care settings on how the approach is being embedded in practice.
- extensive references
- an appendix outlining the unique, and frequently under estimated, contribution of allied health professionals in palliative care and their contribution to the wider multi-disciplinary team.

‘I totally agree that hospices are well placed to enable rehabilitative palliative care but it was fabulous to see this presented so eloquently in one document which can be shared widely with others.’

**Peace Hospice Care**

‘The material is excellent. The whole package is clear with action points after each section which makes it easy to take forward with our teams.’

**Nightingale House, Wrexham**

## Associated resources

The publication is available on [Hospice UK's website](#) where we have also included a selection of case studies, infographics, a collated version of the checklists and links to several films. Two of the films - ‘Patients perspectives and priorities’ and ‘Lucy’s story’ - were commissioned to complement the publication and, as was illustrated at the 3 July launch event, provide a dynamic teaching tool and focus for discussion.

‘Working through the film clip of ‘Lucy’s story’ really brought the theme of rehabilitative palliative care to life and the panel discussion was very stimulating.’

**Strathcarron Hospice**

## Learning events

We held the following learning events as part of the project:

- an [engagement event](#) (1 May 2015) at which 49 allied health professionals working in palliative care from across the UK, including physiotherapists, occupational therapists, dietitians and rehabilitation assistants, offered critical thinking and guidance to help inform the content of the publication.
- a [one-day national conference](#) (3 July 2015) when the publication was launched and at which participants included senior clinicians and nurses as well as AHPs. Ninety-two percent of those who attended evaluated the event as ‘excellent’ or ‘very good’.

‘We are currently restructuring and remodelling our AHP team so the conference was really timely. We are planning a workshop with key staff to start to look at how rehabilitative our approach is currently and what we might do to move forward.’

**Earl Mountbatten Hospice**

‘The doctor and I who attended are going to set up a steering group to try and enable us to implement the approach.’

**Paul Sartori Foundation**

‘We welcomed the opportunity to take the benchmarking tool back to my hospice and complete it with our Head of Care. We’re going to rethink some of the questions we ask at assessment to engender a more enabling approach.’

**Claire Holland House**

'We are at a point of reviewing and reconfiguring our services and the approach and the detail were very timely. They help build a strong case for featuring enablement more centrally. Also loved the case study featuring 'step down' care in the inpatient setting to mirror services once home.'

**St John's Hospice**

## Dissemination

As stated in the foreword to the publication, Hospice UK strongly endorses a rehabilitative approach in hospice and palliative care and encourages trustees, senior managers and clinical leads from all disciplines to explore its messages and potential implications for their own hospice. With this in view, we have disseminated the content, and raised debate about the approach by:

- reporting in ehospice on the engagement event and the conference at which the publication was launched
- previewing the content of the publication at the June conference of Executive Clinical Leads in Hospice and Palliative Care (ECLiHP)
- sending two copies of the printed publication to each of our member hospices
- making the publication freely available on our website along with a selection of case studies and other resources
- promoting the publication at national and regional events which Hospice UK, and the authors or contributors attend
- including a 90-minute session at our annual national conference (10-12 November 2014) with contributions from four hospice staff whose work features in the publication
- facilitating a national benchmarking exercise details of which are included below.

## Outcome measurement and national engagement

The checklists in the publication have been collated and reproduced separately under the title ['How rehabilitative is your hospice? A benchmark for best practice'](#).

We are encouraging hospices to complete this checklist, which can be downloaded from our website, and return it to Hospice UK, with a view to evaluating how rehabilitative their current practice is - and to capture any improvements by repeating the exercise in 12 months' time.

The checklist 'How Rehabilitative is your Hospice?' has been an eye opener. Knowing that the survey will be sent our again in 6 months really adds to the motivation for implementing change. conference attendee,

**Woking and Sam Beare Hospice**

(cont)

The exercise will enable Hospice UK to establish a national picture of Rehabilitative Palliative Care while a summary of anonymised findings from the benchmarking exercise will be made available to all hospices who submit a completed checklist.

Other routes for continuing national debate and discussion of the rehabilitative approach will be through ECLiHP, the Forum of Hospice Chairmen and at Hospice UK's national conference at which chief executives, trustees and senior clinicians are a majority of the attendees.

Jean Hindmarch  
Projects Director  
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