Supporting the hospice workforce to flourish in stressful times

Rehabilitative Palliative Care

Enabling people to live fully until they die

A challenge for the 21st century

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Foreword

In 2013 the Hospice UK Commission into the Future of Hospice Care challenged hospices to look to the future: to critically appraise their fitness to respond to the significant shifts in demography and illness upon the horizon and to be dynamic and innovative in our response to meet the needs of people with a life-limiting or terminal condition.

Hospices face a number of key challenges:

- to respond to a dramatically escalating demand for palliative and end of life care
- to adapt to meet the needs of an ageing population, living with and dying from chronic illnesses and multiple co-morbidities; where longevity is frequently compromised by frailty, disability and dependence
- to deliver equitable, quality care to those who need it in an environment of financial constraint.

These challenges are contextualised in today’s society where personal autonomy is paramount; where people are increasingly expressing the importance of choice and independence as major components of dignity in advancing illness and old age, where most of us expect to make decisions, not only on how we live the last years, months, weeks and days of life but also on how and where we die.

Hospices are recognised as beacons of holistic, person-centred care for people living with a life-limiting or terminal illness and their families. This is important and provides a firm foundation from which hospices can respond to the challenges of the future. However, in the face of change hospices must also be open to change, both of culture and practice.

To meet the needs of the future hospices must be prepared to do things differently – starting with placing patients’ goals for living at the heart of our holistic support. Hospice care needs to be tailored so that we are providing just the right amount of support to empower and enable individuals to achieve their goals – to live their lives until they die – not more, not less. Hospices must shift their paradigm to interweave a culture of enablement alongside their rich culture of care, to enable people greater choice, independence and dignity in advancing illness or old age even if this may feel ‘risky’ compared to what you are used to.

This publication describes such an approach to care, makes the case for change, helps hospices think about what this looks like in practice and provides guidance about how best to achieve it. Hospice UK endorses it and encourages trustees, senior managers and clinical leads from all disciplines as well as allied health professional teams to explore its messages and the potential implications for their own hospice. Rehabilitative Palliative Care is, in our view, an important next step in preparing hospices for the challenges and opportunities of the 21st century.

Dr Ros Taylor MBE,
National Director for Hospice Care,
Hospice UK
## 1. What is Rehabilitative Palliative Care?

**Rehabilitative Palliative Care can be defined as follows:**

Rehabilitative Palliative Care is a paradigm which integrates rehabilitation, enablement, self-management and self-care into the holistic model of palliative care. It is an interdisciplinary approach in which all members of the team, including nurses, doctors, psychosocial practitioners and allied health professionals, work collaboratively with the patient, their relatives and carers to support them to achieve their personal goals and priorities.

Rehabilitative Palliative Care aims to optimise people’s function and wellbeing and to enable them to live as independently and fully as possible, with choice and autonomy, within the limitations of advancing illness.

It is an approach that empowers people to adapt to their new state of being with dignity and provides an active support system to help them anticipate and cope constructively with losses resulting from deteriorating health.

Rehabilitative Palliative Care supports people to live fully until they die.

<table>
<thead>
<tr>
<th><strong>Rehabilitative Palliative Care IS:</strong></th>
<th><strong>Rehabilitative Palliative Care IS NOT:</strong></th>
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<tr>
<td>Person-centred: focusing support to best meet people’s goals and personal priorities</td>
<td>Focused on and driven by the allied health professional agenda but led by patients’ priorities</td>
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<td>An effective integration of rehabilitation and palliative care to actively enhance people’s quality of life</td>
<td>The clash of two contradictory and opposing treatment paradigms</td>
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<td>Interdisciplinary and multiprofessional: all members of the palliative care team actively contribute to Rehabilitative Palliative Care</td>
<td>The sole domain of allied health professionals: physiotherapists, occupational therapists, dietitians, speech and language therapists, rehabilitation assistants</td>
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<td>A collaboration between patients, relatives and carers and the multidisciplinary team</td>
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<td>About optimising people’s ability to function in the widest sense including moving around, eating and enjoying food, communicating with others, managing activities of daily living and participating in meaningful activities</td>
<td>About promoting false hope that someone will recover or return to a previous level of function when this is unrealistic</td>
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<td></td>
<td>Just about mobility and walking</td>
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<td>About adopting an enabling approach to provide patients and their relatives or carers with enough support to empower them to manage on their own</td>
<td>About being less caring but promotes adopting an enabling approach to the way in which we provide care and having a greater focus on support</td>
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<td>A way to give people greater independence, autonomy, choice and dignity</td>
<td>About moving away from the ethos and values of palliative care but enhancing these through shared characteristics of rehabilitation</td>
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<td>About living with dying</td>
<td>About ignoring dying or pretending it isn’t happening</td>
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<td>Everybody’s business</td>
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Rehabilitative Palliative Care is different from ‘palliative rehabilitation’, which refers to specialist rehabilitation interventions and expertise most often provided by allied health professionals, including physiotherapists, occupational therapists, dietitians and speech and language therapists, trained in rehabilitation and palliative care.

The Interface between rehabilitation and palliative care

Rehabilitative Palliative Care is not a new concept to hospices, with principles of rehabilitation evident as central themes in Dame Cicely Saunders’ philosophy and vision for modern palliative care:

“The work of all the professional team is to enable the dying person to live until he dies, at his own maximal potential performing to the limit of his physical and mental capacity with control and independence whenever possible.”

Dame Cicely Saunders

Despite these rehabilitative roots, today hospices are often recognised by their mission to improve people’s experience of death, dying and bereavement. This dominant focus on end of life care has meant that the rehabilitative role of palliative care – to support people to live fully until they die – has become less prominent both in hospice practice and in the public perception of what hospices have to offer.

Complementary approaches to improve quality of life

Rehabilitation is a much misunderstood concept when described in terms of life-limiting illness.

At first impression the term Rehabilitative Palliative Care may appear contradictory as it brings together two somewhat paradoxical concepts – that of rehabilitation, frequently associated with recovery, and palliative care, frequently associated with dying.

This reductionist view of both concepts has negatively contributed to a misperception that active rehabilitation is at odds with palliative care provision, with an ensuing reluctance on behalf of some healthcare professionals to integrate the two, inadvertently depriving patients of opportunities for enhanced quality of life.

However, upon closer inspection the domains of rehabilitation and palliative care are complementary, and share common characteristics, ethos and values.

The goals of Rehabilitative Palliative Care

The overall goal of palliative care is to achieve the best quality of life for patients and their families, by helping patients live as actively as possible until death. The goal of rehabilitation is to help individuals “to reach the fullest physical, psychological, social, vocational and educational potential consistent with his or her physiological or anatomical impairment, environmental limitations, desires and life plans.” Rehabilitation aims to improve quality of life by enabling people to be as active and productive as possible with minimum dependence on others, regardless of life expectancy. In the context of palliative rehabilitation, Jennings highlights the alternative term ‘habilitation’ to dispel any unrealistic expectations of returning to pre-morbid levels of function which the ‘re’ of rehabilitation may imply.

In practice, rehabilitation encompasses a spectrum of goals which offer an active support system to patients at every stage of their illness. These aim to improve function where the patient has capacity, maintain function where the effects of illness and its treatment threaten decline, or ease the transition towards functional decline when deterioration is inevitable. The table on page 4 describes this spectrum in more detail.
**Spectrum of rehabilitation goals**

<table>
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<tr>
<th>Rehabilitation goals</th>
<th>Context</th>
<th>Goal</th>
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<tr>
<td><strong>Restorative goals:</strong> aim to return patients to a previous level of function</td>
<td>Patient has good potential to regain sufficient strength and balance to transfer independently</td>
<td>To regain the ability to stand and transfer from bed to chair independently – within one week</td>
</tr>
<tr>
<td><strong>Preventative goals:</strong> attempt to prevent avoidable deterioration in function related to disease or treatment processes</td>
<td>Patient is at risk of deconditioning and further weakness arising from inactivity</td>
<td>To actively participate in activities of daily living to their optimal level of functioning – ongoing</td>
</tr>
<tr>
<td><strong>Supportive goals:</strong> focus on maximising functioning, independence and participation in meaningful activities alongside disability</td>
<td>Patient has insufficient balance to walk to toilet independently but is safe with support of a walking aid</td>
<td>To walk to the toilet independently using a zimmer frame rather than being dependent on the assistance of a carer – within two weeks</td>
</tr>
<tr>
<td><strong>Palliative goals:</strong> involve supporting people to adapt to and come to terms with irreversible changes in function and associated losses or to ‘habilitate’ to their new reality</td>
<td>Patient is unable to manage the stairs and will not regain this level of function</td>
<td>To safely access both levels of home using a stair lift – within three weeks</td>
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In summary, both rehabilitation and palliative care are holistic, multidisciplinary, person-centred specialisms which place the patient and their family at the heart of the treatment paradigm to ensure the collaborative team input is tailored to best support their needs. Their relationship is described in Figure 1 (on page 5) and confirmed in important policy, in which rehabilitation is promoted as an essential component of a palliative care approach endorsed by national guidance.\(^6,9,10\)

Combined Rehabilitative Palliative Care has the potential to enhance the quality of life for both patients and families, where the sum of these two complementary approaches is greater than the individual parts.
Summary of key points

- Rehabilitative Palliative Care offers a comprehensive approach to enable patients to **achieve their personal goals and priorities for living**.

- **Rehabilitative Palliative Care is everybody’s business** – involving active contributions from all members of the multidisciplinary team, including nurses, doctors, psychosocial practitioners and allied health professionals, in partnership with patients and families. In this way it differs from ‘palliative rehabilitation’, which refers to specialist rehabilitation provided by allied health professionals.

- The compatibility of rehabilitation and palliative care is well established. They share common principles and work well in combination to enhance the quality of life of people with life-limiting conditions.

- The goals that individuals work towards will vary depending on their aspirations, capabilities and priorities. The term ‘habilitation’ can be useful in recognising that people receiving Rehabilitative Palliative Care infrequently return to their pre-morbid level of functioning.
2. Why bother with Rehabilitative Palliative Care?

There are good reasons to grapple with this shift in hospice care:

- in response to patients' priorities and preferences
- in anticipation of future challenge and opportunities
- in acknowledgement of the evidence of its efficacy
- in pursuit of economic efficiencies in service provision.

**a) Patients' priorities and preference**

Imagine for a moment that you had a diagnosis of advanced, life-limiting illness – say metastatic cancer. What would be most important to you?

A significant body of evidence shows that priorities for palliative patients focus on life and living.\(^{11-15}\)

**Maintaining normality of daily life**

Despite a diagnosis of advanced illness patients’ priorities consistently reflect the importance of maintaining continuity of daily life and living a normal life for as long as possible.\(^{11-14}\) Robust qualitative research by Johnston 2010, which triangulated views of 20 patients with advanced cancer, their carers and health professionals through 71 in-depth interviews, found that maintaining normality was the most important priority for patients alongside preparing for death.\(^{14}\)

The study revealed it is paramount to people with advanced illness to be viewed as normal, not as an illness, and that where possible they are able to wash, dress, shop and cook for themselves.

Maintaining normality of daily life is an important route to preserving dignity for patients when they are losing independence and control in so many areas.\(^{13, 14}\) This process of participating and engaging with daily life is primarily a functional experience where the emphasis is on ‘being’ and ‘doing’.\(^{11}\)

Through actively living daily life and maintaining routines, patients strive to maintain an overall sense of wellbeing in the face of terminal illness but most importantly to maintain a strong sense of who they are and what is important to them.

**Maintaining physical function and independence**

Physical function and independence are high priorities for patients living with advanced illness\(^{12, 15-21}\) as they represent important routes to maintaining autonomy, control and dignity. While people living with advanced illness identify practical issues of daily living – including maintaining function, the ability to care for one self and the ability to do what one wants – as specific priorities,\(^{12, 19, 20}\) their overarching priorities relate to having a sense of control and choice in life.\(^{15, 17, 21}\)

Independence in the wider sense concerns attaining the right to be free of the influence and control of others.\(^{17}\) From this perspective independence, while linked with physical function, is not inherently determined by a person’s ability to function. A person with advanced illness may require assistance to fulfil tasks of daily living but this can be delivered in a way which proactively supports them to maintain their independence and control their own lives,\(^{17}\) preserving their sense of dignity and inherent worth.\(^{22}\)
Loss of independence can compromise a person’s sense of dignity and instil a desire for hastened death. Among patients’ end of life concerns, fear of functional decline frequently eclipses fear of impending death.\textsuperscript{16, 23} Where independence and choice is not inherently preserved in people’s care ‘the spectre of dependency’, in which patients dread becoming ‘bedridden’ and a burden on others, has been associated with a number of negative outcomes such as loss of dignity, depression, will to live and request for physician assisted suicide.\textsuperscript{21}

Indeed, reduced function, dependency and loss of dignity are frequently cited among patients’ reasons for seeking assisted dying.\textsuperscript{24, 25} In the Netherlands a study of 185 patients who underwent euthanasia or physician assisted suicide revealed that dependency was reported as one of the top five reasons for unbearable suffering in all diagnoses studied and was the second highest reason cited by patients with motor neuron disease and heart failure for wishing to end their life.\textsuperscript{25}

\textbf{How well does hospice care support patients’ priorities?}

While there is significant research evidencing patients’ priorities for maintaining physical function, independence and normality of daily life (see above), few studies have considered how well hospices address these priorities in our care provision. Two small UK studies touch on these themes.\textsuperscript{17, 26}

Cotterell explored the experience of 25 people living with a range of advanced life-limiting illnesses in receipt of health, social care and hospice support to understand how service delivery impacts on an individual’s experience of independence, choice and control. While patients strove to maintain independence, this was a challenge due to impairments and restrictions of their illness but also due to paternalistic attitudes of some health and social care professionals.

Patients described difficulties gaining the specific assistance and support that they needed:

> “You become sort of dependent and they take over a bit because you’re not really well enough to be in control and fight for what you want. I like to be independent.” (P.05.MS)

Patients attempted to negotiate having more control in their daily lives; however, “this was often frustrated by health or social care professionals who, perhaps inadvertently, ‘took over’ or treated them in predetermined ways”.\textsuperscript{17}

Fisher and Colyer researched decision making about care for hospice inpatients.\textsuperscript{26} While broadly patients described a good relationship with hospice staff, emergent themes suggest the “protective, perhaps paternalistic approach of staff” was not always welcomed by patients, particularly after symptom control had been achieved:

> “I wouldn’t mind helping as much as I could, doing most of the things that I could do myself rather than being helped to do and having things done for me. .... I would say I could do this but they would say no we just want to do it. I would say ‘Oh well so you just want to pamper me up’ (patient laughs). But I could be doing this and I could be helping anyway but they would say no.” (Patient 2)

It has been suggested that “considerable paternalism” exists in palliative care\textsuperscript{27} and it may be that the above themes are under reported in research due to response bias where patients’ vulnerability (inherent in their dependence on caregivers and services) restrict their responses to avoid any compromise of this support. This highlights an area for further research and illustrates the need for greater service user engagement and feedback to inform and sculpt hospice care provision. In the meantime there is strong evidence, well articulated by Cotterell, that “maximising service users’ independence and minimising experiences of dependency should be a priority for those working with service users who have life-limiting conditions”.\textsuperscript{17}
b) Responding to the challenges of the future

The context of hospice care provision is changing, and it will continue to change into the future. Alongside the original mission to provide end of life care to the dying, hospices are proactively widening their support to provide holistic palliative care to people with a life-limiting or terminal condition, irrespective of diagnosis, earlier in their advanced stages of illness. This aligns with the World Health Organization definition of palliative care, which states that palliative care is provided alongside active care, at any point from diagnosis to death, in response to need. It supports hospices’ core values of equality and our commitment that access to quality palliative and end of life care is a universal human right.

As treatments continue to improve and survival for most diseases increases, typical dying trajectories are evolving and converging towards one of chronic illness. This model is amenable to longer-term control, with a slower progression towards death and increased disability preceding death. However, as hospices support increasing numbers of people living with advancing chronic illness such as chronic obstructive pulmonary disease (COPD), heart failure, neurological conditions and dementia, have we adapted our paradigm of hospice care to best meet their needs? Or do we routinely provide ‘total hospice care’ in the way that we would for a person at the end of life? There is urgency for hospices to evaluate our model of hospice care to ensure that it is not only fit for the future but that it is fit for the people we are supporting today.

Changing demography and disease

Our society is ageing. In 2010 1.4 million people were aged over 85 and today this number is rapidly increasing. By 2035 hospices can expect that people aged 85 and older will account for more than 50% of deaths (328,469 deaths). This older population will have a different set of health needs, frequently complex in nature, due to the fact that many people will be living with and dying from chronic illness and multiple co-morbidities. Today at least 15 million people in the UK have a chronic condition and the number of people with more than one chronic condition is growing rapidly – during the period from 2012-2018 the number of people with three or more long-term conditions is predicted to rise by two-thirds.

Even cancer, which continues to be the dominant diagnosis of people cared for by hospices, is now becoming a chronic condition for many people. Over the next 10 years the incidence of cancer in the UK is projected to increase by 30% for men and 12% for women, and as the number of people living with and beyond cancer exponentially grows, by 2040 close to a quarter of people aged over 65 will be cancer survivors.

The other chronic condition dramatically on the rise is dementia. By 2021 over one million people in the UK will be living with dementia and a further half a million are likely to have undiagnosed dementia. By 2050 it is projected that one in three adults aged over 65 will die with a diagnosis of dementia.
Figure 2: The changing context of hospice care, now and in the future

- **Increased Number of Deaths**
- **Ageing Population**
- **Increased Disability**
- **Increased Dependence on Carers**
- **Increased Demand on Health and Social Services**

**Steep increase in deaths from 2016**
- 4,000 deaths per year 2020-2025
- 8,000 deaths per year 2030-2035
  
  (Calanzani, Higginson and Gomes 2013)

**By 2035 people aged 85+ will account for 49.5% of all deaths**
  
  (Calanzani, Higginson and Gomes 2013)

**Longevity compromised: people living with and dying from chronic diseases. Increased frailty.**
- Cancer 30% men
- Cancer 12% women
  
  (Olsen 2008)

- Cancer survivors 23% over 65 by 2040
  
  (Maddams et al 2012)

- Dementia > 1 million by 2021
  - + ½ million undiagnosed
  - 2050 1 in 3 aged > 65 dying with dementia

  (Alzheimers Society 2012)

- Older people more likely to have complex problems and disabilities
  
  (Better palliative Care for Older People. WHO Europe 2011)

**Decreased proportion of younger people, fewer family members available to provide care, families more dispersed.**
- Likely to be elderly also.

  (Gomes, Cohen, Delliens et al 2011)
  (Payne EAPC Taskforce on Family Carers 2010)

**Decrease in health/social care professionals and paid carers.**
- Sufficient services to meet growing need
- Specialist skills and knowledge
- Who will meet the cost - financial implications

**Increased Demand for Palliative Care Services**
Increasing disability and frailty

A consequence of increasing age and chronic illness is that longevity frequently becomes compromised by a picture of progressive disability and/or frailty. Physical function and independence are high priorities for patients with cancer\(^1\) and other chronic illnesses as they strive to maintain a normalcy of daily life in the face of advancing disease.\(^{11, 13, 37}\) However, palliative care teams’ expertise and attention to symptom control\(^{38}\) frequently falls short of assessing the impact of symptoms on a patient’s ability to function and the lived experience of disability this entails.\(^{39}\) This highlights an opportunity for hospices to adopt a goal-orientated approach to our assessment that enables us to better contextualise our care within the bigger picture of what is important to the person.

Frailty is related to but distinct from disability in that many people who have frailty also have disability, but lots of people with a long-term disability do not have frailty.\(^9\) Frailty is a health state related to the ageing process in which multiple body systems gradually lose their in-built reserves. Around 10% of people aged over 65 years have frailty; rising to between a quarter and a half of those aged over 85 years.\(^{40}\) When a person is living with frailty they lose their functional homeostasis or ability to withstand illness without a loss of function\(^{41}\) and are at higher risk of a sudden deterioration in their physical or mental health. This dramatic change can happen in response to a relatively minor event such as an infection or a new medication,\(^9\) placing frail people at increased risk of disability or death from minor external stressors.\(^{42}\)

Disability and frailty can have significant detrimental impacts on a person’s ability to undertake normal activities of daily living (ADLs), and are associated with reduced independence and autonomy, decreased participation in meaningful activities, depression and poorer quality of life. However, both disability and frailty are dynamic states which can be made better or worse.\(^{11}\) There is a robust body of evidence that supports the effectiveness of rehabilitation in the prevention and reduction of disability and frailty in people living with advancing illness or old age.\(^{43}\)

If hospices are to respond to the needs of people who are frail, they will have to develop their workforce accordingly, so that they can recognise and assess frailty, shift their focus of care towards function, consider implications for symptom management, and plan for and respond to sudden changes in frail patients’ function. The rise in frailty also offers opportunities for hospices to work in closer partnership with experts in elderly care.

Hospice patients of the future

In contrast to the cancer population, who represent the dominant recipients of hospice care today, the complexity of need facing hospices in the future is unlikely to fall under a neat category of symptom control. Instead, a typical hospice patient may be living with cancer, dementia and frailty. Patients may or may not be in the last year of life – it may be difficult to tell. They may present with a catalogue of symptoms or no symptoms at all; however, symptoms are likely to represent the tip of the iceberg of the real difficulties these patients face.

Patients’ lived realities are likely to consist of inter-related challenges compromising any combination of reduced physical and/or cognitive functioning, nutritional undernourishment, dysphagia, progressive loss of independence, inability to manage ADLs, high risk of falls, increasing dependence on others for care, emotional sequelae including guilt and depression and poor overall quality of life.\(^{44}\) Their families or partners (who are likely to be elderly themselves) may be struggling under the associated burden of providing care over long periods, frequently years.\(^{45}\)

Already today hospices are finding it challenging to identify when individuals with chronic illness or old age are approaching the end of life, especially if they are living with more than one long-term condition. With this group of patients the Gold Standard Framework prognostic guide ‘Would you be surprised if this person died in the next few months?’ is likely to
generate the answer ‘I wouldn’t be surprised if they died in the next few months but likewise I wouldn’t be surprised if they lived for the next few years.’ This is less than helpful to determine which patients meet hospice criteria. People accessing hospice care now and in the future may live for short months or a number of years.

c) The evidence base for rehabilitation in palliative care

A growing body of robust evidence supports a rehabilitative approach as being both acceptable and effective for people receiving palliative care.

Rehabilitation in advanced cancer

In patients with advanced cancer receiving care from hospices or palliative care teams, rehabilitation has been shown to reduce the impact of symptoms such as pain and anxiety and to improve functional status and quality of life.5

Several retrospective review studies (ranging from 72 to 301 patients) have evaluated the effects of multidisciplinary46-48 and physical therapy49 rehabilitation programmes for patients with advanced cancer in hospital and hospice inpatient settings. Patients participating in rehabilitation programmes experienced clinically significant improvements in physical function, with improvement between 24-31% in scores on the Functional Independence Measure and Barthel Index. This impact was also perceived by the families of patients who participated in a rehabilitation programme, who reported it being an effective and important part of overall patient care.49

Gains in physical function are particularly impressive when considered alongside the tendency for function to deteriorate with advancing disease. This demonstrates the potential for rehabilitation to not only prevent or delay deterioration in function, but for some patients to actively improve their functional status with regards to physical independence, irrespective of advanced disease (as illustrated in Figure 3 below).

Figure 3: Potential impact of rehabilitation on functional trajectories

![Figure 3: Potential impact of rehabilitation on functional trajectories](image_url)

Key:
- Blue: Cancer
- Orange: Organ Failure
- Green: Physical and Cognitive Frailty

Note: Figure is from Murray et al. BMJ 2008; 336:958-959. Modified by Rebecca Tiberini to show potential impact of rehabilitation.
In the outpatient setting, Oldervoll and colleagues explored the impact of a rehabilitation programme for 231 people living with advanced cancer in a randomised control trial. Patients were allocated to participate in twice-weekly circuit exercises using aerobic and resistance training, or usual care, over eight weeks. The exercise group demonstrated statistically significant and clinically meaningful improvements in handgrip strength, shuttle walk distance and health-related quality of life as compared to the group receiving usual care. Of interest, median survival was markedly higher in patients allocated to the exercise group who did complete the programme compared to those who did not (16.3 as compared to 6.3 months). This may indicate that while it is appropriate for patients to participate in some exercise training regardless of prognosis, more intensive outpatient models of rehabilitation may be best offered early in patients’ illness, highlighting the importance of early recognition of rehabilitation needs and timely referral of patients to palliative rehabilitation services.

The feasibility and acceptability of rehabilitation to patients with advanced disease is now well established. A series of pilot studies offering a range of exercise rehabilitation interventions to patients with advanced stage cancer unanimously found it was feasible for this population to participate in exercise rehabilitation, including aerobic, endurance and resistance training. Collectively, these outcomes suggest that along with being acceptable to patients, rehabilitative interventions appear effective in improving strength, fatigue, physical functioning, ADL functioning, social functioning, independence and quality of life. These wide ranging effects are also found in real-world clinic settings.

A large retrospective analysis of 572 terminally ill cancer patients found that rehabilitation interventions (including physical exercise, breathlessness management and relaxation strategies) were acceptable to over 90% of patients, while Yoshioka found that over 80% of 301 patients with advanced cancer participating in inpatient hospice rehabilitation experienced improvement in function. These findings illustrate that rehabilitation initiatives are both feasible and effective in the majority of patients with advanced cancer, with authors calling for improved access to rehabilitation for this group. When asked, the majority of patients with advanced cancer consider themselves physically capable of undertaking some form of exercise and over two-thirds feel prepared to undertake a programme.

Several small qualitative studies in the UK have explored the patient reported impact of participating in rehabilitation on their quality of life. Turner found that in addition to perceived physical and emotional improvements in their wellbeing, patients felt that engaging in rehabilitation gave them a sense of meaning whereby they reclaimed control though active, positive involvement in their own health, greater choice, the opportunity to prolong independence, and confidence and hope to face the future.

“… I am actually doing something to keep well. That feels really good in the situation where cancer makes you feel very powerless because it’s out of your control. I can get to the gym, I can walk, I can make my heart rate increase, I can strengthen my limbs as much as I’m able. That control is very good for someone who feels they have so little control…”

Diana

Malcolm’s findings reinforced the importance of rehabilitation as a means of enhancing a sense of normalcy, where patients had greater independence and ownership of their health.

“… it means that I’m able to just be, just feel like I’m normal, feel like things are normal for me.”

“I think it helps you to ... just get on with being and helping yourself... all of it is leading up to you making that decision for yourself to sort of keep healthy.”

"Rehabilitative Palliative Care: a challenge for the 21st century"
Shleinich and colleagues found that hospice patients rated tips to be as independent as possible to take care of themselves, advice and exercises to keep strong and prevent secondary problems, strategies to improve impaired communication, advice on swallowing, eating and drinking safely and support to best adjust to the changes they were going through among their top priorities for rehabilitation goals.18

**Rehabilitation in advanced respiratory and cardiovascular disease**

Rehabilitation interventions for patients with respiratory or cardiovascular disease are well established, with randomised controlled trial evidence supporting the effectiveness of pulmonary and cardiac rehabilitation programmes. Large Cochrane Collaboration systematic reviews show that pulmonary rehabilitation for patients with COPD (65 trials with 3,822 participants) can relieve breathlessness and fatigue, improve physical function, emotional function and feeling of control, and reduce the frequency of hospital admissions regardless of disease severity.60 Pulmonary rehabilitation in the peri- and early post-hospitalisation phase may counteract the harmful consequences of an acute admission and target modifiable risk factors for re-admission such as physical inactivity, reduced exercise capacity and impaired physical function.61 Similarly strong evidence exists for cardiac rehabilitation, which for patients with heart failure (33 trials with 4,740 participants) reduces hospital admissions and improves quality of life irrespective of the degree of heart failure (includes NY Heart Failure Association Class IV).62

Breathlessness is a common, distressing symptom in advanced disease present in about 90% of people with moderate to severe COPD, 80% of people with advanced heart failure and more than half of those living with incurable cancer.63 There is evidence that nonpharmacological rehabilitation strategies, including breathing techniques, exercise, facial cooling with a handheld fan, pacing and positioning and anxiety management strategies64 are “the most effective interventions currently available to palliate breathlessness in the mobile patient.”65

A major consequence of breathlessness is physical inactivity, which can precipitate a downward spiral of disease whereby breathlessness leads to physical inactivity, causing muscle deconditioning, which itself drives breathlessness, further physical inactivity, etc.66 This limitation in functional ability is also frequently accompanied by escalating anxiety levels and panic attacks.67, 68 Deconditioning is both preventable and reversible through rehabilitation. Incorporating rehabilitative approaches that encourage breathless patients to be more active into individualised palliative care plans can optimise functional capacity and reduce symptom burden.69

A recent randomised controlled trial by Higginson et al, found that a comprehensive multiprofessional approach to support breathless patients – integrating input from physiotherapists, occupational therapists, as well as doctors from palliative care and respiratory medicine – effectively enhanced patient mastery and ability to self-manage their breathlessness.70 This approach focused on patients gaining control over their breathing, being functionally active and living fully alongside breathlessness, rather than just targeting the intensity of the symptom.
Rehabilitation in advanced neurological conditions

In advanced neurological conditions rehabilitation has been found to be both acceptable and effective in supporting people to manage symptoms, maintain function, prevent secondary impairments, adapt constructively to change in function related to their illness and proactively avert crisis situations. A Cochrane systematic review of multidisciplinary rehabilitation which included 954 adults with multiple sclerosis of all severities, found that while there was no change in impairment, there was strong evidence to show multidisciplinary inpatient rehabilitation produced short-term gains in levels of disability and participation, and improved patient experience and quality of life.

Rehabilitation of older people and people with dementia

Rehabilitation of older people has been found to be effective in reducing disability with few adverse effects. Crocker et al reviewed 67 RCTS including over 6,000 people aged over 65 living in permanent long-term care. Rehabilitation interventions aiming to maintain or improve physical function showed small but significant improvements in transfers, walking function and speed and ADLs. One programme for 233 frail elderly people (mean age 81) with multiple co-morbidities used a multiprofessional, goal-based rehabilitation approach delivered from an outpatient day hospital. The programme was effective in improving physical performance and functional independence, with more than half of participants demonstrating meaningful improvement in at least three of five outcome measures. This demonstrates that multidisciplinary rehabilitation can be effective in elderly populations living with multiple chronic diseases.

A significant challenge for the future is the increasing prevalence of dementia, which is the leading cause of non-fatal disability in the developed world. Historically, impaired cognition was perceived to be a barrier to active engagement with rehabilitation; however, recent studies show rehabilitation to be both feasible and effective in this population.

In a study of 201 older adults receiving individualised multidisciplinary outpatient rehabilitation over four to six weeks, 78 participants had cognitive impairment related to dementia. While this group had greater functional dependency at baseline as compared to those without cognitive impairment, functional dependence improved irrespective of cognitive status.

Pitkälä and colleagues further explored models of rehabilitation with 210 community dwelling patients with Alzheimers, randomly allocated to either rehabilitation in an outpatient exercise group (one hour, twice weekly), individualised home exercise with a physiotherapist (one hour, twice weekly) or usual care, over one year. While all three groups lost function over the course of the study, the level of deterioration was greatest in those allocated to usual care. Individualised home exercise was found to be most effective at maintaining function; however, both exercise groups reported reduced falls as compared with the group receiving usual care. The study demonstrated cost-effectiveness of rehabilitation, with significant cost savings associated with participation in rehabilitation.
d) The economic value of Rehabilitative Palliative Care

Over the course of a life, the majority of health and social care costs are generated in the last year.\textsuperscript{50}

![Figure 4: Total healthcare expenditure over a lifespan](image)

Note: Adapted from ‘Living well at the end of life: adapting healthcare to serious chronic illness in old age. Rand Health White Paper WP-137 (2003)’.

In the UK, this steep increase in cost at the end of life is driven by two primary determinants:

- **Hospital costs**: are by far the largest cost element, the bulk of which are due to emergency inpatient admissions, which escalate rapidly in the last weeks of life. Hospital costs in the last three months of life average over £4,500 per person who dies.

- **Authority funded social care costs**: although just over a quarter of people use social care in the final year of life, the high costs associated with nursing and residential care bring the average social care cost over the last three months of life to over £1,000 per person, with costs rising with age.\textsuperscript{51}

Functional disability and reduced independence with ADLs are significantly associated with both hospital stay and need for long-term care.\textsuperscript{52-85}

Kelley et al investigated factors associated with hospital use in the last year of life in 2,493 patients aged 65 or older. Severe disability and functional decline were significantly associated with increased hospital days – therefore programmes to address functional decline and disability may reduce healthcare need and cost.\textsuperscript{52}

Failure of older patients to regain function in the three months following a hospital admission has also been identified as a significant predictor of being institutionalised within the next 12 months. Portejigis et al pooled analyses of three longitudinal studies, totaling 1,085 community-dwelling patients aged 65 years or over, and found that loss of function in ADLs following hospitalisation increased the risk of admission to a long-term care facility. This effect was seen irrespective of the person’s pre-admission ADL impairment. As such, counteracting the loss of function following hospital admission with rehabilitation may reduce or delay the need for institutionalisation.\textsuperscript{83}
In an international prospective cohort study, Verbeek et al explored factors associated with admission to long-term institutional dementia care. Primary data were collected across eight European countries, including the UK, from 2,014 dyads of people with dementia and their informal caregivers; 791 patients were recently institutionalised and 1,223 patients lived at home and were at risk of being institutionalised. While considerable differences were found in patient characteristics between countries, two common factors crucial in the process of institutionalisation were identified: caregiver burden and independence in ADLs.

While the above studies highlight the importance of functional disability and caregiver dependence as factors contributing to healthcare costs, there is currently little direct research concerning the economic impact of a rehabilitative approach within palliative care. A growing and increasingly robust evidence base supports the efficacy of rehabilitative approaches to optimise functional ability and independence in patients living with advanced illness in the last year of life (see page 11).

Extrapolating these findings, the significance of Rehabilitative Palliative Care in the context of health economics is that through active maintenance and/or improvement of people’s function there is potential to:

- reduce the need for hospital admission
- support people to be discharged from hospital or hospice services earlier
- decrease or delay the need for authority-funded care including admission to nursing or residential homes
- decrease health and social care need and costs.

Scialla et al undertook an economic analysis to clarify this relationship in their study of 110 elderly patients with advanced cancer participating in a comprehensive, multidisciplinary inpatient rehabilitation programme. The programme involved a collaborative rehabilitative approach, involving doctors, nurses, physiotherapists, occupational therapists, social workers, psychologists, nutritionists and speech pathologists. It aimed to support patients to achieve their personal goals, most of which related to maximising their function within the level allowed by their impairments.

The study demonstrated an average improvement in a patient’s functional level from ‘in need of significant assistance in all ADLs’ to ‘requiring moderate assistance with self-care’, which equates to an average of eight points difference on the validated Functional Independence Measure (FIM). Every one point gain in FIM score has been shown to decrease caregiver time by three to four minutes, which equates to the multidisciplinary rehabilitative approach decreasing caregiver time by an average of 28 minutes per patient per day.

The report ‘Unit costs for Health and Social Care 2014’ reveals an average cost for a home care worker visit is £19/hour. This suggests that a multidisciplinary rehabilitation programme has potential to save an average £9.50 in home care costs per patient per day, equal to £63 per week, £252 per month, £3,024 per year.

At a population level small improvements in an individual’s functioning can translate into considerable cost savings. In the current and future climate of financial constraint, we cannot afford to overlook the economic contribution of Rehabilitative Palliative Care.
Summary of key points

- There is an urgent need for hospices to offer a different approach to care which better supports people to live until they die, both NOW and in the future.

- The starting point for this change must be patients’ priorities – to maintain normality of daily life, physical function and independence.

- Hospice support must be tailored to the changing demographics and needs of the future to help people cope constructively with the functional impact of chronic illness and increasing age.

- Rehabilitative Palliative Care offers a proactive solution to minimise disability where possible and optimise functional independence – to transform the last years of life into a more active, meaningful existence.

- Rehabilitative Palliative Care approaches are underpinned by a robust body of evidence to support their acceptability and effectiveness for people receiving palliative care.

- Rehabilitative Palliative Care has the potential to translate into considerable cost savings, which hospices cannot ‘afford’ to overlook.
### Person-centred goal setting

#### Why is person-centred goal setting important?

National guidance recommends that patients should "receive an active and planned approach ... involving assessment, goal setting, care planning and evaluation" as an intrinsic part of palliative care provision.\(^6\)

While goal setting is recognised as an important component of palliative care, professionals have a tendency to focus on problems and symptoms, which represent something that we can fix or manage, whereas patients focus on what they want to ‘do’.\(^8\) The implication for hospices is that by failing to explicitly ascertain patients’ goals and priorities, palliative care teams may be providing ‘professional-centred’ care based around what we can influence or what we perceive to be important to the patient.

To provide truly ‘person-centred’ palliative care that is tailored to each patient’s personal priorities, an essential starting point is establishing what is most important for that person. Goal setting around these priorities provides a meaningful focus for collaborative action planning between the patient, family and the whole multidisciplinary team which places the patient actively at the centre of their care.\(^9\) It also provides a unifying framework for different professions within the multidisciplinary team to contribute their unique expertise – including symptom control, rehabilitation, psychological, social and spiritual support – to collectively best support the patient to achieve their goals.

Reframing multidisciplinary palliative care practice with greater collaborative focus on patients’ personal goals has potential to help patients:

- feel listened to and that their priorities are paramount
- find focus and meaning in life
- increase motivation and effort to achieve what is important to them\(^9\)
- develop resilience and coping – enabling reframing of goals as illness progresses and mourning for unachievable goals as an important aspect of adapting to illness\(^92, 93\)
- to live actively while dying.\(^94\)

Person-centred goal setting is not about creating an environment of false hope. While goals should be realistic, research suggests the process of setting goals and working towards them is more important than achieving them and that this can be constructive in helping patients understand, and come to terms with, what is manageable and what is not.\(^95\)

#### Parallel planning

At its best, goal setting in palliative care should actively invite uncertainty into the conversation. Acknowledging that we cannot be certain what the future holds is honest and open and frequently welcomed by patients and families who recognise the truth in this. An important strand of Rehabilitative Palliative Care is ‘parallel planning’ – the process of actively acknowledging and planning for two or more possibilities at the same time. This can be considered in the context of hoping for the
best while planning for the worst and is a useful framework for supporting realistic hope. For example, a patient’s goal is to be able to walk to their local shop independently – this is Plan A. In the goal setting discussion ‘good days’ and ‘bad days’ are explored and the need to actively plan alternatives for days where the patient may be feeling too unwell to manage the walk is introduced and agreed. This allows for planning to provide a wheelchair as a ‘back up’ option which may or may not be needed – this is Plan B. Planning for several possibilities concurrently can help to a) introduce and allow for anticipation of possible deterioration in a safe way and b) help prevent crisis situations which place the patient at risk.

What does person-centred goal setting look like in practice?

**Multidisciplinary support is focused around person-centred goals for each patient**

- All holistic assessments, undertaken by any palliative care professional, in all settings, include a global question to explicitly identify a patient’s goals and priorities. These may include:
  - What is important for you to do in the next few weeks/few months/short while?
  - What are your best hopes for ... this admission/the next few months?
- Together the patient, family and multidisciplinary team formulate an ‘action and coping plan’ to support achievement of the goal.
- Goals and action/coping plan are explicitly documented in patients’ notes.
- For hospice inpatients, patients’ goals are displayed in their rooms (with patients’ consent).
- Input of all the multidisciplinary palliative care team is tailored to best support each patient’s personal goal.
- Multidisciplinary team meetings and ward round discussions are contextualised around each patient’s personal goals.
- Patient goals are appraised and feedback is given – this allows for acknowledgement and celebration of achievements or for reflection and reframing of goals where a patient’s circumstances have changed and the goals are no longer a priority for them or no longer realistic.
- Where goals have been achieved, new goals are established.

‘Parallel planning’ is used to introduce ‘uncertainty’ and actively plan for several possible outcomes

- Multidisciplinary team members actively introduce ‘uncertainty’ into goal setting discussions or at times where foreseeable change lies ahead. This may include a dialogue about ‘hoping for the best and planning for the worst’.
- Action and coping plans are made for more than one course of action at the same time to support patients and families to anticipate and proactively plan for a change in their condition and avert crisis.
Focus on function (beyond symptoms)

Why is a focus on function important?

Maintaining function is a high priority for patients with advanced illness as it represents an important gateway to preserving independence and autonomy, and participating in meaningful activities that add quality to life.

Function requires greater attention in older populations who are at increased risk of functional decline and frailty. For this group, small deteriorations in function can have a disproportionate impact on capacity for independent living.

It is easier to maintain function than it is to regain function once it has been lost. Proactive assessment and identification of factors that may compromise function is key to allow for strategies to prevent avoidable deterioration, eg deconditioning arising from inactivity, to be put in place. Functional assessment is also essential to proactively recognise patients’ needs for specialist rehabilitation input and ensure appropriate early referral to allied health professionals.

Symptoms can be a profound source of discomfort and distress in their own right; however, frequently the magnitude of patients’ experience can only be fully appreciated when symptoms are contextualised within the realm of function. Function is frequently compromised by symptoms and is extrinsically linked to a host of wider losses, which if not properly assessed and addressed can become significant sources of distress for patients and families.

While palliative care defines itself through early identification and impeccable assessment, research suggests that functional concerns of palliative patients are not well identified. Baile et al evaluated concerns of 137 patients immediately before attending a symptom control and palliative care clinic and compared these with concerns identified by the palliative care physician during the clinic. Patients were most concerned about loss of function, the future and caring for themselves. There was generally poor concordance between patients’ reporting of concerns and physicians’ reporting of the patient concerns.

Systematic, routine assessment of function, as a core part of the holistic palliative care assessment, is essential to proactively identify functional concerns and ensure these are adequately addressed. This is important at all stages of symptom control, to ensure that intervention is not ended prematurely at the point where a patient’s symptoms are well controlled at rest, but rather, symptom management aspires to have symptoms well controlled when patients are operating at their maximal level of functioning.
What does a focus on function look like in practice?

**Functional assessment is established as a core component of palliative care holistic assessment**

- Functional assessment is routinely incorporated as a core component of all palliative care holistic assessments.
- Functional difficulties are proactively screened for at first contact and regular follow-up assessments by asking: Are you having any difficulty with moving around or managing your day-to-day activities?
- Where a functional difficulty is identified further assessment is required to establish:
  - specific details of how function is being affected (including impact of symptoms)
  - how this differs from the patient’s normal baseline level of function
  - time period over which the patient’s function has been affected and how quickly it is deteriorating.
- Recognised, validated outcome measures which address function, such as Australian Karnofsky Performance Status, Integrated Palliative Care Outcome Scale and Barthel Index, are routinely incorporated into palliative care assessment.
- All members of the multidisciplinary team are trained in undertaking a functional assessment. This includes:
  - asking appropriate assessment questions and interpreting significance of answers
  - where patients are able, routinely undertaking an objective assessment of function – this can be observing a patient’s mobility when they let you into their property or asking a patient to stand from their chair and walk across the room
  - initiating appropriate and timely actions in response to functional assessment findings.
- Screening of nutritional function is routinely incorporated as a core component of all palliative care holistic assessments.

**Function is explicitly documented in patients’ notes**

- Functional assessment is explicitly documented in assessment at transition points between services (first contact assessment, inpatient admissions) or where a change in functioning is recognised.
- Functional ability, activity and participation for each patient is routinely documented by nursing and healthcare assistant staff over every inpatient shift.
- Functional status and any changes over admission are explicitly noted in patients’ discharge summary.
Symptom control is routinely contextualised in relation to patients’ function

- Assessment of symptoms is undertaken together with functional assessment (see page 21).
- Improvements in symptom control take into account both reduction in patients’ symptoms and improved ability to function.
- Symptom control goes beyond control of symptoms at rest with the aim of achieving effective symptom control when the patient is optimally functioning (in line with their personal goals).
- Where functional compromise is identified, proactive referrals are made to allied health professionals to support patients’ maintenance of function and prevent avoidable deterioration alongside symptom management, rather than waiting to the point where symptom control has been achieved.

Perspective: Palliative medicine consultant

Palliative care often seems to be viewed from the outside as an approach to care that is primarily focused on symptom management at the end of life. While this aspect of care is indeed frequently critical in a population with life-limiting disease the goals of symptom control are not only to make a person comfortable; importantly they should enable a person to function to their fullest potential and achieve optimal quality of life. The primary aim of palliative care is therefore better summarised as the amelioration (or healing) of the suffering of the person, who is often facing an uncertain future. How does a rehabilitative approach sit within this aim?

In the past the idea of rehabilitation in the context of palliative care was counter-intuitive to many, but now it is becoming an essential part of the armamentarium of palliative care and one that addresses issues of quality of life on a number of fronts. Rehabilitative Palliative Care contextualises symptom control in the wider setting of a patient’s function, goals and priorities. The approach actively supports improvement in patients’ symptoms (through nonpharmacological interventions), while enablement-focused approaches to care provision can improve patients’ functional ability.

Loss of function provides a departure point from which patients can be supported to explore the other losses that are commonly felt towards the end of a person’s life, such as loss of independence, role, sense of control or the impending leave-taking from their loved ones that they must accomplish. Ultimately the therapeutic relationship can provide ‘space’ in which to allow the meanings of his or her suffering to be thought about and possibly reframed. By seeking to “integrate biological realities with profound human needs for meaning, comfort and direction” a rehabilitative approach is, in my view, not only entirely consistent with the aims of palliative care, but adds a new and exciting avenue to achieving its aims.

References

Proactive early referrals are made to allied health professionals for specialist rehabilitation input

- Patients are offered referral to physiotherapy, occupational therapy, speech and language therapy and dietetics at the point where early functional decline is first proactively screened for and recognised.
- Referral to physiotherapy at early stage of mobility compromise (patient mentions feeling a bit unsteady when walking to local shop) rather than waiting until marked deterioration in mobility (patient is unable to walk to local shop following recent fall).
- Referral to occupational therapy at early stage when ADLs are beginning to be compromised or for proactive discharge planning (patient mentions difficulty preparing own meals), rather than waiting until patient is struggling to manage ADLs (patient requires social carer twice daily to support meal preparation).
- Referral to dietitian at early stage when appetite has changed rather than waiting until patient has lost significant weight.
- Referral to speech and language therapy at early stage of swallow (patient coughs following drinking fluids) or communication difficulty rather than waiting until patient has developed marked dysphagia (patient is admitted with an aspiration pneumonia) or is obviously struggling to communicate.

Perspective: Palliative care dietitian

Good nutrition has a fundamental role to play in enabling patients to benefit from Rehabilitative Palliative Care. Good nutrition is more than just about eating well; it’s about socialising, spending time with family and friends, regaining a sense of control and normality in day to day life – all of which are central to our holistic approach to Rehabilitative Palliative Care. Eating and drinking can become a significant problem during the palliative course of an illness, not just due to physical difficulties but also the emotional and psychosocial impact of the illness. Great frustration can be experienced by patients and their families when, despite encouragement and time spent creating appetising meals, the patient is only able to eat one or two mouthfuls; both worry about how the patient will ‘keep strong’ when they are eating so little.

The dietitian is not just an expert source of nutrition knowledge but has the skills to support the patient and their family through some of the social and emotional difficulties associated with eating.

Every patient needs to have their nutritional status assessed and addressed as early as possible so that they can fully engage in all that Rehabilitative Palliative Care has to offer.

My vision is that patients are given access to good quality nutrition input as early in the palliative stage of their illness as possible; we shouldn’t wait until patients have lost significant amounts of weight but should be pre-empting this by being proactive. Rehabilitative Palliative Care should include the opportunity to find out what works best for the patient – whether that be for individualised nutrition counselling with a dietitian, access to good quality written information or the opportunity to find support from others in the same situation through group self-management programmes.

Dietetics is under-represented in palliative care – now is the time to reverse this and give patients the opportunity to make the most out of their lives.

Caroline Quilty, Specialist Dietitian – Palliative Care, St Joseph’s Hospice
Enablement

Why is enablement important?

Patients living with advanced illness describe priorities of maintaining normality of daily life, physical functioning and independence, and express a clear desire to be supported to manage their health with choice and control right up until they die.

Enablement in healthcare is a therapeutic paradigm or process which aims to “recognise, support and emphasise the patient’s capacity to have control over her or his health and life”. In the context of palliative care, where realities and losses associated with progressive, advancing illness can erode a sense of control, the practice of enablement can help actively restore the experience of perceived control and self efficacy for both patients and families.

The defining characteristic of ‘enabling care’ is that all patients are consistently offered the opportunity to make the choice for (or against) independence and participation in the first place.

What does enablement look like in practice?

Patients and families are supported to understand and expect that hospices provide enablement focused support which gives them maximum choice and participation.

- Prior to admission to the hospice, patients and families are provided with information to help them prepare for their stay and know what to expect, emphasising our commitment to support them to maintain normality as much as possible.

- Patients and families understand that it is essential they bring in any items that will support them to continue to participate in their normal routines. This includes:
  - day clothes
  - shoes and slippers
  - walking aids
  - personal wheelchairs
  - pressure cushions
  - communication aids
  - nutrition support devices or fluid thickening products.

By integrating enablement as a core dimension of holistic palliative care provision, hospices can better empower patient choice and ensure that care is actively tailored to recognise and support individual patient’s capacities and preferences.

Enablement actively supports patient independence and participation; however, this is always led by patients’ capacity and willingness to engage. In situations where patients make an informed decision to decline to participate, eg in daily care even if they have the capacity to do so, an enablement approach recognises and supports the patient’s choice.
Patients are supported to maintain their normal routines of daily life as closely as possible while in the hospice

- Upon admission assessment the team work with patients to understand their normal daily routine and consider how this can be best supported. This may include:
  - having a bath, shower or seated wash in the bathroom (to maintain this level of ADL functioning)
  - getting dressed into clothes everyday rather than pyjamas (to reduce the sick role experience)
  - spending time during the day out of bed and out of their room (to help reduce inactivity and prevent secondary problems such as pressure sores and chest infections, and to reduce boredom)
  - sitting out of bed for all meals (to support eating and safe swallowing)
  - taking meals in a communal environment on the ward or in the hospice restaurant with other patients and/or family members
  - having meals at the same times that they normally would
  - having maximum choice in meals (to suit their personal and cultural preferences and nutritional requirements)
  - maintaining the amount of walking they would be required to do at home, eg walking up to the toilet rather than using a commode beside the bed (to prevent loss of exercise tolerance and confidence)
  - going out from the hospice ward to the cafe, garden, communal spaces, local park or shops (to reduce social isolation and a narrowing of lived reality).

All members of the multidisciplinary palliative care team integrate principles of enablement in their daily practice and support of patients

- All members of the multidisciplinary team actively give patients the opportunity to make independent choices or do things for themselves before offering assistance.
- Where support is needed with physical activities, verbal prompts or tips to undertake the activity independently are offered before providing hands-on assistance.
- Where hands-on support is required with a physical task this is agreed in negotiation with the patient and provided with their consent, whenever possible.
  
  NB: Even patients who are in the last days of life can be supported through an enablement approach to care – this may simply involve supporting them to wash their own face or genitals if they are able to, or choosing which position is most comfortable.
- Nursing staff and assistants utilise motivational interviewing approaches to engage patients to participate in ADLs when they have capacity. For example, if a patient declines to get out of bed, the staff member explores the reasons why and identifies any factors which could be addressed.
Rehabilitative Palliative Care: a challenge for the 21st century

St Joseph’s Hospice offers nurse-led respite support for patients booked for planned respite stays of one to two weeks, in seven dedicated respite beds. At admission, each patient has a comprehensive assessment to establish their personal goals and priorities and to create a programme of support tailored to reflect these. For the patient this may relate to maximising functionality, promoting independence, advance care planning, review of medical, nursing and medication needs and reflecting on current socialisation opportunities. For the carer, this may relate to coping abilities and future needs.

How Rehabilitative Palliative Care is delivered in daily practice on the respite unit:

- **Approach to care is enabling**, assessing what can be done and what may be retrievable (eg if loss of function is evident) with a focus on doing ‘with’ the patient, as opposed ‘to’ the patient.

- **All support and supervision** recognises the importance of independence and actively creates opportunities to optimise this.

- **Collaborative multidisciplinary approach** to supporting patients’ goals, with early recognition of need and proactive referral to members of the multidisciplinary team for input.

- **Multidisciplinary team meetings and handovers** focus on identifying and optimising patients’ potential, and include carers as the expert voice of care.

- ‘**My day’ document** used to record patients’ normal routines and support these to be maintained when the patient is unable to communicate effectively with the team.

- Respite environment supports social interaction and normal routines.

- **Repetition and reiteration of the emphasis** and approach of rehabilitative care.

How this model best supports patients’ and carers’ needs and priorities:

- Promotes and delivers choice to patients – ensuring they have options.

- Supports patients to maintain their normal routines or allows change in a safe environment. Patients actively encouraged to exert control and structure over their day.

- Patients are supported to adopt self-management techniques in their daily activities including self medication.

- Patients are encouraged to integrate and socialise with other patients, carers, staff and volunteers in line with their wishes, eg communal eating, activities, current issues discussion.

- Empowers patients through setting and achieving their own goals – preparing them to proactively manage their health upon return home.

Diane Laverty, Nurse Consultant, St Joseph’s Hospice

Debbie Pegram, Respite Ward Manager, St Joseph’s Hospice
Hospices create enabling environments

- Hospices have a range of enablement equipment to support patients’ activity and independence. This includes:
  - riser-recliner chairs
  - adjustable height armchairs
  - toilet aids – raised toilet seats, mowbrays
  - environmental controls.

- Hospices create environments to support patients’ normal routines:
  - tea and coffee making facilities
  - communal eating areas
  - simulation spaces for ADLs such as kitchen tasks and bathing.
Hospices practice proactive discharge planning

Proactive discharge planning is important to guide patient, family and multidisciplinary team expectations for the admission and to enable forward planning (rather than waiting until symptom control is achieved). When practiced in combination with parallel planning (see page 18) this can be a constructive process even if discharge timeframes need to be extended, discharge location changed (eg to nursing home) or discharge cancelled (if patient becomes terminal). Proactive discharge planning gets people home earlier and supports people to achieve their preferred place of care and death. It also allows more efficient, cost-effective use of specialist palliative care beds.

- When patients are admitted for reasons other than terminal care, discharge plans are discussed with the patient and family upon admission to the hospice.

- Where discharge destination is home, and the patient’s functional abilities have changed, early referral is made to an occupational therapist.

- In the days prior to discharge when a patient’s symptoms are well controlled and their condition has stabilised, hospice support is tailored to mirror the package of care that the person will receive once home. For example, if a person will receive a four-times daily package of care, then nursing and healthcare assistants simulate four-times daily care in the hospice. If the person will receive significant support from family members at home, family are invited to actively engage with support at the hospice. This model helps patients and families actively prepare for the transition from hospice to home and builds coping and confidence. It also allows for staffing efficiencies on the inpatient unit so that nursing support can be focused on those with the greatest need.

- Following long inpatient admissions, graduated discharge is offered to support a successful and safe transition from a 24-hour support environment to home. This will differ for each patient but may involve a patient spending several hours at home with a healthcare assistant or family member, the patient then spending several hours at home alone, the patient spending a night at home alone – returning to the hospice following each graduation. While this may seem resource intensive it is more cost efficient than extended inpatient stays following an unsuccessful discharge. The main reason discharge fails relates to anxiety and lack of confidence on behalf of the patient and family. Graduated discharges can proactively prepare them for this adjustment.

- Hospices invest in the development of Independent Living Flats: a single bedroom flat which replicates a home environment as closely as possible in terms of equipment, meal preparation and care provision. This ‘step down’ facility provides a safe space for patients and families to ‘trial’ independent living, to optimise rehabilitation potential, to gain confidence and to enable transition from the maximally supportive ward environment to manage independently at home.
**Successes and innovations: Independent living suites to support self-management and rehabilitation**

St Margaret’s Hospice in Taunton and St Margaret’s Hospice in Yeovil used a Department of Health grant to extend their inpatient units to include a one-bedroomed self-contained flat at each site (called Sunflower Suites). These ‘safe but separate’ facilities enable hospice staff to prepare patients (and their carers) more effectively for discharge home by offering a more independent living environment with replication of care services and equipment that will be available to the patient at home.

Sunflower Suites offer a ‘halfway house’ option so that self-management strategies can be tested, practiced and tweaked as necessary. Patients and families are supported to transition from a highly supportive ward environment to home with increased confidence, increasing the chances of a successful discharge. The suites are also used to support people admitted for palliative rehabilitation who are ready to benefit from a more independent living environment.

**What inspired this innovation?**

Moving back home from the safe environment of an inpatient unit can be a huge and frightening leap for some patients and their families. There is a great difference between the level of care and support that is available to our patients on the inpatient unit and that which is available in the community, even if a care package is provided.

We recognised that even when patients had apparently reached functional independence in the ward environment, their confidence (and often the confidence of family/friends) in their own ability to manage on their own was lacking. The flats give patients a perfect environment to demonstrate clearly to themselves, families and staff that all aspects of an appropriate and safe discharge have been duly considered and prepared as necessary.

Ensuring that we respond appropriately to patients’ wishes for their future sometimes means that risk assessment/risk taking is an essential part of discharge planning. Providing a ‘halfway house’ towards independent living provides a safer environment in which patients can really explore their functional boundaries and make informed decisions for their future.

**What difference has it made to your team’s Rehabilitative Palliative Care?**

Supporting a patient within a Sunflower Suite is a whole team effort – from the kitchen’s understanding whether they are continuing to provide meals or provision of supplies for the patient to cook their own food, to the volunteers knowing not to pop in to say hello if the patient is acclimatising to seeing no-one all day as it will be at home. We have seen team working at its absolute best.

Discharge planning has become even more focused and enabling. It is not only the patient that benefits from being in a more independent setting – those staff who were more used to ‘caring’ than ‘enabling’ have responded in such a positive way to support the rehabilitation process.

Patients have not needed such intense support from the community teams post discharge, as anxieties have already been addressed more comprehensively.

Karen Kidsley, Lead Physiotherapist / Therapy Coordinator, St Margaret’s Somerset Hospice

Alison Hodgson, Lead Physiotherapist, St Margaret’s Yeovil Hospice
Patients in the community are offered models of palliative care support that optimise choice, normalcy and independence

- Patients are actively given the opportunity to attend outpatient services for support rather than the default option of home visits.

- Where patients are attending outpatient hospice services for a number of services, wherever possible these should be coordinated, including access to outpatient clinical nurse specialist clinics.

Perspective: Palliative care occupational therapist

If Rehabilitative Palliative Care is the answer… what is the question?

Palliative care has helped us understand that there is life beyond treatment and before death. It has opened up a little formulated but increasingly common phase of our life which is the living with dying phase. Patients that I see in a hospice setting are often surprised that they don’t have to take to their beds and wait for death. Rather, there are many occupations of value, purpose and meaning that with encouragement, adjustment, acceptance and opportunity, can make this period of time the most critical and rewarding part of a life’s journey.

In short, Rehabilitative Palliative Care is the answer to the question: How can I live and die with dignity?

- It may mean finding strategies to manage common barriers to achieving goals such as fatigue, breathlessness, anxiety and depression.

- It may mean redefining a wheelchair as a means to take control back, thereby being able to get onto the moors to smell the Yorkshire air, rather than the commonly heard first response: “I am not ready for that, yet.”

- Over the years, I have never met anyone who has said to me the time is now right for a bath aid, but I have met many people who have said, “I really miss being able to have a bath”.

Palliative rehabilitation looks different to every person I have ever worked with, but it is based on a patient’s need to find purpose and meaning in the life they have left to live. The occupational therapist is ideally placed to work with patients to ensure their strengths and skills are working in a suitable environment to allow them to do the things they want to do (hopefully in negotiation and sometimes in conflict with the significant people in their lives). Occupational therapists are also well placed to lead and support the wider multidisciplinary team to adopt a rehabilitative approach to palliative care practice that supports these aims.

Sharon Wilton, Occupational Therapist, Marie Curie Hospice and Sue Ryder Manorlands Hospice, Bradford. HOPC committee member
Supported self-management

Why is supported self-management important?

Self-management is about supporting people to take responsibility for their own health and wellbeing. Self-management is closely related to and often used interchangeably with self-care. Collectively, these terms aim to empower patients to have greater control in the way they live with illness, and to play an active role in managing their illness and the effects of their illness, themselves.

For people living with advanced illness ‘taking charge’ represents a central priority. The right to exercise choice and control, even when extremely ill, is important to patients and is often related to preserving their dignity and maintaining normality.

What does supported self-management look like in practice?

Self-management strategies are actively incorporated across all hospice support services

- Across all hospice settings, patients are empowered and encouraged to assertively voice their opinions, preferences and needs.
- Professional interactions with patients first seek to identify what they are managing well themselves and positively reinforce this, before exploring self-management strategies the patient and family could employ to address any difficulties currently being experienced.
- Patients are fully informed about the range of support options available to them including information support services, allied health professional rehabilitation, volunteer support and self-management programmes and are encouraged to self refer to these.
- Patients are routinely encouraged to undertake the elements of self-care they can manage themselves which are important to maintaining their sense of self. This may range from washing one’s own genitals, making their own cup of tea through to going out independently.
- Assessments routinely include a question ‘how much do you understand about your condition?’ to ascertain patients’ (and families’) information needs.
- Patients and families are actively provided with information to learn about and better understand their condition in response to their information needs and wishes. This may include written information, verbal explanations or signposting to information support services.
- Patients are proactively referred to allied health professional services for nonpharmacological management of symptoms to learn strategies to self-manage breathlessness, fatigue, pain, lymphoedema – as an integrated component of best practice symptom management in line with latest evidence.

In the context of palliative care, supportive self-management and self-care ‘does not necessarily mean remaining entirely self maintaining or fully functional’, instead it involves “maintaining one’s usual practices of self-care; those things that are important and unique to oneself in maintaining one’s sense of self” and “being given the means to master or deal with problems, rather than relinquish them to others.”

Supportive self-management is about redressing the power relationship between health professionals and people (patients) to put the person and their family back in charge.

Continued on next page...
Self-management strategies are actively incorporated across all hospice support services (Continued)

☐ All members of the multidisciplinary team have a clear understanding of nonpharmacological symptom management strategies and are competent to employ these in their daily practice, to support patients to self-manage their symptoms and reinforce positive coping behaviours.

☐ Patients are proactively offered the use of aids and adaptations which may enable them to manage daily tasks or activities without or with less assistance.

☐ Hospice offers self-management supportive group programmes, to equip patients and families with knowledge about their condition, strategies to self-manage their symptoms, and to share tips and coping strategies in a supportive social space with people in similar circumstances. These should include:
  ☐ Breathlessness Management Programmes
  ☐ Fatigue Management Programmes
  ☐ Pain Management Programmes
  ☐ Falls Prevention Programmes

☐ Hospice utilises the Patient Activation Measure to evaluate individuals’ knowledge, skill and confidence for managing their health and healthcare as a recognised measure of self-management, engagement and empowerment.

☐ Hospice utilises volunteers trained in rehabilitative and nonpharmacological symptom management to actively support patients to integrate self-management behaviours into their daily lives.
Perspective: Palliative care clinical nurse specialist

Samuel, an 89 year old widower with uncontrolled heart failure, described his struggle to maintain his independence:

“I wouldn’t say it was my symptoms it’s just err well it is tiredness umm the effort that has to be put into it to actually carry it out even a simple thing and ummm you could very easily I feel let yourself go.”

Patients with long-term conditions frequently experience episodes of decline, from which they struggle to reach their previous level of function. Like Samuel, they describe the battle of maintaining independence and not ‘letting themselves go’. Nurses involved in their care must strive, alongside the broader multidisciplinary team, to support patients to make tough decisions about their individual compromises between striving for their previous level of function and activity, and accepting help or making adaptations. By embracing enablement approaches to care provision, nurses can empower patients to maintain independence with ADLs and help them to actively identify where support is needed.

Individual choice is critical and palliative nurses have an important role to play in supporting patients to actively express their choices, preferences and goals around which all palliative care interventions should be based. There is increasing evidence demonstrating the importance of ‘patient activation’ – the knowledge, skills and confidence a person has in managing their own health and healthcare⁠¹ – to improve ability of individuals to make health-related decisions. Consequently, palliative care multidisciplinary teams must cultivate the skills to promote patient activation and develop an evidence base of how approaches such as motivational interviewing, integral to health coaching, and self-management can be adapted to the palliative phase of advanced illness. These represent core elements of Rehabilitative Palliative Care.

Nurses have an essential role to play in Rehabilitative Palliative Care. This requires a change of perception – rehabilitation cannot be restricted to an activity conducted in a gym, led by physiotherapists but instead must be an integrated component of all palliative care activity, to allow all members of the multidisciplinary team to support the ethos of living well until death.

References:

¹ Hibbard J, Gilburt H. Supporting people to manage their health. Kings Fund; May 2014.

Mary Brice, Heart Failure Nurse Consultant, St Christopher’s Hospice
Patients are supported to take informed and optimally managed risks

Supportive self-management involves giving the control back to the patient. Hospices may encounter situations where a patient’s goals or choices predispose them to some element of risk. While we have a duty of care to protect patients from harm, if a patient’s mental capacity is intact they have the right to make their own choices, even if these place them at risk. For example, a patient may choose to walk to the toilet independently even if they are at high risk of falling, a patient may choose to be discharged home even if there is a high risk of them failing to cope, a patient may choose to eat and drink even if there is a high risk that they will aspirate. Taking risks represents a way for people to exert choice and control over the things important to them. It also represents a way for patients to challenge their limitations and come to terms with losses of function or independence.

- Hospice teams provide patients and families with accurate information about the risks associated with their behaviours to enable them to make an informed choice.
- Hospice teams respect and honour patients’ decisions even if they deem these risky.
- Hospice teams actively take steps to reduce and manage identified risks where possible – eg a graduated discharge may help a person explore and understand the risks in a safer, supportive way.
- Where risk is identified, this is documented in patients’ notes with reference to mental capacity and informed decision making.
The ability to communicate one’s needs, thoughts, feelings and wishes is central to a person’s sense of wellbeing and quality of life. It enables patients to be active participants in goal setting within the wider rehabilitation process, expressing their needs, wishes and priorities and contributing to personalised advance care plans. When communication is compromised, significant frustration and distress can result for both patients and their caregivers.

Speech and language therapists (SLTs) are skilled in assessing, diagnosing and advising on a wide variety of communication difficulties. Particularly when working with patients with life-limiting and rapidly progressing conditions, it is essential that intervention begins at an early stage in order to plan and prepare for any deterioration in communication abilities.

FF was referred to speech and language therapy shortly after her initial diagnosis of motor neurone disease. At this stage, she was still able to communicate well with only a mild dysarthria (speech difficulty); however, the various options for alternative communication aids were discussed in anticipation of a decline in her speech function. As her speech gradually deteriorated, she started using a light writer (text to speech communication device) to support her communication and she was referred for an early assessment of an eye-gaze communication system. Utilising this advanced system FF was able to continue to use this to communicate with her husband and friends until shortly before her death.

Eating and drinking also plays a key role in Rehabilitative Palliative Care in order to maximise not only nutritional intake but to optimise energy to participate in activities that add quality of life. Difficulties in swallowing (dysphagia) can result from various medical conditions and are frequently seen in patients as they approach the palliative stage of illness. SLTs are able to provide an expert opinion in the assessment, diagnosis and management of dysphagia, giving advice and guidance on dietary modifications and compensatory strategies with the aim of maximising a patient’s comfort and reducing any distressing symptoms which may arise.

SLTs provide specialist expertise and leadership to the hospice multidisciplinary team, to support patients and families in challenging decisions around alternative feeding and/or acknowledged risk feeding. Supporting people’s wishes to eat and drink where there is a significant risk of aspiration or choking can be extremely worrying for staff, and yet may provide critical quality to people’s lives. Empowering staff to be aware of, and work supportively alongside, risk is a challenging element of Rehabilitative Palliative Care where SLTs offer leadership and guidance on how to constructively manage the risk while enabling patients’ autonomous choice.

Speech and language therapy roles are extremely rare in hospices and subsequently patients and families are deprived of dedicated SLT expertise to optimise communication and swallowing function essential to quality of life.

To provide comprehensive Rehabilitative Palliative Care, specialist speech and language therapy must be available to all patients receiving hospice support.

Eleanor Davies, Palliative Care Speech and Language Therapist, St Joseph’s Hospice
A clinical example of Rehabilitative Palliative Care in practice

John, a patient with advanced COPD, is admitted to the hospice for a ‘symptom control’ admission to better manage his breathlessness and anxiety. The joint assessment with the doctor and physiotherapist begins by asking John: What is most important for you to do in the next few weeks? He replies that he wants to get home to his wife, Mary, as soon as possible; he then hesitantly explains that he also wants to be able to walk up to the toilet on his own without being incontinent, as he has had a couple of ‘accidents’ and feels terribly embarrassed that Mary has to help clean him up. The worry of this happening again has made him feel very anxious. Note – the patient does not mention his breathing once.

Contrast this with the response the professionals are likely to illicit by asking: We understand you have been having some difficulty with your breathing recently, tell us about that...? This approach immediately narrows the discussion to a symptom focus, failing to establish the wider context of those symptoms in terms of function and personal priorities. A problem-centric approach can also serve to disempower the patient by focusing on what they are finding difficult, with little attention to what they are managing or achieving.

Together John, Mary and the professionals agree on two person-centred goals:

1) To be able to walk up to the toilet independently without episodes of incontinence

2) For John to return home as soon as possible

The multidisciplinary team document his goals in his clinical notes and collectively formulate an action and coping plan to support their achievement. This involves:

- **doctors**: optimising John’s symptom control of both his breathlessness and continence

- **physiotherapists**: providing John with a walking aid and working on self-management strategies to manage his breathing and anxiety including provision of a handheld fan, pacing, breathing control techniques

- **occupational therapists**: early involvement to begin proactive discharge planning which includes assessment of John’s home environment with adaptations to his bathroom to help safely transfer on and off the toilet, and forward planning so he doesn’t leave mobilising to the toilet until the last minute when he really needs to go

- **nurses and support assistants**: encourage John to get dressed into clothes himself each day and enable him to walk up to the toilet independently as he wishes to at home; they also order a urinal bottle for emergency use so that John has a back up plan

- **social worker**: providing psychological support to John about his anxiety, fear of being a burden and support to Mary as the main carer.

At the multidisciplinary team meetings the team members discuss how their contribution is supporting John to work towards his goals, including any challenges or setbacks. At the multidisciplinary ward round, team members review progress with John and Mary and give positive feedback that he has consistently walked independently to the toilet over the past week without episodes of incontinence. When John and Mary express their anxieties about managing at home on their own, the team suggest a graduated discharge. John goes home for the afternoon with Mary and then returns to the hospice. While at home he walks up to the toilet by himself with no problems. He has the urinal bottle beside the bed and knows he can use this on ‘bad days’ or overnight. Both are pleased the visit went well and feel ready to return home the following day.

By embedding a Rehabilitative Palliative Care approach, the multidisciplinary team has collectively supported John to achieve his goals: enabling him to successfully return home to his wife, empowered to self-manage his condition on their own.
Summary of key points

Rehabilitative Palliative Care in practice must include the following core elements:

- **Person-centred goal setting**: to tailor multidisciplinary support to address patients’ priorities.

- **Focus on function (beyond symptoms)**:
  - to ensure all members of the multidisciplinary team proactively recognise change in patients’ function and take appropriate actions to enable patients to maintain and, where possible, regain function
  - to ensure holistic symptom management optimises both patient comfort and their ability to function to their fullest potential

- **Enablement**: to empower patients to have maximum choice and control over their own lives – through all members of the multidisciplinary team actively creating opportunities for patients to choose what they want to do, to undertake what they can themselves and to provide just the right amount of support to meet patients’ individual needs and preferences.

- **Supportive self-management**: to enable patients to ‘take charge’ – through a consistent multidisciplinary approach which encourages patients (and families) to play an active role in managing their illness, and the effects of their illness, themselves.
If hospices are committed to working towards a model of Rehabilitative Palliative Care then they will need to attend to:

- the culture of care
- the skills of their workforce

**Attending to the culture of care**

Hospices need to be able to tailor support to enable people to live well alongside illness, while maintaining quality end-of-life care for those that are dying. To do this effectively we need to be able to hold two paradigms in balance – one of enablement and one of care – tailoring these to each individual’s needs. These paradigms are in no way mutually exclusive. Enablement is still caring and nurturing, but it attempts to preserve choice, participation and autonomy and, likewise, care delivered in the right way can be enabling.

**Avoiding the detriment of over-caring**

People with a life-limiting or terminal illness are often vulnerable people, facing the ultimate threat to their own existence: impending and inevitable death. In caring for this group of people hospices should not be ‘doing for’, rather we should ‘be alongside’.

While all hospice staff would quickly appreciate the detriment of under-caring – of leaving a patient with their needs unmet – how many hospices have stopped to consider that over-caring can be as detrimental to patients and families as under-caring. Despite well-meant intentions, providing care where it is not needed can actively deprive patients of an opportunity to do something for themselves. In hospices, where a culture of care dominates, unintentional over-caring can diminish patients’ function, independence, autonomy and dignity, eroding patients’ confidence and ability to do things for themselves.

**Embracing a culture shift towards enablement**

Hospices excel in providing total care to patients and their families at the end of life, but as we care for greater numbers of people earlier in their illness we need to diversify our care approach. A starting point is to challenge the assumption that all people with advanced illness want and need ‘care’. Instead, hospices need a bottom-up approach to service provision, founded on patients’ priorities for normality and functional independence. With these at the forefront of our consciousness, hospices can begin to offer a spectrum of support from supportive self-management through to total care (Figure 5), where the balance of enablement and care provision are tailored to each individual’s needs and wishes.

This approach, known as enablement, lies at the heart of Rehabilitative Palliative Care. It is the bridge between caring and fostering autonomy. It is the important shift in hospice care to place living before dying.
The enablement paradigm

- Starts from the underpinning assumption that a person would like to choose if they want or need support.
- Focuses on providing support to a person (rather than care to a patient).
- Begins by ascertaining what support or assistance a person would like and how they would like this (before automatically providing it).
- Provides support which involves ‘being alongside’ or ‘doing with’ the person (rather than a default of ‘doing for’).
- Enables people to play an active role in their support and care whenever possible.
- Is always led by peoples’ priorities, goals and preferences (as opposed to professionals’ needs to ‘care for’ patients or ‘fix’ their problems to make everything better).
- Promotes choice and fosters independence.
- Is empowering and nurturing.

Truly personalised hospice care recognises that not everyone wants or needs care and knows that sometimes providing less can actually mean we are providing much, much more. By shifting hospice culture to deliver enablement alongside care – just the right amount of support, at the right time, in the right way – we can be confident we are preserving and nurturing patients’ self efficacy, dignity and sense of self value.

Adopting and embedding a culture of Rehabilitative Palliative Care

To successfully adopt a culture of Rehabilitative Palliative Care and embed it actively in everyday hospice practice, three core ingredients for culture change – values, language and behaviours – must be addressed. Successful culture change requires a shared understanding of the new culture we are aspiring towards, which must start by establishing and eliciting buy-in to the values underpinning it. This is what makes the change ‘valuable’ and forms the foundation and motivation for the desired behaviour change.
1. Organisational values that support Rehabilitative Palliative Care

The values of Rehabilitative Palliative Care are those dominant in the priorities of people living with advanced illness – choice, autonomy and dignity. Each of these is important and relevant to patients at all stages of illness. They are values of our evolved society that hospice staff can relate to on a personal and professional level.

In hospices committed to Rehabilitative Palliative Care, their organisational values will reflect the intention of the values of rehabilitative care. These in turn influence strategic priorities and how they are achieved.

Research has shown that in hospices where senior management teams understand and value the contribution of rehabilitation, the practice of Rehabilitative Palliative Care is further evolved. Hospice senior management teams have traditionally included doctors and nurses – the predominant staff groups in UK hospices. As a consequence, decisions about palliative rehabilitation provision are frequently made by people for whom rehabilitation may not be a primary concern. This highlights an important need for closer engagement between senior management teams and allied health professional leaders, to ensure the value of rehabilitative approaches are recognised and prioritised at an organisation level. Some hospices, depending on their strategic direction, will wish to incorporate allied health professionals on their leadership teams. Examples of where organisational culture and strategy has been strongly influenced by a rehabilitative agenda include St Christopher’s Hospice and St Joseph’s Hospice, the latter of which has an overarching goal pertaining to rehabilitation in their current three to five year strategic plan. St Christopher’s Hospice has a value related to empowerment alongside compassion.

St Joseph’s Hospice strategic goal 2015-18:

“Help build the capacity of our local communities to be well informed, to support each other and to enable people to care for themselves and remain independent for as long as possible.”

2. Language of Rehabilitative Palliative Care

To establish a collective understanding of Rehabilitative Palliative Care we must first establish a common language to ensure that when discussing Rehabilitative Palliative Care everyone knows what this means and interprets it within the same framework. As we have seen in earlier chapters, misperceptions regarding rehabilitation in the context of palliative care abound and these need to be brought out into the open in a reflective discussion from which a constructive shared understanding can be agreed.

To establish a culture of Rehabilitative Palliative Care within hospices we must critically appraise the language we use and be prepared to change this where it is no longer fit for purpose. A shift in language drives a shift in behaviour. In hospices, where the care paradigm dominates, the use of ‘care’ focused language is all-pervasive. Consider for a moment how frequently we use the word care: ‘palliative care’, ‘care plans’, ‘healthcare assistants’, ‘carers’, ‘home care’, ‘respite care’, and the list goes on. Hospices market their collective services as ‘hospice care’, yet have we ever stepped back to consider that this may reinforce a public message that hospices focus on ‘care’ of the dying as opposed to support of the living? We use the word care unconsciously. It has become assimilated into our practice at an automatic level that makes it feel instinctive, to the point that we never stop to think whether it is appropriate for the people we serve.

People living with advanced illness want to be supported to maintain physical function, independence and normality. Now consider this in the care context: people living with advanced illness want to be ‘cared for’ to maintain physical function, independence and normality – it just doesn’t fit. If we mean to create space to integrate an enablement paradigm alongside our culture of care provision, hospice language must change to reflect this.
The language of Rehabilitative Palliative Care is an active language. Rehabilitative Palliative Care ‘offers’ ‘support’ to ‘people’ ‘living’ with advanced illness and their ‘families’. Contrast the message this gives with the language ‘provides’ ‘care’ to ‘patients’ with advanced illness and their ‘carers’.

As hospices describe their work – for potential users, funders, the public and other stakeholders – careful attention is required to the words we use to convey a commitment to a rehabilitative model.

3. Behaviours that reflect the philosophy of Rehabilitative Palliative Care

With the foundations of shared values and a common language of Rehabilitative Palliative Care in place, the transformation of a culture from concept to practice is realised through behaviour change. New thinking must be put into action, new actions must be put into daily practice and new behaviours must be adopted as best practice.

The key to Rehabilitative Palliative Care being successfully integrated in hospice services lies in the collective understanding, buy-in and behaviour change across all levels of the hospice organisation. This includes hospice leadership at board of trustee and senior management team level, allied health professionals, clinical leaders and all members of the multidisciplinary team. Hospices are encouraged to utilise the checklists throughout this document to evaluate how well they are currently delivering Rehabilitative Palliative Care and to consider how specific recommendations could be successfully integrated into local practice to address any gaps identified.

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**Rehabilitative Palliative Care is an explicit priority in hospices’ strategic direction**

- The senior management team and hospice trustees understand and recognise the value of Rehabilitative Palliative Care at an individual, organisation and economic level.
- Rehabilitative Palliative Care is represented in the hospice’s values and as a strategic priority in their strategic plans.
- The hospice has a robust operational plan to support the culture change and successful implementation of Rehabilitative Palliative Care across clinical services.
- The hospice has established a multidisciplinary Rehabilitative Palliative Care work group, including at least one member of the senior management team, to collaboratively take forward the enablement agenda.
- Senior managers actively engage commissioners and funders to resource Rehabilitative Palliative Care initiatives.
- The hospice fundraising and marketing teams understand Rehabilitative Palliative Care and promote hospice support which focuses on life and living to service users and the general public.
Rehabilitative Palliative Care offers a refreshing public health approach to meet the challenges of an ageing population, living with chronic disease and disability.

The focus of Rehabilitative Palliative Care on early, proactive intervention, reduction of avoidable decline in function, self-management, nonpharmacological symptom control and constructive coping strategies for patients and families, not only has benefit implications at an individual level for those in the last years of life but also at a population level. Rehabilitative Palliative Care has the potential to help avoid unnecessary hospital admissions, reduce the need for domiciliary social care and care home placement, and to offer an alternative to overburdened GP practices where patients whose primary complaints of increasing disability, frailty and fatigue have little to be gained through medical management.

Forward thinking commissioners and leaders of hospice and health and social care will recognise Rehabilitative Palliative Care as a vehicle to optimise wellbeing of people in the last years of life, with an essential contribution to make to integrated care and cost efficiencies across the system.

I personally have been convinced by the Rehabilitative Palliative Care approach and believe it must be part of the future offer; not just for patients with advanced illness receiving hospice services but to optimise health and wellbeing of all those in the last years of life, benefitting both our local communities and the wider health economy.

Liliana Risi, GP Clinical Lead Primary Care Quality, Tower Hamlets CCG

Successes and innovations: Multidisciplinary Rehabilitation Working Group

Background: Over the last five years, allied health professionals at St Christopher’s have been developing gym-based exercise groups with great success – reflected in increased numbers, attendance, and in a formal (published) evaluation of physical and wellbeing based measures and patient feedback. This also prompted the title for two study days for allied health professionals: ‘Rehabilitating the Dying’ and ‘Life, Death and Exercise’. Both were repeated due to sell-out attendance.

However, while physiotherapists and occupational therapists were successfully developing palliative rehabilitation, at St Christopher’s there was little overlap into other disciplines and traditional models of medical care:

- A patient on the ward had been washed in bed in the morning by the nurses, and then came down to the rehab gym where they were able to work on the treadmill and exercise bike, and then afterwards returned to the ward where they ate lunch back in bed, all the while wearing their pyjamas.

- Another patient had been at home able to attend to his own personal care and the next day on admission to the hospice had been washed and dressed by healthcare assistants, in the bed. When asked why he had not got up and asked to get dressed he replied: “I didn’t think I was allowed”.

- Another patient was visited at home in the morning by a clinical nurse specialist and then travelled in as an outpatient to attend the gym in the afternoon.
As this incongruity was explored by members of the multidisciplinary team, there was acknowledgement of the need to move from a traditionally paternalistic attitude towards a more rehabilitative approach and that this was in fact the original vision of palliative care that Dame Cicely Saunders had: helping patients to live until they die.

How does this model work in practice?

We established a Multidisciplinary Rehabilitation Working Group, including staff from different locations (inpatients, community, day services) and disciplines (social work, nursing, complementary therapy, doctors, arts) alongside representation from our senior management team. It was widely agreed that rehabilitation cannot be something that allied health professionals do in isolation in the gym, but a rehabilitative approach needed to be embraced by all the multidisciplinary team.

Over six months the group met four times and began to explore some key questions about practice, care delivery and professional attitudes. In order to affect change, subgroups were also formed for the different locations of service delivery, eg inpatient unit, community, to establish short and long-term goals as well as ‘quick wins’ that could be implemented immediately.

For example:

- encouragement of ward patients to get up, wash in the bathroom, get dressed, self-medicate, eat meals away from the bed area
- encouraging self-care and independence on the ward rather than always offering assistance
- working with patients to make plans for the day using timetables and diaries if needed
- focused multidisciplinary team meetings on goals rather than problems
- a language change, eg from “what’s the matter with you?” to “what matters to you?”
- replacing a nursing post with an occupational therapist/physio when a vacancy came up in day services
- some healthcare assistant quick rehab training slots with physio working with real patients on mobility.

Looking to the future, our shared goal is to cultivate a multidisciplinary culture of enablement and patient empowerment (as opposed to over caring and institutionalisation), where troublesome and debilitating symptoms are controlled not as an end in itself but as a step towards facilitating achievement of a goal or a wish that maximises the quality of someone’s life right up to death.

Helena Talbot-Rice, AHP Lead, St Christopher’s Hospice
Allied health professional expertise and leadership

Allied health professionals (AHPs) are experts in palliative rehabilitation and are frequently best placed to lead hospices to establish a rehabilitative culture with greater emphasis on enablement. While it may seem obvious, an essential starting point is to ensure that all hospices have access to AHP expertise.

UK policy recognises rehabilitation as an integral component of a holistic palliative care approach and recommends that all patients have access to physiotherapy, speech and language therapy, occupational therapy and dietetic expertise. The unique contribution of allied health professionals in palliative care are detailed in Appendix 1. The guidance explicitly recommends that patients with complex palliative care needs have access to “highly specialist assessment from expert AHPs” who are “advanced practitioners working predominantly or exclusively in palliative care who provide expert advice and input for clearly defined rehabilitation needs”. Despite this, a recent benchmarking survey in UK hospices revealed that rehabilitation was not always a core component of hospice service provision; patients rarely had access to expertise across all AHP disciplines and AHP staffing did not relate to overall staffing or population size. Of the 41 hospices who took part in the survey the median number of full-time AHP equivalents was one to two, most frequently physiotherapists followed by occupational therapists. A minority of UK hospices employed dietitians or speech and language therapists, and one hospice employed no AHPs.

Perspective: Palliative care physiotherapist

Physiotherapists offer a vital and dynamic approach to Rehabilitative Palliative Care. Not only can physiotherapists deliver high quality physical assessments and treatments tailored to an individual’s need, but these can be utilised across a range of advanced diagnoses and uncontrolled symptoms. Their proactive approach, with attention to quality of life and risk management in dual measure, allows them to work in partnership with patients to plan for future challenges and prevent avoidable crises.

Everything physiotherapists do has an emphasis on enablement, which empowers patients to achieve their personal goals. In doing so, it endorses a self-management model and by focusing on the patient’s own priorities it minimises unintentional disempowerment which is sometimes seen in the evolving model of hospice care. The utilisation of physiotherapists as extended scope practitioners in a hospice setting presents an innovative and cost-effective avenue for symptom management in an area of service provision historically lead by doctors and consultants, which warrants active consideration for the future.

Physiotherapists’ pragmatic and solution-focused leadership skills place them in a prime position to lead on service and professional development, and they have an essential role to play in educating and supporting the multidisciplinary team in delivering a Rehabilitative Palliative Care approach. An enabling approach is often embraced by palliative patients, it promotes a service with an emphasis on living well and being as independent as possible for as long as possible. This in turn will decrease carer burden, allow patients to stay home longer and reduce the demand on hospice resources, which is necessary if we are to be sustainable in the future. In order for Rehabilitative Palliative Care to be truly successful, it needs to be a united holistic multidisciplinary approach which is upheld organisationally in order to allow patients to benefit from the full potential that it has to offer.

Lara Cowley, Specialist Palliative Care Physiotherapist, St Wilfrid’s Hospice
AHP leadership

AHPs bring a new, refreshing perspective to holistic support and hospice leadership. AHPs are pragmatic, solution-focused thinkers whose clinical skills in supporting patients to surmount or work around limitations translate naturally into the leadership arena. The biopsychosocial model which actively underpins AHPs professional culture bridges nursing, medical and social perspectives, making AHPs well placed to unite and engage the unique strengths of different team members to ‘think outside of the box’ and innovate service delivery, while their aptitude for considered and informed risk taking means they can contribute confident leadership to hospices to risk trying a different approach.

Perspective: Palliative care clinical manager

Diversity in leadership – what difference does it make?

Leadership is important. Ultimately a leader’s clinical background (if they have one) will be irrelevant because good managers and leaders have some awareness of their own lens through which they view the world and are open to seeing through others. But what happens when those other lenses and perspectives are entirely missing?

I am relatively new to hospice care, being in my current middle management role for just over three years and being in a community palliative occupational therapy role on the periphery of a hospice for two years before that. In that time I have observed and learned a lot about the history of palliative and hospice care alongside the current context, but perhaps most importantly, about the culture of hospice care.

I recognised early on that:

- rehabilitation and a rehabilitative approach was not as accepted or practiced as in my previous NHS roles
- there was a huge disparity in what, indeed if any, AHPs were employed in hospices and that this does not reflect the NICE guidance
- most leadership roles in hospices are only open to nurses
- palliative care education and training has been established to be nurse focused and for AHPs and other professions to take part they may have to adapt the programme
- leadership is recognised as a need for the future of palliative/end of life care but investment is limited to nurses only even as recently as 2014.

These days AHP and other health and social care professional roles are integrated into the NHS to form multidisciplinary teams; however, this is not uniformly the case in hospices… yet.

With my interest piqued by what I had observed, I conducted research on the provision of palliative rehabilitation in adult UK hospices when I completed an MA in Hospice Leadership in 2013. I found some interesting things to go some way to explaining why rehabilitation seemed to sometimes rub against, rather than blend with, hospice care. The main finding: that there is a dominant culture of nurses and ‘caring’ in hospices, and that currently the enabling paradigm that underpins the ethos of AHPs can clash with this. However, a few hospices are joining the two paradigms – and this new paradigm is helping hospices meet the growing and complex needs of their communities in a more sustainable way.
Perspective: Palliative care clinical manager
(Continued)

So what? Without AHPs and other health and social care perspectives available and included at leadership and decision-making levels in hospice organisations – hospices have huge blind spots. When considering an ageing population, with multi-morbidities who will live longer with more associated disabilities in a climate of limited resources, AHPs do have alternative ideas on how to support those people sustainably through hospice services. AHPs are problem solvers, with pragmatic and valuable contributions to make – and in my experience are often at the forefront of supporting change to improve services. The AHP workforce is well trained, motivated and current – most have established AHP and/or discipline specific groups affiliated with their professional bodies such as ACP0PC (Association of Chartered Physiotherapists in Oncology and Palliative Care) and HOPC (College of Occupational Therapist Specialist Section in HIV, Oncology and Palliative Care). Why would hospices not want to develop such people into leadership roles and have management and leadership opportunities available and open to them?

The drawback of hospices being almost singularly ‘nurse’ focused at the leadership level is that it will almost certainly remove many alternative possibilities that could contribute to the ‘hospices fit for future’ dialogue that we are currently having. In the same way that AHPs bring a different perspective to the MDT and holistic care of the patient, they bring a different perspective to the solutions needed right now to meet the needs of people living with and affected by life-limiting illness.

So diversity adds values, this is something we already know, but it has yet to be translated into the hospice leadership context. I challenge hospices: look at your management structures, in fact go further, look at your clinical structures too – do you have AHPs? Are they truly part of the multidisciplinary team or do they sit on the sidelines? Are your management and leadership roles open to professions other than nurses? Are the same education opportunities available? And if not, what steps will you take to address this – now – for the future?

References:


Penny Wosahlo, Independent Living Team Manager, Farleigh Hospice
Hospices invest in allied health professional expertise and leadership

- The hospice employs (or subcontracts) more allied health professional (AHP) disciplines – physiotherapy, occupational therapy, speech and language therapy and dietetics – to ensure patients have access to a comprehensive range of rehabilitation expertise in line with NICE guidance recommendations.

- The hospice capitalises on the unique contribution of AHPs as autonomous practitioners including:
  - AHP triage and first contact assessment of patients (physiotherapists possess robust skills in physical examination including functional, neurological and respiratory assessments. They are ideally placed to undertake comprehensive subjective and objective assessment of patients, contributing essential assessment skills that other professions may not possess).
  - AHPs lead on the management of patients receiving predominant input from hospice AHP services. This may be appropriate for patients whose primary needs relate to function, mobility or symptoms amenable to nonpharmacological symptom management in a stable phase of their illness. AHPs maintain close liaison with multidisciplinary colleagues to ensure robust governance structures and safe transfer of care to other professionals in response to patients’ changing needs.
  - AHPs lead the multidisciplinary team in the shared management of patients admitted for palliative rehabilitation and key work these cases.
  - AHPs are supported to lead the multidisciplinary Rehabilitative Palliative Care agenda across the hospice. This involves:
    - AHP resourcing sufficient to enable AHPs to work in leadership roles and ensure AHP clinical service needs are met
    - AHPs leadership roles are created with sufficient seniority to influence change across the organisation
    - AHPs are actively invited to engage with senior management and other leadership forums across the hospice.
  - The hospice supports the development of extended scope practitioner AHP roles, eg AHP prescribers and AHP consultants.
  - The hospice supports AHPs to actively participate in research to build the evidence base for palliative rehabilitation.
  - The hospice actively seeks to attract AHPs to senior leadership roles – ensuring these are reviewed and where appropriate opened to AHPs when vacancies arise.
Success and innovations: Multidisciplinary First Contact Assessment Team

The St Joseph’s Hospice’s First Contact Team (FCT) is a multidisciplinary model of triage and assessment, developed in 2012 in response to a need to improve patient and carer access to all the services of St Joseph’s Hospice. We recognised a need to improve the quality of our services, to improve the response times for patients, their families and carers who were referred, and to ensure all those referred were appropriately signposted to the whole range of services provided by the hospice.

From the outset, the model has pioneered holistic assessment through the introduction of a multidisciplinary approach to triage, utilising the skills of health and social care professionals across the hospice team.

How does the model work in practice?

Following comprehensive telephone triage by a team of trained administrators and clinical nurse specialists, new referrals to the hospice are discussed at a daily multidisciplinary morning meeting. Here the professional or professionals best suited to undertake the First Contact assessment of the patient’s (and/or carers’) needs is identified and agreed. This may be undertaken independently or as a joint assessment, either in the community or outpatient settings.

How does this model best support patients’ needs and priorities?

- Patients have access to the multidisciplinary team skills and knowledge best suited to assess their needs. For example, patients whose presenting issues relate to compromised mobility and function, breathlessness, fatigue or lymphoedema are first assessed by a physiotherapist. Physiotherapists bring specialist skills in physical assessment including the ability to undertake comprehensive assessment of respiratory and neurological systems, alongside function. This represents a significant benefit for patients, eg whose history suggests a risk of malignant spinal cord compression or acute exacerbation of COPD, and can reduce the need for multiple professional assessments.

- Utilising the skills of the multidisciplinary team in planning care from the start of the hospice journey, patients and their families can now hope to receive all the appropriate services that the hospice offers in a proactive, timely way.

- Patients can be supported at an earlier stage in their illness by accessing appropriate multidisciplinary team services relevant to their needs and preferences. Rehabilitation can be a positive gateway into hospice services, helping to engage patients earlier or when they may be reluctant to use hospice services due to well-recognised stigma and fear.

- Patients are supported by a lead professional in the multidisciplinary team which corresponds to their needs. For example, if a patient is stable and their predominant input is from the physiotherapy service, then the physiotherapist may take this lead role. The lead professional maintains strong communication with the wider multidisciplinary team to ensure robust governance and safe, timely transfer of care to involve other services when a patient’s needs change.

Nigel Dodds, Nurse Consultant – Community Palliative Care, St Joseph’s Hospice
Development of a rehabilitative workforce fit for the future

A founding principle of Rehabilitative Palliative Care is that it is multidisciplinary, with all members of the hospice team actively contributing to an enabling approach irrespective of profession, qualification or seniority. Because Rehabilitative Palliative Care represents a new way of thinking for many hospices, it is important to identify where existing staff may require development and support to competently deliver enablement-focused support and where new staff with different skill sets, experience and expertise may be needed. This highlights two key areas of workforce development for attention: education and recruitment.

Education: Hospices educate and train staff to understand and competently deliver enablement-focused Rehabilitative Palliative Care

- AHPs work in partnership with multidisciplinary colleagues to raise the profile of Rehabilitative Palliative Care and actively lead/develop/contribute to rehabilitative education initiatives.
- All patient-facing staff have Rehabilitative Palliative Care responsibilities reflected in their job descriptions.
- All staff with Rehabilitative Palliative Care responsibilities in their job descriptions are required to attend practical mandatory training on enablement. This could include development of existing mandatory training programmes on moving and handling to be widened (under AHP leadership), to encompass moving and handling as one element of a comprehensive rehabilitative approach alongside:
  - principles and core elements of Rehabilitative Palliative Care
  - practice of enablement approaches with real patients (who share their perspectives, guide and provide feedback to staff)
  - clinical reasoning to inform how and when elements of Rehabilitative Palliative Care should be safely applied or tactfully withdrawn, including informed risk taking.
- Clinical staff provide evidence of Rehabilitative Palliative Care practice in their annual appraisal relevant to roles and responsibilities.
- Joint working is established between AHPs and nursing staff as routine practice on the inpatient unit, to model Rehabilitative Palliative Care approaches, learn from and support each other.
- Perceived or actual barriers to delivering Rehabilitative Palliative Care approaches across the multidisciplinary team are actively sought out and explored. Collective solutions are identified and learning is incorporated into enablement training.

Continued on next page...
Education: Hospices educate and train staff to understand and competently deliver enablement-focused Rehabilitative Palliative Care (Continued)

- Healthcare assistants (or equivalent roles), who provide the majority of support to patients with ADLs, receive comprehensive training and support to ensure they are competent and confident to provide enablement support:
  - healthcare assistants have explicit responsibilities to provide enablement focused support in their job descriptions linked with competencies to reflect these
  - healthcare assistants spend a protected rotation working alongside the AHP team to learn rehabilitative skills, apply these in practice with patients in a supportive learning environment and have competencies signed off
  - nursing managers are responsible for ensuring healthcare assistants’ competencies are upheld and actively integrated into daily practice.

- AHPs actively contribute to multidisciplinary journal clubs and other hospice wider education events to share current evidence and best practice on rehabilitation in palliative care.

Successes and innovations: Enablement-focused Wellbeing Assistant roles

In 2012, St Wilfrid’s Hospice recognised and responded to an opportunity to change their provision of assistance support across wellbeing services which provide outpatient and day therapies to people living with advanced illness. The innovation involved redesigning the roles of existing healthcare assistants to include provision of enablement, rehabilitation and holistic assessment to better meet patients’ needs in the most cost efficient way.

Creating Wellbeing Assistants was achieved through:

- renaming the roles as Wellbeing Assistants
- adapting existing job descriptions to include explicit responsibilities pertaining to rehabilitation, enablement and holistic patient assessment
- developing a programme of competencies, linked to pay incentives within the level three banding
- developing a training programme delivered by AHPs to equip staff with skills and knowledge required for new roles, including expectations of Wellbeing Assistants, understanding rehabilitative and enablement approaches, contribution of AHPs, nonpharmacological symptom control strategies for common symptoms such as breathlessness, simple equipment provision, therapeutic manual handing and undertaking a straightforward holistic assessment
- AHPs providing on the job training and support to Wellbeing Assistants to embed learning into daily practice.

Impact of Wellbeing Assistant roles:

- Following triage by a professional, Wellbeing Assistants undertake straightforward assessments of new patients referred to Wellbeing Services – freeing up AHPs to focus on more complex or specialist assessments.
- Wellbeing Assistants lead generic gym classes – enabling greater numbers of people to access and benefit from rehabilitation services without increased AHP resource.
**Successes and innovations: Enablement-focused Wellbeing Assistant roles**
(Continued)

- Wellbeing Assistants demonstrate improved clinical reasoning, enablement-focused support, champion a rehabilitative approach and have greater job satisfaction.

**Challenges and keys to success**

The greatest challenge relates to getting staff buy-in, as many healthcare assistants don’t perceive rehabilitation to be relevant to their role. Transforming the initiative into a success required leadership from senior hospice managers to bring staff on board and a commitment from AHPs to prioritise investment of time and resources to develop Wellbeing Assistants with the knowledge that the gains will be reaped in the future.

We are seeing real benefits of the Wellbeing Assistant model, both in supporting patients’ priorities and delivering service efficiencies. Our aspiration is to increase the number of healthcare assistants trained in enablement and Rehabilitative Palliative Care to roll the model out in our inpatient unit in the future.

*Emily Bowler, Occupational Therapist and Wellbeing Manager, St Wilfrid’s Hospice*

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**Recruitment: Hospices proactively identify gaps in workforce skillset and undertake targeted recruitment to build rehabilitative experience and knowledge across multidisciplinary teams**

- The hospice employs a range of AHPs – including physiotherapy, occupational therapy, speech and language therapy and dietetic – at senior levels (Band 7) to provide advanced practitioner expertise but also at more junior levels (Band 5 and 6) to attract and develop new generations of palliative care AHPs and provide career development opportunities.

- The hospice establishes new roles to actively integrate traditional healthcare assistant and rehabilitative roles. Organisations who have adopted this model have used the terms ‘rehabilitative support’, ‘multidisciplinary’, ‘wellbeing’ and ‘enablement care’ assistants.

- Recruitment to hospice nursing and ‘enablement care’ assistant roles target those with experience in stroke or elderly care rehabilitation to bring rehabilitative experience and competence to the team.

- AHPs are invited to be part of the interview panel.

- Recruitment to palliative care medical roles target geriatric and care of the elderly experience.

- The hospice discerningly recruits and trains volunteers to provide rehabilitative support to patients both in inpatient and community settings.
Rehabilitative Palliative Care: a challenge for the 21st century

Successes and innovations: Empowered Living Team Rehabilitation Volunteers

The Empowered Living Team (ELT) is a project where volunteers are comprehensively trained and supported to provide rehabilitative support to patients in their own homes. The project was developed in response to a recognised need for providing greater individualised support to patients to help adopt self-management behaviours and embed these with confidence into their daily lives. Due to limited allied health professional resource to provide this level of support in the community setting, the team at St Joseph’s developed an innovative model to utilise volunteers in this role.

How does the model work in practice?

Volunteers undergo a robust recruitment and screening process. They complete three days of training delivered by a multidisciplinary team which includes communication skills, boundaries to role, recognising change in patients’ condition and responding appropriately, alongside practical rehabilitative approaches including safe support of mobility and nonpharmacological symptom management strategies. Patients referred to the service are each assessed by a physiotherapist who formulates an Empowerment Plan for them focused around their personal goals. ELT volunteers work specifically to support this plan, working in partnership with patients on a weekly basis for eight weeks. They have access to telephone support from a palliative care physiotherapist and ELT Facilitator at all times and receive monthly group supervision.

How does this model best support patients’ needs and priorities?

This approach has enabled over 70% of patients to achieve their personal goals – adding significant quality to their lives. Many of these relate to confidence to access the community independently. The ELT has added an essential layer of support to hospice rehabilitation services and trends indicate it supports reduced utilisation of hospital and healthcare services. The ELT approach is a successful example of the use of volunteers in the community setting and of considered and supported risk in action. The ELT illustrates how just the right amount of rehabilitative support can make all the difference to enable patients to take back control and manage their own health and wellbeing.

Matthew Wheatley, Specialist Palliative Care Physiotherapist, St Joseph’s Hospice
Summary of key points

- If hospices wish to embrace Rehabilitative Palliative Care as a way of supporting people seeking their help, they must actively develop a culture of enablement and embed this in daily practice alongside our rich culture of care.

- This requires that they review their organisational values and ensure they reflect the values of choice, autonomy and dignity which underpin the rehabilitative approach. Such values influence, in turn, how their strategic priorities are identified and shaped.

- Hospices must consciously and critically appraise the language they use and be prepared to change this where it is no longer fit for purpose – adopting a common language of enablement.

- Hospices successful in this implementation will actively encourage behaviours that are consistent with Rehabilitative Palliative Care.

- Hospices engaged in Rehabilitative Palliative Care will ensure allied health professionals – including physiotherapy, occupational therapy, speech and language therapy and dietetics – are employed as core members of their multidisciplinary teams and are utilised to their full potential in expertise as autonomous practitioners and dynamic leaders of the future.

- Hospices who are committed to this approach will invest in developing their workforce across the board by:
  - integrating Rehabilitative Palliative Care in job descriptions of clinically-facing staff
  - proactively identifying and responding to training needs
  - undertaking proactive, targeted recruitment for rehabilitation skills and experience, across the multidisciplinary team, where this is lacking or could be augmented.
As hospices look to the future we face a time of unprecedented change. Not only is the demand for hospice support forecast to dramatically increase over the next 20 years but the needs of the population we support at the end of life are changing. People are living longer, with (frequently multiple) chronic diseases and their realities are complicated by increased disability, frailty and dependency in the years and months preceding death. More positively, there is a growing interest on the part of many to take control of their condition and its implications where possible. To be fit to respond to these challenges of the future we believe that hospices must be prepared to do things differently.

Rehabilitative Palliative Care presents fresh thinking on how hospices can prepare to be fit for now and the future. Rehabilitative Palliative Care is centred on patients’ personal goals and provides a culture of enablement, through which the multidisciplinary hospice team support patients to live their priorities. Rehabilitative Palliative Care optimises choice, independence, autonomy and dignity. It has potential to reduce disability and dependence, both on families but also on hospices and health and social care services, which on a wider scale translates into important cost economies.

As we think together about the opportunities and challenges that this shift represents we are encouraged on a number of fronts.

First, hospices have always been pioneering and person centred in their approach. Cicely Saunders established a movement that embraced change to meet the unmet needs of the dying. She believed that hospices should constantly evolve to best meet the needs of people seeking help from them. She always aspired that hospices enable people to live well, for as long as possible. We believe hospices will continue to find a way to do this, albeit with a changing group of beneficiaries.

Second, along the journey of writing this, we have met many inspirational allied health professionals, doctors, nurses and hospice managers who are strongly committed to adopting and refining a rehabilitative approach to palliative care. We hope that they will do it together, across the sector, learning from best practice and encouraging its development and replication across the UK.

Finally, as a physiotherapist and a nurse, we have brought different professional backgrounds and perspectives to this publication. Our debates and shared deliberations have been enriching and exciting for each of us. We want other professionals to engage in the same as a basis for finding the right way forward.

Our final word, however, is focused on our common ambition, so well articulated by Derek Doyle, another pioneer in hospice and palliative care. He talked of palliative care rehabilitation as being “the transformation of the dying into the living…the restoration of a patient to a person” (2004). We believe that through the adoption of Rehabilitative Palliative Care hospices will actively fulfil this vision.

Rebecca Tiberini, Specialist Palliative Care Physiotherapist and Therapies Services Manager, St Joseph’s Hospice
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The unique contribution of allied health professionals in palliative care

Palliative care physiotherapists:

- Work as autonomous practitioners offering specialist, evidence-based assessment, diagnosis, treatment interventions and guidance.

- Optimise patients’ quality of life by maintaining and improving physical function to attain the highest level of independence possible in advanced illness through:
  - robust clinical reasoning skills underpinned by knowledge of anatomy and physiology of advanced illnesses including oncological, respiratory, cardiac and neurological conditions and multiple co-morbidities associated with ageing
  - specialist skills in holistic assessment: utilising both subjective and physical assessment; including respiratory, neurological, musculoskeletal, lymphoedema and functional assessments, to systematically identify factors impacting on a patient’s ability to function and make clinical diagnoses
  - palliative rehabilitation: specialised interventions and guidance to optimise a person’s mobility and functioning by analysing, treating and managing impairments; including muscle weakness, fatigue, balance, breathlessness, pain, lymphoedema, anxiety, to work in partnership with patients to achieve their personal goals
  - advanced communication skills to help patients and their families proactively plan for the future, anticipate potential functional changes, avert functional crises and adapt constructively to the spectrum of losses related to functional decline in advancing illness
  - nonpharmacological symptom management of breathlessness, fatigue, pain, lymphoedema, anxiety in advanced illness through provision of specialist treatment interventions including personalised exercise prescription, manual treatments, provision of equipment and aids, rehabilitation and expert guidance
  - self-management education and strategies to empower patients and carers to understand and cope with symptoms, maintain function and participation in meaningful activities, reduce dependence on others and foster a sense of control and self efficacy
  - risk assessment, management and supportive risk taking: including comprehensive evaluation of patients’ safety to manage functional activities, recommendations to actively manage risks through provision of support, activity modification, use of equipment and aids and enabling supportive risk taking to support patient choice and quality of life even when risks are evident

Appendix

Continued on next page...
Palliative care physiotherapists: (Continued)

- expertise and leadership to the multidisciplinary team on:
  - Rehabilitative Palliative Care encompassing person-centred goal setting, functional assessment, enablement and self-management in the context of changing illness trajectories
  - complex moving and handling: risk assessment, personalised management plans, education and support to patients, carers and multidisciplinary team.

Palliative care occupational therapists:

- Work as autonomous practitioners offering specialist assessment, interventions and guidance specifically focussed around occupation. Occupation encompasses all ADLs and dying.

- Optimise a person’s quality of life by supporting maintenance of role, identity and sense of ‘self’ through participation in activities that are important or meaningful to them despite their disabilities or prognosis through:

  - specialist assessment of a person’s ability to function in the unique context of their physical environment and interpersonal relationships with attention to cognitive, psychological, social and physical aspects of a person:
    - analysis of the individual components of occupation to enable targeted interventions to modify or adapt the activity to support participation, independence and quality of life
    - cognitive and perceptual assessment to identify factors affecting a person’s ability to plan, sequence and execute activities in order to improve or maintain existing capacities
    - assessment of care and support needs to determine a person’s ability to participate in ADLs. With attention to both risk and independence in order to tailor support to enable personal choice and priorities while optimising safety, including analysis of carer’s ability to provide support
    - assessment of complex posture, seating, and manual handling issues in order to provide recommendations and interventions to manage pressure and other risks and to maximise participation in occupation
    - environmental assessment to evaluate a person’s functioning within their home (or other) physical and social environment to identify difficulties and risks and to help maintain the person within their own home and maximise participation in occupation
  - environmental adaptation, assistive technology and equipment prescription: to optimise safety in the home (or other) environment to enable people to be as independent as possible, re-engage with activities of purpose and meaning, reduce burden on carers and support people to achieve their preferred place of care and death
  - advice and guidance on symptom control and self-management strategies for fatigue, breathlessness, pain, anxiety and sleeplessness using a range of interventions to facilitate occupational engagement

Continued on next page...
Palliative care occupational therapists: (Continued)

- complex discharge planning: including environmental modification, equipment provision, rehabilitation, supportive risk management, care support recommendations, creative problem solving and leadership to the multidisciplinary team to enable a safe and timely inpatient unit discharge and thereby optimise inpatient service efficiencies and to achieve the persons preferred place of care and death
- adjustment to loss of occupational engagement due to progression of illness and a focus on the occupation of living with dying
- bridging between health, voluntary agencies and social care, as the occupational therapy profession trains and spans all these paradigms in terms of a biopsychosocial and occupational approaches, shared language and services
- leadership of a rehabilitative approach to palliative care.

Palliative care dietitians:

- Work as autonomous practitioners offering specialist, evidence-based assessment, diagnosis, interventions and guidance.
- Optimise quality of life by supporting patients and families to achieve good nutrition through:
  - **specialist knowledge of anatomy and physiology** of the gastrointestinal tract and the impact of disorders that impact on nutritional wellbeing in advanced illness such as cancers, neurological conditions and other illnesses that compromise nutritional intake
  - **specialist assessment of patients’ nutritional status** including change in appetite, Body Mass Index, specific nutritional deficiencies relating to macronutrients and micronutrients that impact on patients’ wellbeing
  - **specialist advice and interventions** to optimise ways of meeting patients’ nutritional requirements which range from:
    - minimising deterioration in nutritional status through early nutritional intervention
    - adapting food to make it as nourishing as possible, eg use of food fortification techniques, texture modification
    - supplementing nutritional intake to address specific nutritional deficiencies
    - calculating nutritional requirements and devising practical enteral feeding regimes that meet an individual’s nutritional requirements
  - **psychosocial support for patients and families** who have difficulty eating to explore issues such as loss of pleasure, compromise of personal relationships, exploration of relationship between eating and dying, accepting losses related to eating in a safe and supportive space
  - **leadership and expertise to the multidisciplinary team** around complex decision making in relation to artificial nutrition and hydration (enteral and parenteral feeding), including advance care planning and ethical consideration
  - **leadership of a rehabilitative approach to palliative care.**
Palliative care speech and language therapists:

- Work as autonomous practitioners offering specialist, evidence-based assessment, diagnosis, interventions and guidance.

- Optimise patients’ quality of life by supporting communication with family and others to enable people to express thoughts and feelings, and eating and drinking through attention to swallowing, allowing patients to execute choice and autonomy until death:
  - **specialist assessment of swallowing and communication**
  - **specialist knowledge of anatomy and physiology** of disorders of swallowing and communication in advanced illness and application to clinically reason and explore differential diagnoses
  - **specialist intervention and advice** to patients, families and multidisciplinary team on strategies to:
    - minimise secondary complications, such as aspiration, that may prematurely shorten life
    - optimise balance between safe swallow and quality of life gained through eating and drinking (even if this is associated with risks) through modification of food and fluid consistencies and compensatory techniques, eg modification of rate of eating, size of mouthful, position
    - optimise communication through use of alternative communication, eg alphabet/picture charts, iPad apps, eye gaze technology
  - **leadership to the multidisciplinary team** around complex decision making in relation to risk feeding, alternative feeding (NG/PEG) and advance care planning (assessment of mental capacity when a person’s communication is compromised, supporting communication through advanced technology)
  - **leadership of a rehabilitative approach to palliative care.**

These ‘Unique contributions of allied health professionals (AHP) in palliative care’ have been developed through the AHP Rehabilitative Palliative Care Consultation Event held at St Joseph’s Hospice on 1 May 2015.

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