

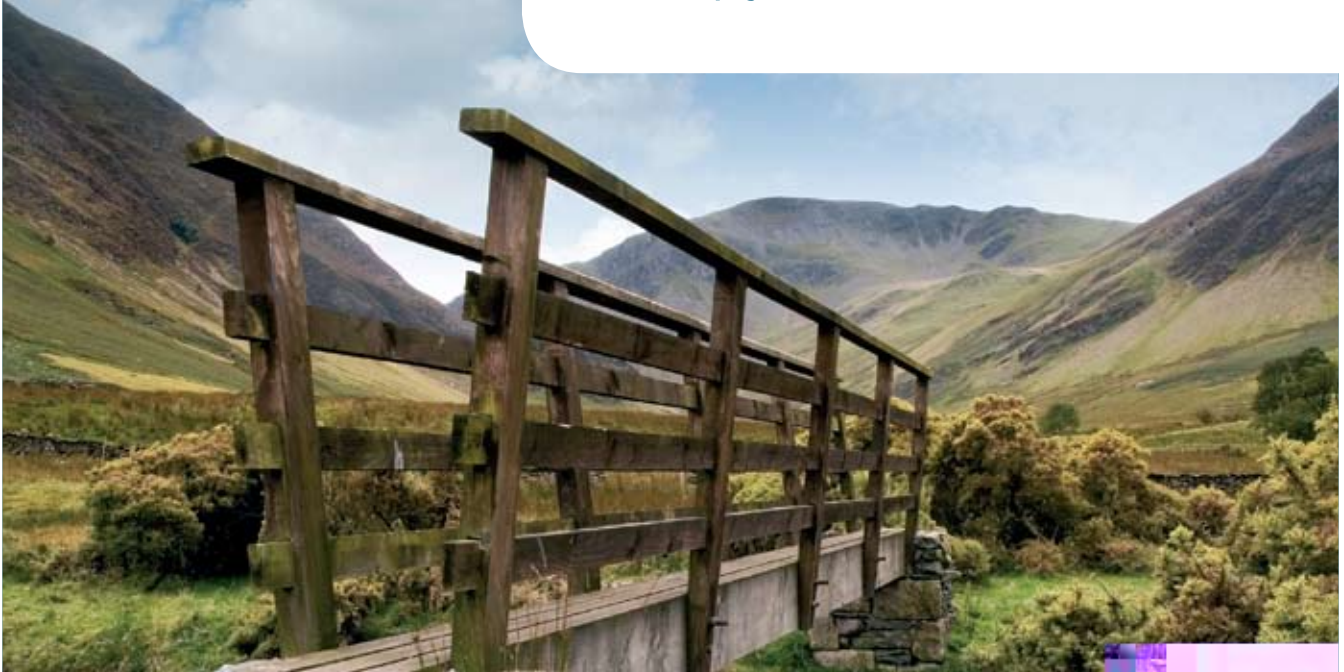


College of
Occupational
Therapists



National End of Life
Care Programme
Improving end of life care

The route to success
in end of life care – achieving
quality for occupational
therapy





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The care of people who are nearing the end of their lives is often complex and challenging. However, it can also be a privilege to be able to work with people at what is a very important and often intimate time. It is important that the right quality care is provided by the right people, in the right place and at the right time, and that staff receive support to carry out their role.

This publication not only provides an essential resource for occupational therapists, but is a valuable document for other health and social care professionals. Managers and commissioners will be able to clearly identify the unique core skills of occupational therapy and ascertain the actual and potential role occupational therapists have in the care of people facing the end of life. This therefore is a useful resource to promote the profession to commissioners, as end of life care will be a key priority and occupational therapists have an important role to play.

The publication is aimed at providing a practical and useful resource to enable occupational therapists working in a variety of settings to implement the end of life care pathway which was outlined in the *End of life care strategy: promoting high quality care for all adults at the end of life* (Department of Health, 2008)¹. It also enables all persons interested or involved in end of life care to increase their awareness of the role occupational therapists have to offer at each of the six steps of the end of life care pathway. What is particularly impressive about this publication is how the occupational therapy role is clearly detailed at each of the six steps of the end of life care pathway whilst also providing some very useful 'top tips' and case studies. The latter part of the document offers occupational therapists the opportunity to expand and debate the next steps which will hopefully lead to a further dialogue of issues to be pursued in the future.

To have a *route to success* document which focuses specifically on occupational therapy and the delivery of end of life care is fantastic in helping to define the unique contribution occupational therapists have to make in providing high quality care for people facing this phase of their life. Our thanks go to the authors, Tes Smith and Amy Edwards, for enabling the document to be produced.

It is hoped that this resource will enable every occupational therapy practitioner to engage with the end of life care pathway and feel confident in articulating and promoting with enthusiasm the occupational therapy role in end of life care.

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This guide has been developed by the National End of Life Care Programme (NEoLCP) as part of its *route to success* series and in conjunction with the College of Occupational Therapists (COT). It is largely based on views shared by occupational therapy practitioners, educators, students and managers, at a stakeholder event held in November 2010. The aim of the event was to produce a resource “by occupational therapists, for occupational therapists” and to enable dilemmas and debates to be discussed where the occupational therapy role is still perhaps uncertain. It is intended to be a practical tool, offering advice on what staff can do themselves, as well as how and when to access specialist help.

The guide will also be useful to health and social care professionals who work in

partnership with occupational therapists, in clarifying the occupational therapy role.

The guide:

- Supports proactive intervention for those reaching the end of life as well as the support required by carers
- Provides advice on what interventions may be appropriate at each step of the pathway
- Identifies the areas of knowledge with which occupational therapists should be familiar when working with people reaching the end of life
- Combines both health and social care, in particular recognising the valuable contribution made by the social care workforce
- Supports occupational therapy values of delivering holistic, person centred care.



Occupational therapists have shown a great deal of interest in developing their role when working with people at the end of life, but have requested assistance in defining exactly what that role should be. There are intuitive similarities between occupational therapy values and training (such as holistic assessment, person centred approach and highly developed communication skills) and the delivery of high quality end of life care, the key features of which are given in the end of life care pathway.

The desirable role will be discussed in this guide and includes:

- Promoting meaningful occupation
- Holistic assessment
- Use of communication skills, both when working with the person and his/her family and when co-ordinating intervention with other health and social care professionals and services
- Enabling the person to set realistic goals
- Advance care planning
- Vocational rehabilitation, when appropriate
- Giving support to carers, including bereavement support
- Providing support to people in care homes, including provision of training to families, carers, and housing and care home staff
- Promotion and maintenance of dignity

Whilst it is appreciated that financial and service constraints, as well as training, may preclude occupational therapists from fulfilling all aspects of the role, it is important that the desirable role is defined, in order to inform future decision making. It is hoped that this publication goes some way to providing that definition.

According to the 2008 *End of life care strategy*, high quality end of life care “should be available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere. Implementation of this strategy

should enhance choice, quality, equality and value for money.”¹

This strategy poses particular challenges in relation to those occupational therapy workers (OTs) supporting people to remain in their own home, being discharged from hospital or in care homes. The occupational therapy role is often misunderstood in relation to end of life care. The workers may be overlooked when policies are developed, so it is sometimes difficult for them to be engaged in service development. By providing this guide, it is intended that those health and social care professionals who work with occupational therapists also gain a clear understanding of their role. The complexity of the role and the service delivery process for these workers often mirrors the complexities around end of life care itself.



This guide is informed by the *End of life care strategy*¹ and the social care framework *Supporting people to live and die well: a framework for social care at the end of life* (NEoLCP, 2010)². It is therefore relevant for occupational therapists working with adults, rather than with children. The strategy itself applies to England, so the current publication will be of primary relevance for occupational therapists working in this country. However, many of the recommendations will also be of general relevance for occupational therapists working in Scotland, Northern Ireland and Wales.

For the purposes of the guide, the term 'social services' has been used, as this will be most familiar for occupational therapists, but the term 'local authority' can also apply.

A final point to note is that different personal pronouns are used in different sections of the guide, with occupational therapists being referred to as 'you' for the steps of the pathway (pages 15-35) and as 'he', 'she' or 'they' for the remainder. This is so that the guide is 'user friendly', enabling recommendations to be applied in a practical way, but also so that broader, more abstract and professional issues can be discussed.



This guide is based on views shared by occupational therapy practitioners, educators, students and managers at the stakeholder event. One of the main concerns identified on that day, which prevents occupational therapists from playing their full role in end of life care, is a lack of clarity and awareness of the role, both amongst occupational therapists and amongst other social and health care professionals and managers.

This guide has therefore been produced for two purposes. Firstly, the aim is to provide a practical guide which supports occupational therapists and support workers to engage with key professionals in ensuring that those who may be in the last months of their life receive high quality end of life care. The guide can be used as a resource by any occupational therapist working with a person who is reaching the end of life. It gives suggestions, based on the experience of occupational therapists who are already involved in delivering end of life care. The aim is to encourage occupational therapists to engage with the end of life care agenda and to explore their current and potential role.

Secondly, the guide will be useful to health and social care professionals who work in partnership with occupational therapists to clarify the occupational therapy role and to ensure that people can access appropriate occupational therapy care and support (see Appendix 1: Occupational therapy core skills and their practical application to end of life care).

In keeping with the “by occupational therapists, for occupational therapists” theme, case studies have been provided which give real life examples of occupational therapists working in their everyday roles. This has been

done in order to link theory and strategy recommendations with day to day practice, and to encourage further engagement by occupational therapists. All the case studies have been anonymised to ensure respect for the person and use pseudonyms throughout. Those who have provided case studies are acknowledged at the end of the document.

Whilst this guide has been produced in order to help occupational therapists to work with people who are approaching the end of life, it must be remembered that it is not a directive, nor is it a guideline based on peer reviewed evidence. Occupational therapists should always be guided by the COT's *Professional standards (2007)*³ and *Code of ethics and professional conduct (2010)*⁴ when carrying out their role.

Individuals approaching the end of their lives need high quality, accessible care if they are to make genuine choices about how they are cared for and where they wish to die. Competent and compassionate care is also critical to giving people the opportunity to have a dignified death and offering families,



staff and others bereavement support following a death.

This care should be of the same high quality regardless of diagnosis and of whether the care is carried out at home, in hospital or in the community, including supported housing, care homes, prisons and hostels or any other setting. The guide is intended to support practitioners and staff working in the occupational therapy role to develop their awareness and understanding of the end of life care pathway and how it relates to people in the diversity of settings in which they work. This guide also offers signposting to further appropriate resources.

Core principles for delivery of end of life care

The principles include:

- Care is client-centred and integrated
- Treat individuals with dignity and respect
- Identify and respect people's preferences
- Provide care after death.

The importance of getting this care right has never been more apparent and care standards and flexibility of the care organisations, including occupational therapy, is very much to the fore at this time. In 2011 the health secretary and the care services minister set out their vision for adult social care provision, promising personal budgets for eligible people by 2013 underpinned by a new legal framework, more outsourcing of local authority services and emphasis on reducing council back-office costs, portability of care assessments, plans for new workforce development, leadership, and personal assistants' strategies and a greater role for local communities. The fact that NICE Quality Standards for end of life care are also being developed reflects the importance of this area of practice. The standards will be used to enable evidence based decision making by practitioners, as well as forming a basis for commissioning decisions.



When to start thinking about end of life care

It may be helpful to consider the following when referring a person and/or their carer to the palliative care services or end of life care services:

It is difficult to predict when people are approaching the last six to twelve months of their lives, but there are many ways occupational therapists and assistants can work with colleagues in health and social care to improve recognition and consider the important issues that should be addressed at this time.

Providing effective, high-quality care for someone during the end of their life is challenging. Without support and information,

staff and carers can find the experience overwhelming.

Identifying end of life care needs at an early stage is beneficial and can allow more time to plan appropriate support needs effectively with and for someone. It may be that on initial referral no specific action is taken but a person's future support needs and wishes may be identified, and their illness progression can be monitored and reviewed when appropriate.

This guide is intended to help occupational therapists deal with the challenges of supporting someone who is dying and identify how and when they need to access specialist support from health professionals and other organisations.

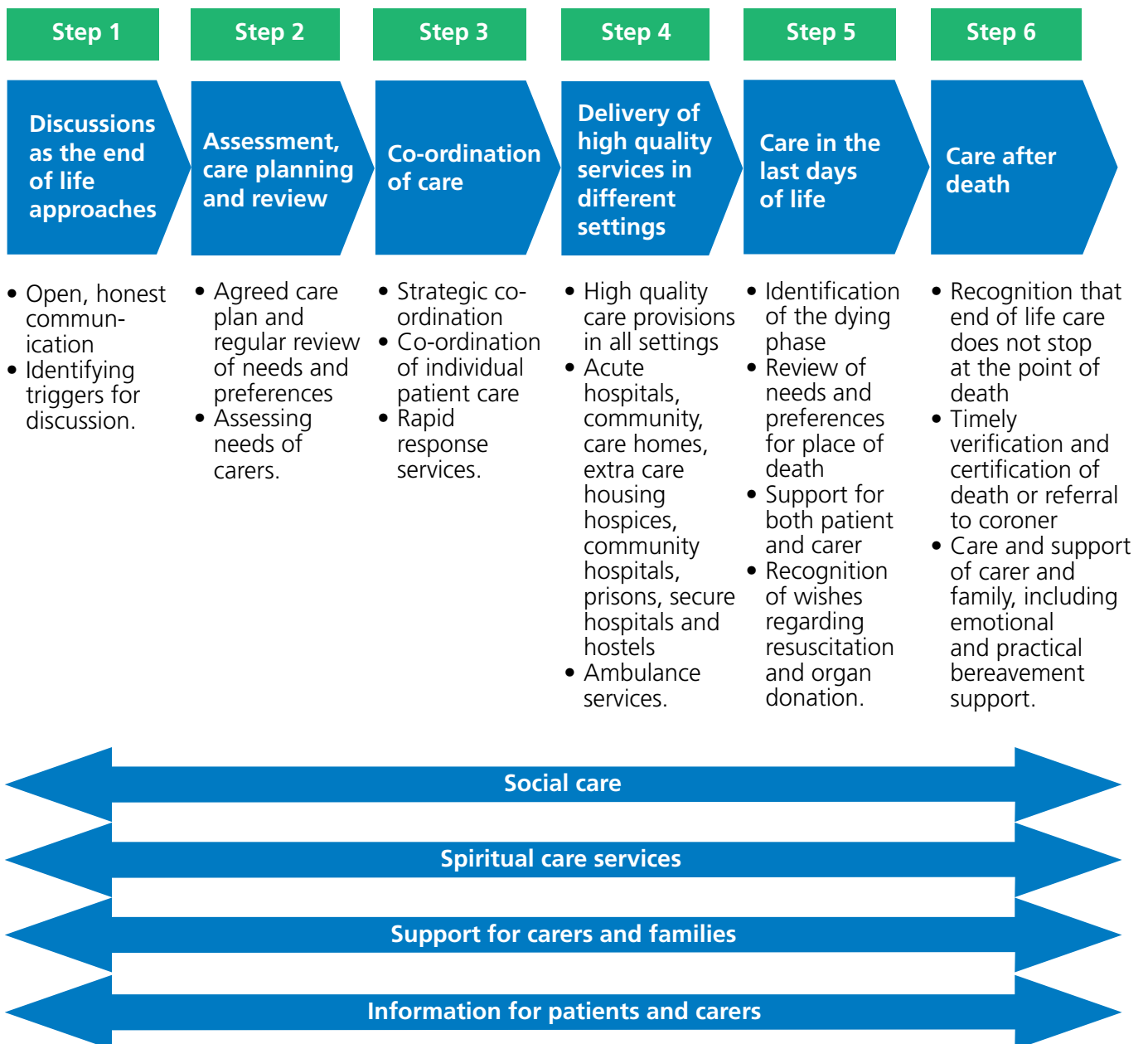


End of life care pathway

The guide follows the six steps of the end of life care pathway, beginning with initiating discussions as end of life approaches and concluding with care after death.

Each section outlines the relevant step of the pathway and outlines questions to ask about the individual's care and the practitioner's role

in that care. The social care framework for end of life makes the point that "The pathway through end of life care offers a helpful structure for planning services. However, in reality, it is not a tidy linear progression. People move back and forth, go through 'steps' in a different order, or miss out some stages altogether."²



Reference can also be made to the relevant quality markers for end of life care. (See Appendix 2 for full list.) These quality markers are not necessarily profession specific, but will hold relevance in the setting in which the occupational therapist is employed/based.

We also include case studies which illustrate the occupational therapy role. **The guide will reflect the need to work with other professionals in health and social care and assist occupational therapists to:**

- Identify when someone is approaching the end of life phase
- Assess needs and develop a care plan
- Review care planning
- Help to review practice
- Support communication and team working
- Understand that staff and colleagues may be affected by the death of a client and identify some measures to support them and provide information.





Diversity of occupational therapy role in different settings

It is recognised that occupational therapists work in a diversity of settings and they will be involved in the delivery of end of life care in different ways and at different times. Some of these are illustrated below to enable further understanding of this:

Acute setting

Occupational therapists working in the acute setting have an important role in helping the person to determine his/her priorities regarding future care. They will be involved in assessing the person's functional ability, in discharge planning, and in enabling the person to be cared for in his/her preferred place of care where possible. Frequently this place is at home, so occupational therapists often carry out home visits from hospital and make the

onward referrals to ensure the necessary community support is arranged. They have a vital role in ensuring timely delivery of equipment to support discharge. Provision of the necessary equipment at the right time can enable the person to die at home rather than in hospital.

Rehabilitation

Rehabilitation can take place in acute care, intermediate care and community settings, (including care homes) and hospices. The occupational therapy role will involve helping the person to identify and achieve particular goals, optimising independence and function and helping the person to manage particular symptoms such as pain or fatigue.



Hospice

People are admitted to a hospice for holistic palliative care, including symptom control. Admission will also provide respite for carers. Hospice-based occupational therapists specialise in palliative care and will focus on contributing to advance care planning, management of symptoms, rehabilitation and providing a link between hospital and community, often through discharge planning. Occupational therapists in this setting may be able to provide bereavement support for carers, both leading up to and following the person's death. Specialist palliative care occupational therapists will also have an education role, providing advice both to the person, to his/her carers and to staff (including occupational therapists) working in more generic roles and settings.

Social services and reablement

Occupational therapists involved in reablement will be facilitating people to remain in the community, providing 'tailor made' support. This is often through a combination of care provided by specially trained carers, which focuses on the person's specific strengths and needs, provision of manual handling equipment and advice where necessary, and through prescription of other types of assistive technology.

Another key role for occupational therapists working in social services settings is to promote function through environmental adaptation. They will assess for equipment which may be needed over the longer term and for major housing adaptations such as stair lifts or level access showers. They will help with applications for Disabled Facilities Grants where appropriate and will also make recommendations for re-housing.

Occupational therapists may now also be assessing for personal budgets and providing information for support planning.



Community

Community-based occupational therapists could be working in specialist palliative care teams, teams specialising in a different area of practice (for example, neuro-rehab, people with learning disabilities) or in generic community teams. They work with people in their own environment, whether that is their own home, a relative's home or a care home. In common with reablement services, community occupational therapists will work to ensure the person is in his/her preferred place of care, and will often also have a rehabilitation focus. Community-based palliative care occupational therapists will have a more specialist role, similar to that described for hospice-based occupational therapists.

Care homes

If a person needs to move to a care home, it is important that the person still feels 'at home', despite the new surroundings. If the occupational therapist has been working with the person prior to the move, this can help maintain a sense of continuity and belonging. Occupational therapists may also advise on practical matters, such as positioning, moving and handling, communication or optimising independence.

Services for people with learning disabilities

For occupational therapists working with people with learning disabilities, the role often centres around enabling effective communication, advocacy and use of practical strategies. Ideally, the occupational therapist will intervene at an early stage, so that the person can make decisions about his/her care, as well as experiencing the use of moving and handling equipment before it becomes necessary to use it (this of course will be relevant for other people reaching the end of life, not only people with learning disabilities). This anticipatory approach is also important when introducing other changes in day to day activities, such as providing help with personal care (the person needs to understand why a carer might be needed to help with toileting or changing clothing) or providing equipment such as profiling beds or pressure relieving mattresses.

The occupational therapist will work with the person to enable understanding of his/her condition and to express questions, concerns, needs and wishes. This is important, especially if the person is not able to verbalise his/her needs. Advocacy is also part of the role, and the occupational therapist will need to liaise with specialist palliative care services and others to ensure that the person is able to communicate as effectively as possible. This could be crucial, for example, when carers need to be able to interpret signs of pain or distress. The occupational therapist will work as part of the multi-disciplinary team to ensure that the person's wishes are met wherever possible.

Day care

Occupational therapy staff may work in generic day centres, or those attached to hospices. Although the occupational therapist will assess and treat each person individually, there is more opportunity for group work here than in other settings. Such groups may include activity groups (if appropriate), anxiety management groups or groups which offer support for carers. The occupational therapist may enable the person to practice particular activities which would be more difficult in his/her own home due, for example, to lack of space or moving and handling equipment. Such activities might include transferring in and out of a car, walking, turning in bed etc. The person may also be able to try out equipment to see if they would find it useful at home, and the occupational therapist often then provides the link between the day centre and home.

Prisons

If a prisoner is reaching the end of his/her life, it is important that he/she is treated in the most appropriate setting, according to his/her occupational and healthcare needs.



The occupational therapy role tends to focus on the mental health aspects of care but will also involve:

- Advocacy on behalf of the person and liaison with those involved in all aspects of the person's healthcare needs
- Communication - expression of feelings and wishes regarding end of life
- Identifying any goals which might be important for the person and helping them to achieve these.

Occupational therapists working in independent practice

Occupational therapists may work independently or as part of a private company offering occupational therapy services. They may be commissioned by housing associations, private hospitals or equipment supply companies, as well as by individuals. When working with people at the end of life, independent occupational therapists will be involved in the same professional activities as those working for public sector employers but may be able to work with the client more flexibly, depending on the contract which has been agreed. Activities may include prescription of wheelchairs and assistive technology, symptom management, housing adaptations – particularly where the individual is having the alterations done privately – and enabling the person to optimise his/her independence. Independent occupational therapists may also be involved in providing training and consultancy, for example to care homes.

Case study: Tom

Tom was a 38 year old man who had been diagnosed with renal cell cancer, with lung and brain metastases. He lived with his wife, who was his main carer, and their two young children. Although Tom was not able to work his employer was supportive, paying his salary for the previous five months. Tom's condition appeared to be fluctuating, and when first seen by the occupational therapist he presented with a three day history of right hemiplegia as a result of disease progression. Tom was on a high dose of steroids to reduce the brain inflammation and started two cycles of chemotherapy before having a week of whole brain radiotherapy. All activity proved exhausting for him.

Occupational therapy took place in an acute hospital. As well as gaining relevant information about Tom's home and social circumstances, the occupational therapist assessed Tom's physical difficulties, which were resulting from his dense right-sided weakness. He was found to have adequate sitting balance and head control for one person to support him whilst he washed and dressed, but no right hip or knee control, so he was unable to stand without support. Other possible impairments which might have affected Tom, such as sensory, cognitive or perceptual difficulties, were assessed but were not found to contribute to Tom's difficulties. Using a functional activity such as washing and dressing was useful in contributing to this assessment, and it also helped to establish that Tom did not have any problems with communication.

Rehabilitation included encouraging Tom to be aware of and to use his right side. The occupational therapist worked closely with the physiotherapist to ensure the same techniques were used when carrying out personal activities of daily living and during exercise sessions. The occupational therapist supported Tom on his right side as he used his left hand to wash himself. By blocking his right hip and knee, Tom was able to stand to wash, dry and dress. These treatment techniques were documented in Tom's notes, so that nursing staff could also follow them, ensuring a consistent approach.

Discussions were held with Tom and his wife regarding future plans for discharge home. This was broached sensitively to reassure them that the hospital would not hurry his discharge home, but it ensured that all necessary arrangements were made in a calm and thorough fashion. This included the feasibility of basing Tom downstairs with appropriate adaptations and equipment as well as support services. Tom's wife had already been giving this some consideration and was able to take control of these decisions, with some suggestions from the occupational therapist.

Tom's hemiplegia started to resolve within four days, and he began to gain active and useful movement in his right arm and hand. After eight days, he regained hip and knee control and began to walk using a rollator zimmer frame.

The occupational therapist carried out a home visit with his wife present, but Tom felt too tired to attend. The occupational

therapist suggested an additional banister rail on the stairs and strategically placed grab-rails by the toilet and shower cubicle, and had already shown Tom and his wife the range of equipment available in the occupational therapy department at the hospital. A joint decision was made to keep the adaptations to a minimum, since Tom's condition was fluctuating, but introduce them in the future if they became necessary.



Step 1

Discussions as the end of life approaches

Identifying when people are approaching the end of their life can be complex. In practice, occupational therapists will often take this initial step in conjunction with step 2. Many people may have a combination of health and mobility problems where the stages of deterioration can be unpredictable. A key challenge is knowing how and when to

begin a discussion with individuals about their wishes as they near the end of life and whether they should be referred to other services. End of life issues are often brought up by the person or his/her carers when discussing discharge from hospital, or future needs. It is important to be able to respond appropriately and to be able to discuss these issues in more depth.



Occupational therapy role

In relation to people/carers:

- Which other health and social care professionals are already working with the person and his/her family? How can you ensure that your intervention complements theirs and offers a co-ordinated approach?
- Have you gathered all the information you need before seeing this person?
- Elicit the person's wishes and priorities (including distinguishing these from those of carers and family if necessary). This will help in setting realistic goals later in the pathway. Gather information about the person's circumstances/home and their role within the family
- Ensure you have knowledge about the person's condition, as well as maintaining a focus on how they are functioning
- Explain the occupational therapy role to carers and/or relatives and give them your contact details
- Reinforce coping strategies; encourage the person's attendance at support groups if necessary
- Offer psychosocial support, group support, training in relaxation and energy conservation as necessary and according to your level of competence
- If appropriate, ask about the person's wishes for future care.

In relation to other professionals:

Occupational therapists' core skills and knowledge mean they are well placed to drive delivery of high quality person centred end of life care, for example through:

- Effective communication and holistic assessment skills. These can be used to elicit the person's and his/her carers' needs and priorities, help them set realistic goals and prepare for death (and, in the case of carers, for life beyond this)
- A flexible, creative and compassionate approach which helps anticipate and respond to individuals' and carers' changing needs
- Team-working skills to facilitate/mediate between individuals/carers and the rest of

the multi-disciplinary team (MDT)

- Practical skills and knowledge which could be shared with colleagues (from in-service training on safe manual handling to advanced communication skills)
- Although currently not always regarded as high priority areas for occupational therapists working with people reaching the end of life, there is also potential for a greater role in aspects such as advance care planning, vocational rehabilitation (for both individuals and carers) and bereavement support.

Top tips

- Prioritise the individual
- Develop a rapport/relationship
- Use this first step of the pathway as a basis for ongoing assessment/review
- Emphasise function, ensuring that this is informed by knowledge of the person's condition or conditions
- Use open questions and encourage the person to ask questions. Find out the person's knowledge of their own condition and their expectations
- Think about the questions the person might ask, so that you can be prepared
- Have awareness of advance care plans and how occupational therapists can help
- Make sure you are aware of your obligations regarding mental capacity and safeguarding
- Have awareness of services available in your own area
- Try to be proactive and avoid 'crises' by promoting your role amongst health and social care colleagues, and requesting timely referrals
- Be proactive in making referrals to other health and social care professionals as necessary.

Case study: Sue

Sue was a woman in her 60s who had been diagnosed with lung cancer; there had been metastatic spread to her pelvic bone, and she was awaiting an opinion as to whether an internal fixation for this was possible. She lived with her husband in their own house, and she was also supported by two daughters who lived nearby. Sue's husband was also experiencing mobility problems and was awaiting a hip replacement. Sue was initially referred to the occupational therapist by the Macmillan nurse, as she was having difficulty with climbing stairs. Although the occupational therapist worked with Sue to find solutions for many of the functional problems which the pain and reduced mobility caused, one of the most important aspects was the assistance provided with re-housing. Sue and her husband submitted a housing application to the local housing office, which was directed to the medical re-housing team. The occupational therapist was able to advocate for her client, requesting provision of level access to bedroom, bathroom and toilet facilities.

As Sue's condition progressed, she received the orthopaedic opinion that it was not possible to internally fixate her pelvic fracture. This, combined with her deteriorating mobility, made the need for re-housing more imperative.

A one bedroom ground floor flat became available to the couple in an area that was close to their family support network and across the road from local shops. The flat had level access and although small, had good turning space for the use of a wheelchair. The bath could have been

adapted with a swivel bather bath seat, to enable the client to transfer over the bath side to use the shower. However, the client's husband wished to adapt the bathroom to a wet room to meet both their needs. Although the couple had concerns about the size of the flat, reassurance was given that the circulation space within the flat was good. A key role was played securing a little additional time for the couple to make a decision about whether or not to accept the flat.

Sue and her husband made the decision to move to the ground floor flat and funded the level access shower adaptations privately, in order for the work to be completed prior to moving in. Recommendations were given regarding the facilities which would be needed, working in partnership with the adaptations agency.

The move improved the client's and her carer's quality of life, since they were no longer obliged to sleep in different rooms.



Reflective analysis

Although re-housing can be stressful, particularly in the context of living with a palliative illness, the client and her husband had already been considering re-housing prior to Sue's diagnosis, in order to maintain their independence. They were therefore psychologically prepared to leave their family home and were focusing on the future, both short and long term, as Sue's husband had been struggling with the stairs already. The speed of re-housing and the availability of a property in an area which maintained support systems (as their family lived close by) was crucial to the success of re-housing. Although Sue's physical needs had been met with the provision of a profiling bed and commode on the ground floor of their existing house, the couple's social and psychological needs had not been met, and these were not resolved until they were able to sleep in the same room, when they re-housed to the flat.

Although Sue's long term needs were addressed early on in the assessment process, continued reassessment ensured that Sue remained at home until the last week of life. Although admission to a hospice was required in the last week, this was for pain management rather than the client's or family's ability to cope with increasing dependency.

Although re-housing can be perceived as a stressful life event, in this situation rehousing had a positive impact on the quality of life for Sue and her carer at end of life. Re-housing at end of life should therefore not be dismissed as a potential solution to meeting clients needs.



Step 2

Assessment, care planning and review

An early assessment of an individual's needs and wishes as they approach the end of life is vital to establish their preferences and choices, as well as identifying any areas of unmet

need. It is important to explore the physical, psychological, social, spiritual, cultural and, where appropriate, environmental needs and wishes of each person.



Occupational therapy role

In relation to people/carers:

- What are your core occupational therapy skills, and how can you use them to help this person? (Refer to Appendix 1)
- Does this person have an advance care plan? Are you able to contribute to this?
- Develop rapport with and show empathy for the person in order to carry out a holistic assessment
- Use advanced communication skills such as active listening and open-ended questions to elicit the person's 'story' and their key priorities
- Use core occupational therapy skills to carry out holistic assessment. This could cover physical, psychological, social, environmental, emotional, spiritual, functional, sex and sexuality and financial needs, depending on your work setting and area of practice
- Identify any occupational goals which are important for the person
- Identify the care needs of the person, and his/her family or carers
- Establish priorities for the individual and his/her significant others. Identify the person's preferred place of care and support him/her to achieve this
- Assess needs of carers, including bereavement risk and bereavement support and follow-up/onward referral
- Be a resource for the person and provide information as necessary.

In relation to other professionals:

- Obtain sharing of information document as required
- Input into advance care planning – who is the best person in the team to do this?
- Liaise with other professionals and share information with the MDT
- Provide education and training on the occupational therapy role.



Top tips

- Make sure you use a compassionate approach
- Make sure your intervention and any onward referrals are as timely as possible
- Assessment is a starting point: ongoing review and re-assessment is vital as anticipated needs will change, sometimes quickly and unpredictably
- Use effective communication with the person and with professionals, avoiding jargon
- There may be a number of significant people in the person's life, and they may have taken on a caring role. Their needs should be taken into account, alongside those of the person. Sometimes pets are very important
- Be relationship-centred as well as task-focused
- Be aware that the occupational therapy role may vary across different settings.

Case study: Hillary

The initial assessment can be as long as it is thorough, and when necessary I return to complete it. However, Hillary was able to complete the initial interview in a single two hour visit. I encourage the person to share his/her journey, particularly with cancer diagnosis.

Hillary knew she had a very probable lung cancer and had an extensive history of chronic obstructive pulmonary disease (COPD) that had limited her activities of daily living (ADLs) for many years. She was uncertain about the future, but was concerned more by her worsening shortness of breath and the impact this had on her function and life, than by her probable new diagnosis.

The initial interview focuses on history of function and deterioration to the present day and I use the Australian Therapy Outcome Measures (AusTOMs) 0-5 scale to rate current function (5 being fully able and independent, 0 being unable).^{*} This includes leisure activities and roles as well as mobility/transfers, self care and domestic tasks. I assessed mobility and transfers during the visit but didn't attempt stairs as Hillary had been up and down the stairs just before my arrival. She became short of breath just when talking, so I did not wish to distress her further. It was very clear from the information Hillary and her husband gave, together with my assessment of her mobility, that stairs were the main issue, made even more important by the fact that the toilet, bedroom and shower room were all located upstairs. This area of the initial interview demonstrated

that Hillary was:

- Managing stairs with physical assistance from her husband (AusTOMs activity rating 3)
- Unable to go out at all (AusTOMs activity rating 0)
- Managing to sleep independently but lacking quality (AusTOMs activity rating 4).

Her impairment I rated as 1 on the 0-5 scale – this being her shortness of breath being so severe and evident on low level activities such as talking.

The initial interview schedule also covers energy levels (fatigue), mental health and well being, tissue viability, and respiratory, cognitive, neurological and general issues, such as pain, mouth care and nausea/vomiting. Hillary's shortness of breath and poor sleep identified problems with the energy and respiratory sections. Pain in her chest and back was also identified.

I was able to assess Hillary's physical and social environment, which again demonstrated the problem using the stairs. Hillary was generally continent, but her shortness of breath had worsened so she was having accidents on her way to the toilet. There was already a level access shower with seat – Hillary was independent with this set up, as long as she paced her activity. Her armchair was appropriate and her bed was a good height with a rail. Hillary was unable to lie flat because of her shortness of breath.

I use the distress thermometer^{**} for the person to measure their own distress. Hillary circled the distress thermometer at

* Each of the AusTOMs for occupational therapy considers impairment, activity limitation, participation restriction and wellbeing. For further information about AusTOMs see About the AusTOMs for occupational therapy (Unsworth/Duncombe) on LaTrobe University's website at http://www.latrobe.edu.au/austoms/OT_sc.htm

** The distress thermometer and information about it is available on the website of the UK Oncology Nursing Society (UKONS) at <http://www.ukons.org/downloads/index.html>

8/10 – due to her incontinence/difficulty reaching the toilet throughout the day and also getting so short of breath whenever she did. Participation is also measured by the therapist – this relates to the participation/control the person has and ability to reach potential. I rated this as a 3 on the 0-5 scale (5 being no issue) as Hillary was relying on her husband a lot.

The summary of needs and action plan/goals is formulated with the person. Hillary was clear on her own goals:

1. To manage the stairs independently (and thereby reach the toilet)
2. To access the community with assistance of her husband or son – to increase leisure activities, particularly when the weather became warmer
3. To manage bed transfers independently and improve sleep – Hillary was unable to lie flat at night, and pillows ending up on the floor were waking her regularly.

The action plan was:

- The occupational therapist (OT) was to explore stair lift options – this was needed urgently given Hillary's likely diagnosis and prognosis
- Hillary and her husband were to arrange a short-term loan wheelchair. The number of the service was provided and their son was to collect the wheelchair
- The OT was to refer for a wheelchair assessment to also take into account Hillary's husband's needs, as he was not only her carer but also had his own cancer diagnosis
- The OT was to order and trial a mattress variator
- The OT was to provide some breathing techniques to improve Hillary's control over her breathing on activity.





Step 3

Co-ordination of care

Occupational therapists have a key role in identifying priorities and helping the person to set occupational goals. The role will also include facilitating the person to die at home, if this is their choice. The social care framework highlights that “If people can stay in their own homes for longer they are likely to retain better quality of life right up until the point of death.”² For many people, their home is their care home, so enabling people to remain or return there is important. Occupational therapists working in acute care will have a key role in discharge planning; those working in social services, in assessing

for and recommending housing adaptations, if appropriate. This role requires effective co-ordination and liaison with other services once the person’s permission has been obtained.

Once a care plan has been agreed it is important that all the services the person needs are effectively co-ordinated. Individuals should be asked for permission to share information with other services. This is also an opportunity to establish contact details for anyone they would like to be notified if there is a change in circumstances.

Occupational therapy role

In relation to person and carer:

- Take the action necessary to implement the occupational goals and priorities identified in step 2
- Ensure effective discharge planning to the person’s preferred place of care if the person is in hospital and if this is appropriate. Enable the person to remain in their preferred place of care wherever this is possible
- If the person requires equipment, assistive technology or housing adaptations, ensure this is actioned and co-ordinated as quickly as possible
- Follow up and review (in the preferred place of care).

In relation to other professionals:

- Use electronic care records where available
- Make use of opportunities presented by changes in day to day discharge policy (eg, departure destination) which may enable occupational therapists to be involved earlier and with greater authority.





Top tips

- Put the individual at the centre of care
- Try to allocate a key worker – this could be the occupational therapist if he/she has the necessary competencies
- Make use of joint working/visits where applicable
- Establish a directory of contacts/resources in each locality which can be used for signposting. Build on existing frameworks where possible
- Work with care homes on education and training.

Case study: Phillip

This case study shows the occupational therapist's role when the person was reaching the last days of life. The occupational therapist was able to recognise that there was a sudden and rapid deterioration in the person's condition, that his wife would struggle to care for him without additional support, and that urgent input from the wider team was needed:

Referral

An urgent referral to the hospice occupational therapist was received on Friday from the community palliative care team nurse following a phone call from Phillip's wife reporting decreasing mobility. Phillip was previously very active and was finding it hard to accept either his deteriorating condition or assistance; therefore specialist occupational therapy input was felt to be appropriate. He had last been seen by the palliative care team nurse two weeks previously.

Medical history

Phillip was a 65 year old man. Glioblastoma had been diagnosed 18 months ago and had been treated with surgery, radiotherapy and chemotherapy. Initially results had been good, but there had been a recurrence three months ago requiring further surgery. Phillip was currently receiving palliative chemotherapy.

Social situation

Phillip was living with Susan, his wife, in their own house. Two daughters were living fairly locally. A referral to the district nurses had been made the previous week, but, to date, no care package had been arranged or equipment provided, apart from a hired wheelchair.

Initial assessment

The occupational therapist visited Phillip at home on the following Monday. Susan reported that Phillip now needed assistance to mobilise and was very slow. He was coming downstairs daily with assistance. She had to assist him with all personal care.

Phillip was noted to have a dense right hemiplegia, with no functional use in his right arm or hand. He was able to weight-bear on his right leg but was unable to lift his foot or step, and he was walking with a shuffling gait. Phillip required assistance to transfer out of bed and to mobilise a few steps to the en-suite bathroom.

Severe speech problems were noted (dysphasia); Phillip was only able to say a few words. Phillip was due to attend chemotherapy the next day; Susan felt it was the chemotherapy which was making him so weak, but she was hopeful that this would improve.

Phillip was obviously not keen to accept equipment – the occupational therapist explained that none of the equipment needed to be fixed, and that it could be removed if he wasn't happy with it. Susan felt that she now needed some input from formal care services, but wasn't sure how to go about this; options of social services, continuing care or private care were therefore discussed.

Recommendations

The occupational therapist recommended the provision of equipment - next day delivery was requested - and an urgent referral to the community physiotherapist for an assessment for walking aids.

Review

The occupational therapist visited again late on Thursday afternoon with the physiotherapist from the neurology service. Equipment had been delivered the previous day and the physiotherapist had assessed for and provided the walking aid. On arrival, it was clear that Phillip's condition had deteriorated significantly since the previous visit just three days before.

Physical

Susan reported that Phillip had not received his chemotherapy on Tuesday as a deep vein thrombosis (DVT) was diagnosed. The district nurse had visited that morning and referred Phillip to social services for care. In addition, the speech therapist had assessed Phillip's swallow and, as it was becoming a problem, advised use of thickened fluids.



Phillip had been unable to walk on the day of the review visit and needed full assistance from the occupational therapist and physiotherapist in order to get back to bed safely.

Discussion of future care

Susan started the visit by stating that the deep vein thrombosis was the cause for his inability to stand and it should improve with anti-coagulant therapy.

The occupational therapist asked if they had considered admission to the hospice, especially in view of the lack of community care. They also discussed other options for care, including private care, and the fact that carers would be unable to assist Phillip on the stairs; he may now need a hospital bed downstairs.

On reflection Susan requested an admission “for a few days to treat Phillip’s DVT and get him back on his feet” and to set up care.

The occupational therapist spoke to the hospice medical team who recommended liaising with the hospital oncology team as Phillip was still receiving chemotherapy and may have needed more active treatment. Susan contacted the hospital clinical nurse specialist who agreed to discuss with the oncologist whether admission should be to the hospice or to the hospital.

The occupational therapist suggested that the deterioration in Phillip’s condition was unlikely to be due to the DVT, as his arm, speech and swallow were also affected. The deterioration may have been due to chemotherapy or to disease progression and there was a possibility that his mobility may not improve.

The occupational therapist asked if the family had ever discussed where Phillip would want to be cared for when his condition deteriorated; such discussion had not taken place. The occupational therapist also suggested that admission to the hospice was likely to be for more than a few days.

The occupational therapist then liaised with the hospice team advising that Phillip might need admission the next day if he did not go to hospital.

Conclusion

Phillip was admitted to the hospice on Friday and the medical team explained to the family that he was now dying.

Phillip’s family was seen by the occupational therapist in the hospice on Monday and Tuesday – just over a week after the initial referral. The family was grateful for admission to the hospice as the pressure was taken off them. They now fully understood that Phillip was dying and were happy that he was in the hospice.

Phillip died on Tuesday night.



Step 4

Delivery of high quality care in different settings

In the last year of life, individuals and their families may need access to a complex combination of services across a number of different settings. They should be able to expect the same high level of care regardless

of where they are being looked after. For some - such as those who are frequently in hospital - it may be useful to have a more proactive approach.



Occupational therapy role

In relation to individuals/carers:

- Facilitate the person's wishes wherever possible and respect his/her individuality
- Facilitate optimum function and quality of life
- Support continued participation in activities which are important for the person. The specific intervention will depend on the specific activity but could involve assistance to remain at work, maintaining independence in self care, continued involvement in leisure activities, visiting a particular place or person
- Depending on training and experience, specific interventions may also include:
 - Non-pharmacological management of specific symptoms such as pain, anxiety or fatigue
 - Moving, handling and posture management– providing assistance and advice to the individual, carers and families
 - Use of assistive technology
- Ensure continuity of care, eg through a single point of access or key worker.

In relation to other professionals:

- Ensure quality and timeliness of referral information; provide clear referral criteria
- Maintain communication within the service and across agencies
- Ensure permission to share information has been obtained.

Top tips

- Balance the person's and family's aspirations with realistic expectations. Help the person and family to achieve their aspirations wherever possible
- Strive for continuity of care within and across services and agencies. Minimise personnel change
- Network to build local knowledge and contacts.

Case study: Joan

Week 1: Joan was a 54 year old woman admitted to hospital with a four week history of constipation. It was discovered that she had had a breast lump for eight months. On examination she was found to have pleural effusions and was in a high state of anxiety. She was extremely fatigued, had no appetite and could only manage to walk a few steps. Breast cancer with lung and bone metastases was diagnosed and her prognosis was poor. She was given chemotherapy but was unable to tolerate it and by this time she was unable to get out of bed.

Week 3: Joan was transferred to the hospice. On admission she was treated for shortness of breath and given mouth care, and the medication for her constipation was adjusted. Anxiety remained the overriding problem.

Following holistic assessment by the team, the main problems noted were body image, anxiety, spiritual concerns, practical issues (Joan wished to make a will) and mobility.

Discussions also took place with her husband, David, around his concerns. Over the next four weeks Joan was given complementary therapy, was seen by the hairdresser, received communion, made a will and gradually gained confidence in the staff.

Week 7: Joan commenced physiotherapy. Following assessment, work began on a daily basis with the Rehab Assistant working on gentle exercise and gaining confidence in moving. The occupational therapist and the physiotherapist worked

together with Joan to improve her ability to transfer independently, and eventually she moved from using the hoist to using the standing aid.

She was encouraged to attend day care and to commence relaxation to alleviate some of her anxiety.

Discussions took place with Joan and David about returning home. The occupational therapist accompanied them on a home visit and an agreement was made around downstairs living and the equipment required. They also agreed to a package of care with two carers calling three times a day.

Week 11: Joan was discharged home with a follow-up visit by the occupational therapist to ensure that David could assist safely with transfers and use the portable ramps which had been provided to enable Joan to go outdoors.

Joan attended day care to continue with her physical rehabilitation as well as addressing her ongoing psychological needs, which centred around Joan being able to manage her anxiety. Staff at the day centre gave lots of positive reinforcement and listened actively to her concerns. Joan had been reluctant to attend any hospital appointments due to her anxiety about the disease. Time was spent with her prior to the first hospital appointment to allow an open discussion around her fears regarding prognosis. Support was also given to David, especially when he needed to return to work.

Over the next nine months Joan continued to make progress and achieve her goals. Her anxiety levels reduced with anxiety management, her confidence increased

and physically she progressed to being independently mobile using a wheeled walking frame. Liaison with the social services' occupational therapists resulted in a permanent ramp for access and a stair lift installed at home. Her next goal was to use the bath with equipment and to return to sleeping upstairs which, with assistance from the occupational therapist, she was able to do.

Joan was finally discharged from day care twelve months after diagnosis. She attended for a review eight weeks after discharge and did not require any further intervention at that time. Joan died peacefully at home two months later.

This case study demonstrates a patient's journey through specialist palliative care multi-disciplinary team work together with each discipline taking the lead at the appropriate time.





Step 5

Care in the last days of life

A point comes when an individual enters the dying phase. For some this may appear to happen suddenly and without warning but for many others it can be a gradual process.

At this stage, occupational therapists will often be working indirectly with the person and his/her carers. They will be ensuring that the

discussions, assessment, co-ordination and provisions of the previous steps have been completed and that the person is in the care of appropriate health care professionals. How someone dies remains a lasting memory for the individual's relatives and friends and the care staff involved.



Occupational therapy role

In relation to individuals/carers:

- Enable the person to be in his/her preferred place of care (across all settings) wherever possible
- Provide emotional and practical support to the person and his/her carer(s)
- Continue to support the person's carer; check that all the provisions identified in earlier steps have been implemented
- Provide education, for example on positioning and pressure care to minimise discomfort.

In relation to other professionals:

- Liaise and communicate across the team/services.
- Input into discharge planning if this has not been covered in earlier steps
- Discharge/departure decisions may not reflect the persons preferences; use the introduction of departure destination policy as an opportunity to challenge decisions where appropriate and to push for involvement earlier on in the discharge planning process.

Top tips

- Maintain good open channels of communication with clients/carers as well as the other health and social care professionals who are involved
- Don't assume that all your recommendations have been carried out, always go back and check
- Be creative, using problem solving skills
- Work with care homes on education and training.

Case study: Daphne

Daphne was a 64 year old woman who lived alone (apart from her cats) in her own house. She had pancreatic cancer and liver metastases diagnosed in February. She was admitted to the hospice in June because she had become drowsy and confused with high fever.

She stated on admission that she would like to go home when she was "well enough". Eleven days after the admission it was clear to her and to us that she was deteriorating and she expressed her wish that, despite our and her cousin's misgivings, she wanted to return to her own home to die.

I spent time talking with her to ascertain what this meant to her psychologically and emotionally. I explored what being at home would be like as she saw it. I found her very sensible and realistic and it was easy to support her in her request to the MDT, her cousin and the community services. She was disappointed that she could not go immediately! However she was able to understand our need to plan properly. A home visit was planned for the next day to check on the environment and Daphne stated that, despite her frailty, she wanted to come on the visit. With a nurse escort we carried out the visit and her cousin met us there. She had all the equipment she needed in her lounge already (electric profiling bed, mattress and commode) but we went through her day's routine and practised use of the lifeline I fitted on the visit, which was new to her. She had a very weak voice and the unit needed repositioning, and it took several attempts before we had success and she

managed a loud “HELP”. She struggled with the bed controls so we worked together on the controls and came up with a ‘pattern’ that Daphne could follow. I also spent time reassuring her cousin about the community support available to them and clearly planning the first few days at home when her cousin would be staying with her.

The outcome was, unsurprisingly, that Daphne wanted to “give it a go” and her cousin was willing, although openly anxious, to support her in this. We decided on the next day for discharge and that her cousin would bring her home by car.

The next day she was very weak and needed two people to help her to transfer so I decided to meet them at her home to assist her getting into the house. Daphne was calm and determined and, although it was a struggle, we managed to help her inside and into bed. When asked if there was any more I could do for her she gave me a beautiful smile and said “piss off”. I took this as the thank you that I am sure it was meant to be. I provided a detailed plan of the names and phone numbers of the community staff involved and the care agency who were visiting three times daily.

She died peacefully at home two days later with her cat on the bed next to her.

Important points from this case study for me are:

- Establishing rapport quickly so that I could have an open discussion with Daphne about what she wanted and her understanding of what that would actually mean to her

- A safe and timely discharge, within a very short time scale
- Support to her cousin to enable her to provide what Daphne wanted and needed. In my experience the family/carers have a huge influence on whether discharges can even go ahead, let alone be successful
- Being able to assess for and put in the right amount of support and input to make it work.





Step 6

Care after death

Good end of life care doesn't stop at the point of death. When someone dies all staff need to follow good practice for the care and viewing of the body as well as being responsive to family wishes. The support provided to staff, friends and relatives will help them cope with

their loss and is essential to achieving a 'good death'. For occupational therapy, roles may vary widely and may be restricted by local circumstances and logistics at the time of death.



Occupational therapy role

The role may include:

- Carrying out bereavement visits, helping with bereavement cards, attending funerals
- Working with carers to help them adapt to a change of role. Intervention may include grief/anxiety management or helping the carer to develop particular life skills
- Signposting to other services where necessary such as counselling services or bereavement services
- Supporting the carer practically by arranging for collection of equipment
- Some occupational therapists may be involved in much broader aspects of bereavement support. For example, working with the bereaved person to prepare memory boxes, or taking up other meaningful activities after the caring role has finished. Involvement will depend on the occupational therapist's competences, work setting and experience.

In relation to other professionals:

- Continuity helps avoid people having to establish new relationships at the bereavement stage; take a case-by-case approach and be aware of which member of the team has the closest relationship with the carer. For example, the key worker may have developed a stronger relationship with the carer than the occupational therapist.

Top tips

- Provide support for the carer, but also be aware of when you should refer on
- If you have been supporting the carer as well as the person, the relationship will have developed before the person's death
- Follow guidance when working with children; memory boxes can be very helpful here
- Bereavement results in a huge change of role for carers. There is potentially a very important role for occupational therapists in supporting them through this period, extending beyond counselling to health promotion and vocational rehabilitation.



Case study: Edith

Edith was an 88 year old woman who lived alone following the death of her husband two years previously. She had a diagnosis of dementia as well as a history of depression and congestive cardiac failure. Edith had one daughter, Marie, who visited at least three times a week. Marie also had her own family.

Edith was referred by a community psychiatric nurse (CPN) to occupational therapy for an assessment because of concerns about her safety (she had been found wandering in her local community and was reported to have left the gas on in her kitchen). The district nursing service visited regularly to monitor her medication. Edith had refused home care services, saying she did not have any difficulties.

The occupational therapist met Edith for the first time on a joint visit with the CPN and subsequently when her daughter, Marie, was visiting. Having Marie present enabled the occupational therapist to find out more about Edith's life as well as enabling Edith to become more trusting of the OT.

Because Edith was having difficulties looking after herself, and she was not accepting home care, there was the risk of a crisis admission. Reducing this risk and maintaining Edith's dignity and self-respect was a priority for the occupational therapist; therefore the aim was to establish a therapeutic relationship with Edith, using a person centred approach; Edith enjoyed talking about her early life. A second priority was to liaise with her daughter and other team members. Marie was experiencing stress with the care demands of her mother, therefore with her agreement, the O.T referred her to the

Admiral Nurses® service within the trust.* Over a period of time the occupational therapist developed a therapeutic relationship with Edith. She assessed Edith's domestic and other self care skills. The OT worked with Edith, her daughter, the homecare services and district nursing service and, in time, Edith accepted homecare.

On one of the visits by the district nurse Edith was found to be physically unwell and was admitted to an acute ward. A few days later Edith died of chest infection and heart failure; her daughter was with her. The district nursing service informed the occupational therapist. The OT checked that the home care service were aware of Edith's death, and she also informed the CPN and Admiral Nurses® service.

The OT sent a card to Marie, followed this up with a telephone call and arranged a single follow-up visit. Marie found she had "time on her hands" since her mother's death. The OT discussed with her other activities she might be interested in pursuing when the time was right. Marie continued to see the Admiral nurse for a couple of months after her mother's death. The OT kept in touch with her progress by liaising with the Admiral nurse.



End of life care is a challenging area of practice. Firstly it is suggested that it is challenging on an emotional level, since we cannot work effectively with people reaching the ends of their lives without perhaps being reminded of our own mortality, or that of those closest to us. We may therefore need to examine our own attitudes towards death and dying. Secondly, it is challenging on a clinical level, requiring us to use our communication, reasoning, decision making and practical skills to the full. We have to have the right knowledge and judgement in order to support people who are dying and their families, as well as those who are bereaved. Thirdly, it is challenging at a logistical level, requiring us to be aware of all the resources potentially available to us and the clients we are supporting (including our own skills) and to use these effectively and efficiently.

The following issues for consideration have been raised by occupational therapists working with people at the end of life, whether as professionals specialising in this field, or working in more generic settings:

Breadth of the occupational therapy role

Occupational therapists often comment that their training means that they could potentially offer comprehensive interventions, taking into account people's physical, social, psychological and functional needs, but that frequently that role is reduced to assessment for equipment and discharge planning once they come to practice. In the context of end of life care, equipment provision and discharge planning does in fact play a crucial role, since it can help people to die in their preferred place of care. Occupational therapists should not, therefore, hesitate to promote their vital role in ensuring high quality, person centred



care in this setting. Occupational therapy stakeholders have also suggested that new initiatives/directives in discharge procedures (also known in some areas now as 'departure destination') are a potential opportunity to influence at an early stage, especially in instances where departure destinations do not appear to reflect peoples' wishes. Social care occupational therapists are now often carrying out full community care assessments for the personalisation agenda.

Generic versus specialist role

Another related question in end of life care is how should the 'generic' and 'specialist' occupational therapy roles be defined, and how do they differ from one another? The *End of life care strategy*¹ itself goes some way to resolving this issue, in that staff are grouped into three categories: staff working in specialist palliative care, staff who frequently deal with end of life care as part of their role and staff working as specialists or generalists within other services who infrequently have to deal with end of life care.

The *End of life care strategy*¹ defines the minimum levels of skills and knowledge required for each group:

Group	Examples of health and social care workers in this group	Minimum levels of skill and knowledge
Group A: staff working in specialist palliative care and hospices who essentially spend the whole of their working lives dealing with end of life care.	Allied health professionals, all health and social care staff working in or with hospices.	<p>All staff should have the highest levels of knowledge, skills and understanding through specialist training as part of further specialist registration and/or continuing professional development (CPD).</p> <p>These should include communication skills, assessment, advance care planning and symptom management as they relate to end of life care.</p>
Group B: staff who frequently deal with end of life care as part of their role.	<p>Secondary care staff working in A&E, acute medicine, respiratory medicine, care of the elderly, cardiology, oncology, renal medicine, long term neurological conditions, intensive care, hospital chaplaincies and some surgical specialities.</p> <p>Primary care staff.</p>	<p>Staff will need to be supported to enable them to develop or apply existing skills and knowledge to end of life care through CPD or further specialist training and to overcome any personal or team barriers.</p> <p>This group has the greatest potential training need, particularly those who may be key in the 'trigger' discussion at the start of the pathway and with ongoing continuity of care.</p> <p>These should include communication skills, assessment, advance care planning and symptom management as they relate to end of life care.</p>
Group C: staff working as specialists or generalists within other services who infrequently have to deal with end of life care.	Other professionals working in secondary care or in the community. For example, care home staff and extra care housing staff, day centre and social care staff not involved in hospices, as well as domiciliary care and prison services staff.	This group must have a good basic grounding in the principles and practice of end of life care and be enabled to know when to refer or seek expert advice or information.

(adapted from Table 4: workforce groups in Chapter 6 of the *End of life care strategy*)¹

Training and support

How should the training and support needs of occupational therapists working with people at the end of life be met? Working with people at the end of life is challenging on emotional, professional and practical levels, so it is vital that occupational therapists are able to gain the support they need in order to carry out their roles. As a starting point, useful resources and sources of support are suggested in the Resources section of this publication. It is important that occupational therapists recognise the support that is available from all other health and social care professionals who also work with people at the end of life. Many aspects of care do overlap, and working with people who are not occupational therapists can be mutually beneficial in promoting understanding of and respect for one another's roles.

Influencing decision making

One of the key reasons occupational therapists have identified a need to clarify the occupational therapy role in end of life care is so that the role can be promoted. At the stakeholder event held in November 2010 key points raised included:

- Occupational therapists use an anticipatory and flexible approach, as well as focusing on the person's function and quality of life. This means that they are well placed to contribute to delivering high quality end of life care. These aspects of occupational therapy need to be promoted, particularly in the current health and social care environment with radical changes in commissioning procedures underway. Occupational therapists need to be able to promote their role with commissioners and primary care as well as with other team members and organisations
- Occupational therapists can be used as a resource. For example, providing training on positioning, moving and handling, liaising between different departments and

organisations, providing information on relevant services available in the local area or becoming key workers for certain people reaching the end of life

- There need to be more occupational therapists in management and leadership roles in order to promote the profession's contribution in this area of practice. Where the person specifications for management posts inadvertently exclude occupational therapists, for example, by confining requirements to specific health or social care professionals, occupational therapists should be encouraged to make applications and need to have confidence that their skills are transferable and appropriate
- Promotion of the occupational therapy role needs to be supported by sound evidence. A key example might be demonstrating admission avoidance and the cost savings made through the employment of an occupational therapist's skills.

The *End of life care strategy* identifies a number of key challenges, one of which is “Health and social care staff often find it difficult to initiate discussions with people about the fact that they are approaching the end of their life. Death may be seen as a failure by clinicians, who may not have received training in how to have such discussions”.¹ Occupational therapists can contribute to the resolution of this challenge, by applying their core values of quality of life and person centred care, whatever the person’s condition, impairment or prognosis may be.

As previously stated, this guide is based on views shared by occupational therapy practitioners, educators, students and managers. As well as enabling the development of an end of life care pathway for occupational therapists, there was also an opportunity for discussion of professional issues, and of the barriers which may prevent occupational therapists from engaging actively with the end of life care agenda. A number of these and the initial next steps were identified, and these are presented on the following page.



Identified need	Next steps
Occupational-therapy-specific guidance linking policy recommendations to practice.	Resources, including this publication, which link policy recommendations to practice to be produced and made available to occupational therapists.
Ensure that all occupational therapists working with people nearing the end of life are aware of the guidance and recommendations for end of life care, not only occupational therapists working in oncology services.	NEoLCP and COT to publicise the current publication. Production of articles which could be used in newsletters, journals and other publications read by occupational therapists (for example, newsletters of the of COT specialist sections).
Provision of support for occupational therapists working in palliative care services, who may be working in isolation.	Links to useful information and support to be provided via the COT Specialist Section - HIV/AIDs, Oncology and Palliative Care website. COT website link to frequently asked questions about lone working received by COT professional practice enquiries service.
Support needed to promote the occupational therapy role in advanced care planning, such as the use of the preferred priorities for care tool.	Illustrate through use of publicised case studies, working with COT Specialist Section - HIV/AIDs, Oncology and Palliative Care.
Need to promote the occupational therapy role in relevant care pathways and strategies as they relate to end of life care.	Provision of links to relevant care pathways and strategies along with brief guidance on how they can be used. A good starting point may be the recently developed national cancer rehabilitation care pathways; others include the national stroke strategy and the national dementia strategy.

Other needs identified where simple next steps were not immediately obvious or practicable included:

- A strategic approach to education, training and CPD for end of life care, including entrepreneurial and self-promotion skills
- More occupational therapists needed in management and leadership roles in order to influence decision making
- Need to improve achievement of preferred place of care, especially in instances where people wish to be cared for at home but require major equipment to be installed or housing adaptations to be made in order to do so
- Need to promote the occupational therapy role in care homes, including the provision of training and education to clients' relatives as well as care home staff
- Promotion of the occupational therapy role needs to be supported by sound evidence. For example, demonstrating admission avoidance and the cost savings made through the employment of an occupational therapist's skills
- Need to influence commissioning decisions, especially given the new arrangements for purchasing and provision of care.

This guide therefore, is a starting point for occupational therapists to get involved in these debates. The needs identified are important, and can only be addressed by occupational therapists working together, as well as with key partners, to promote their role. End of life care will continue to be a priority; occupational therapy staff are therefore encouraged to use the resources provided in this guide and to contact the NEoLCP and COT with any further suggestions and ideas.



Occupational therapy core skills and their practical application to end of life care

As highlighted in the aims of the guide, one of the barriers identified by stakeholders, which prevents occupational therapists from engaging with end of life care, is a lack of clarity as to what that role should be. The intention in this Appendix is to make the desirable role more explicit.

The approach taken is to review occupational therapy core skills, with which all occupational therapists will be familiar, and to then show how these can be applied to the end of life care setting. In the final section, the areas of knowledge with which occupational therapists will need to be familiar are identified, based on the recommendations made in the *End of life care strategy*.¹

It is anticipated that this will enable occupational therapists to take a proactive approach within the end of life care setting. It will also enable other health and social care professionals to engage with what occupational therapy is and what occupational therapists can do. It will be particularly relevant to those who may wish to commission end of life care services in the future.

A useful starting point when discussing the occupational therapy role is to consider what most people consider to be 'a good death'. The *End of life care strategy*¹ (England) suggests that this generally "involve[s]:

- Being treated ... with dignity and respect;
- Being without pain and other symptoms;
- Being in familiar surroundings;
- Being in the company of close family and/or friends."

Keeping these points in mind should help to guide occupational therapy intervention.

Core skills and key areas of intervention

"Occupational therapy is a client-centred health profession concerned with promoting health and well being through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. Occupational therapists achieve this outcome by working with people and communities to enhance their ability to engage in the occupations they want to, need to, or are expected to do, or by modifying the occupation or the environment to better support their occupational engagement." (Information page on World Federation of Occupational Therapists website).⁵

Although this definition identifies occupational therapy as a 'health' profession, it is widely recognised that OTs are employed in all care sectors, including local authorities and charitable organisations.

From the World Federation definition, occupational therapists are therefore concerned with:

- How they can enable people to function at an optimal level, despite impairments
- How people feel about themselves (subjective feelings of wellness)
- How the physical and the social environment can be altered so that people can live their lives as independently as possible.

In order to address these concerns, occupational therapists are able to use core skills which can be adapted to working with people reaching the end of life. COT/BAOT

Briefing 23: Definitions of core skills for occupational therapy (COT/BAOT, 2009)⁶ uses Creek's definition of core skills:

"The core skills of the occupational therapist are built around occupation and activity. These are complex skills made up of many component sub-skills which include, for example, cognitive skills and group leadership skills.

The occupational therapist's core skills are:

- Collaboration with the client: building a collaborative relationship with the client that will promote reflection, autonomy and engagement in the therapeutic process
- Assessment: assessing and observing functional potential, limitations, ability and needs, including the effects of physical and psychosocial environments
- Enablement: enabling people to explore, achieve and maintain balance in their activities of daily living in the areas of personal care, domestic, leisure and productivity
- Problem solving: identifying and solving occupational performance problems
- Using activity as a therapeutic tool: using activities to promote health, well being and function by analysing, selecting, synthesising, adapting, grading and applying activities for specific therapeutic purposes
- Group work: planning, organising and leading activity groups
- Environmental adaptation: analysing and adapting environments to increase function and social participation." (*Occupational therapy defined as a complex intervention*, J Creek, 2003).⁷

This definition of core skills gives a good overview of the skills occupational therapists can apply when working with people reaching the end of life. Skills which are implied rather than explicit include communication skills and skills in working with and supporting families and carers. This raises the question: how can

some of these skills be applied when working with people reaching the end of life?

Practical application of occupational therapy skills

As previously stated, there are intuitive similarities between occupational therapy values and core skills, and the delivery of high quality end of life care. How might an occupational therapist apply those skills and move from the intuitive to the specific? Practical suggestions are given below:

Facilitating occupation

Central to occupational therapy is the belief that we influence our own health and wellbeing through occupation. An occupational therapist might help a person to decide what activities might hold meaning at the end of life, and how they might best be pursued. Such activities could range from being able to listen to particular music, to attending a particular important event such as a wedding or an award ceremony, to ensuring that pets which have become companions over the years are properly looked after.

There is a possible link here between meaningful occupation and spiritual concerns. Grant et al give some helpful suggestions as to what those spiritual concerns might be. "Searching for meaning: 'What was the purpose of my life?' ... [or] Searching for reconciliation of memories, and of broken relationships, for reunion and community of spirit among all relations" (*Spiritual dimensions of dying in pluralist societies*, Grant et al, British Medical Journal, 25 Sep 2010)⁸. Spirituality is often related to faith and/or religion, but there is also an occupational dimension in terms of identifying what activities are the most important for the person. When reaching the end of life, the occupational therapist may help the person decide on what his/her most important goals are, as suggested below:

Goal setting using person centred approaches

Does the person have a particular goal? What does the person see as a meaningful goal? Could it involve communicating with a particular person? Taking part in a particular hobby which has always held interest? Continuing to manage the most basic of tasks independently? Being in a particular place? The occupational therapist will be guided by the person as to what his/her most important goals are, and work out strategies to enable them where possible. Goals could be related to achieving 'a good death'. For example, being in familiar surroundings and with familiar people.

Activity analysis

Occupational therapists are able to break tasks down into their component activities in order to identify the key demands (physical, cognitive, social and/or environmental). They then compare the person's skills, strengths and resources with the demands of the activity and teach skills or modify the activity where possible to make it manageable for the person. Practical strategies might include re-design of the layout of a living area, getting help with personal activities of daily living so that the person has more energy when with his/her children, employing assertiveness techniques, breaking tasks down so that they can be completed in manageable stages etc. Personalised services and reablement initiatives are implemented by occupational therapists, who use these activity analyses to contribute to social care recommendations.

Adapting the environment

Occupational therapy might involve making an environment suitable for the person's needs. This could be their home (including care home) or workplace, and adaptations could involve changes such as putting in ramps - so an area can be accessed using a wheelchair or by fitting a stair lift. Occupational therapists also work with housing authorities to design more

complex adaptations. Timing and proactive intervention is crucial in the context of end of life care, since time is needed to make alterations, but the person also needs time to accept that such adaptations may be necessary and to weigh up any alternatives. Additionally, the person and his/her family have to cope with the stress involved in having building works carried out during what is already a stressful time.

Special equipment

Occupational therapists have a role in prescribing equipment and assistive technology which could include:

- Equipment to assist with mobility, personal and/or domestic activities of daily living
- Moving and handling equipment
- Computer adaptations
- Environmental controls
- Telecare equipment.

Simple equipment such as chair raisers, rails and perching stools can make a big difference to quality of life, as well as the more complex assistive technology. Whilst equipment can help in many situations, it can be crucial when a person is reaching the end of life. For example, access to the necessary equipment is a key to the person being able to remain in or to be discharged to their preferred place of care.

Having reviewed occupational therapists' core skills and how they might be applied, the knowledge base and key interventions for occupational therapists working with people at the end of life will be discussed.

Knowledge base required for end of life care

This is what occupational therapists need to know to apply their skills specifically to end of life care, based on the recommendations made in the *End of life care strategy*.¹

Intervention

Intervention will follow the basic occupational therapy process: a person centred and holistic process consisting of information gathering, building rapport, assessment, identification of priorities, goal setting, intervention and review. However, there will be particular aspects which will make intervention specific for a person reaching the end of life.

Firstly, the assessment will include an assessment of the person's strengths, needs and wishes, as well as those of his/her family. The assessment is an opportunity to contribute to advance care planning as appropriate.

Secondly, in terms of identifying priorities and goal setting, occupational therapists will have a key role in facilitating the person to die at home if this is their choice. The social care framework makes the point that "If people can stay in their own homes for longer they are likely to retain better quality of life right up until the point of death."² Thirdly, for many people, their home is their care home, so enabling people to remain or return there is important. Occupational therapists working in acute care will have a key role in discharge planning, those working in social services in assessing for and recommending housing adaptations, if appropriate. It is also important to be aware of any additional occupational goals which are important for the person and his or her family.

Intervention will be based on activity analysis and matching of the person's abilities with the required activities. Depending on training and experience, specific interventions may include:

- Non-pharmacological management of specific symptoms such as pain, anxiety or fatigue
- Moving, handling and posture management – providing assistance and advice to the individual, carers and families
- Supporting continued participation in activities which are important for the person

- Adapting the environment
- Assessing for and prescribing equipment and assistive technology, including telecare
- Maintaining dignity and privacy where appropriate in daily living activities.

The review process provides further opportunity for the person to discuss his or her preferences and concerns, and to provide support for carers.

When the person has died, it may be possible to offer bereavement support, enabling the bereaved person to talk about their feelings and to pursue alternative meaningful activities when they are ready. Sometimes the continuity provided by the occupational therapist who saw the person when he/she was alive can be helpful.

Communication and co-ordination

Throughout the process, occupational therapists will need to make full use of their interpersonal and communication skills. This will be with the individual and his/her family, using active listening skills, determining specific goals and providing information as necessary. It will also be with other health and social care professionals, within and between different teams and organisations. Occupational therapists may also need to liaise with third sector organisations – see 'Services in your local area' (below). Finally, occupational therapists will need to be able to access and use electronic records where they are available.

Promoting equality

Occupational therapists should ensure that they provide an equitable service irrespective of the person's age, gender, disability, sexual preference, culture, religion or ethnicity. Additionally, "Those caring for the dying and bereaved should have a reasonable knowledge of various practices of different faith groups, know the limits of their knowledge and, where necessary, seek help and support."¹

Personalisation and person centred services

"Personalisation is about giving people much more choice and control over their lives and goes well beyond simply giving personal budgets to people eligible for council funding. Personalisation means addressing the needs and aspirations of whole communities to ensure everyone has access to the right information, advice and advocacy to make good decisions about the support they need. It means ensuring that people have wider choice in how their needs are met and are able to access universal services such as transport, leisure and education, housing, health and opportunities for employment, regardless of age or disability." (*Personalisation: a rough guide (SCIE report 20)*, S Carr, Social Care Institute for Excellence, 2010)⁹

It is important, therefore, that intervention is tailored to meet the needs of the person wherever possible. Although personal budgets are only one aspect of personalisation, they are relevant for the occupational therapy role described above in matching the person's skills and abilities with meaningful activities, and devising solutions to make those activities possible.

Services in your local area/directories

It is worth occupational therapists making themselves aware of services in their local area which may be able to offer support for the person or his/her family. Such services might include charities which may be able to assist with funding for equipment or other services, advocacy services, care and repair schemes, respite care services, hospice-based services, shopping services, befriending schemes etc.

Proactive approach

All UK strategies advocate a proactive approach to end of life care. Being aware of disease trajectories, (which can be sudden, gradual or 'stepped' in progression) may be useful for occupational therapists, especially

those providing long term community support, or where the person is having repeated admissions to hospital.* Advance care planning is also recommended; this facilitates discussion of individuals' concerns, values or goals for care, understanding of illness and prognosis, preferences for treatment and availability of these.

Specific tools

Preferred priorities for care (PPC)

is a specific tool which facilitates advance care planning and is a tool for starting conversations and recording an individual's care choices. <http://www.endoflifecareforadults.nhs.uk/publications/ppcform>)

Gold Standards Framework (GSF) is a recommended tool developed originally for use in primary care; it can also be used in care homes. The tool helps to identify people who are reaching the end of life, assess their needs and preferences, plan care and communicate across agencies. It is useful if occupational therapists can make themselves aware of this. (<http://www.goldstandardsframework.nhs.uk>)

The Liverpool Care Pathway (LCP) guides delivery of care in the last few days of life, including symptom control, comfort, anticipatory prescribing, discussion of appropriate interventions, psychological and spiritual care and care of the family. Occupational therapists may be less involved in this pathway, but it is useful to have a basic awareness of what it is and when it is used. (<http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/>)

Decision regarding Do not attempt cardiopulmonary resuscitation (DNACPR)

A person who has been identified as reaching the end of life may have made decisions about their future care, including whether or not he/she would wish to be resuscitated. An occupational therapist may need to be

* *The End of life care strategy*¹ gives useful information about disease trajectories. Refer to pp 45-7.

aware of this decision, depending upon the setting in which he/she works. The decision is highlighted here as occupational therapists will need to clarify what their responsibilities are, as well as their employers' policies. Whenever possible, it is always best to know what the person's DNACPR status is.

Mental Capacity

Mental capacity "... refers to a service user's ability to make decisions for themselves. This will include their ability to retain, understand and weigh up information and be consistent in decision making." (*Briefing 60: Mental Capacity Act 2005*, COT/BAOT, 2007)¹⁰

Amongst groups of people covered by the *Mental Capacity Act (2005)* are people who have "physical/medical conditions that cause confusion, drowsiness or loss of consciousness."¹⁰

"All care staff must have the ability to make an assessment of capacity and select what is in a service user's best interests before providing any care or interventions." (C Wall¹¹ quoted in *Briefing 60*¹⁰)

It is important therefore that occupational therapists/ occupational therapy staff working with people reaching the end of life are familiar with the Act and the implications for their practice. COT/BAOT *Briefing 60* is a useful resource for this. There is also a support sheet at the end of this guide (Appendix 3).

Safeguarding agenda

All occupational therapists need to be aware of their responsibilities regarding protection of vulnerable adults (as well as children, if appropriate) and take any necessary actions if abuse is suspected.

Quality markers for end of life care

(End of life care strategy: quality markers and measures for end of life care, Department of Health, 2009)¹²

1. Have an action plan for the delivery of high quality end of life care, which encompasses patients with all diagnoses, and is reviewed for impact and progress.
2. Institute effective mechanisms to identify those who are approaching the end of life.
3. Ensure that people approaching the end of life are offered a care plan.
4. Ensure that individuals' preferences and choices, when they wish to express them, are documented and communicated to appropriate professionals.
5. Ensure that the needs of carers are appropriately assessed and recorded through a carer's assessment.
6. Have mechanisms in place to ensure that care for individuals is coordinated across organisational boundaries 24/7.
7. Have essential services available and accessible 24/7 to all those approaching the end of life who need them.
8. Be aware of end of life care training opportunities and enable relevant workers to access or attend appropriate programmes dependent on their needs.
9. Adopt a standardised approach (Liverpool Care Pathway or equivalent) to care for people in the last days of life.
10. Monitor the quality and outputs of end of life care and submit relevant information for local and national audits.

Support sheet Mental Capacity Act

Compiled from the *Mental Capacity Act 2005 code of practice*¹³ by Julie Foster, end of life care lead, Cumbria and Lancashire End of Life Care Network

The Act is intended to be enabling and supportive of people who lack capacity, not restricting or controlling of their lives. It aims to protect people who lack capacity to make particular decisions, but also to maximise their ability to make decisions, or to participate in decision-making, as far as they are able to do so.

The five statutory principles are:

1. A person must be assumed to have capacity unless it is established that they lack capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

How should people be helped to make their own decisions?

To help someone make a decision for themselves, check the following points:

Providing relevant information

Does the person have all the relevant information they need to make a particular decision? If they have a choice, have they been given information on all the alternatives?

Communicating in an appropriate way

Could information be explained or presented in a way that is easier for the person to understand (for example, by using simple language or visual aids)? Have different methods of communication been explored if required, including non-verbal communication? Could anyone else help with communication (for example, a family member, support worker, interpreter, speech and language therapist or advocate)?

Assessing capacity

Anyone assessing someone's capacity to make a decision for themselves should use the two-stage test of capacity. Does the person have an impairment of the mind or brain, or is there some sort of disturbance affecting the way their mind or brain works? (It doesn't matter whether the impairment or disturbance is temporary or permanent.) If so, does that impairment or disturbance mean that the person is unable to make the decision in question at the time it needs to be made?

Assessing ability to make a decision

Does the person have a general understanding of what decision they need to make and why they need to make it? Does the person have a general understanding of the likely consequences of making, or not making, this decision? Is the person able to understand, retain, use and weigh up the information relevant to this decision? Can the person communicate their decision (by talking, using sign language or any other means)? Would the services of a professional (such as a speech and language therapist) be helpful?

Assessing capacity to make more complex or serious decisions

Is there a need for a more thorough assessment (perhaps by involving a doctor or other professional expert)?

1. *End of life care strategy: promoting high quality care for all adults at the end of life*, Department of Health (DH), 2008 <http://www.endoflifecareforadults.nhs.uk/publications/eolc-strategy>
2. *Supporting people to live and die well: a framework for social care at the end of life*, National End of Life Care Programme (NEoLCP), 2010 <http://www.endoflifecareforadults.nhs.uk/publications/supporting-people-to-live-and-die-well-a-framework>
3. *Professional standards for occupational therapy practice*, College of Occupational Therapists (COT), 2007 <http://www.cot.co.uk/library-publications/cot-publications/standards-and-strategy>
4. *Code of ethics and professional conduct*, COT, 2010 <http://www.cot.co.uk/library-publications/cot-publications/standards-and-strategy>
5. What is occupational therapy? (information page) on website of the World Federation of Occupational Therapists <http://www.wfot.org/information.asp>
6. *Briefing 23: Definitions of core skills for occupational therapy*, COT/British Association of Occupational Therapists (BAOT), 2009 (COT members can access this briefing online at <http://www.cot.org.uk/various-aspects-of-ot/briefing-23-definitions-and-core-skills-occupational-therapy>)
7. *Occupational therapy defined as a complex intervention*, J Creek, 2003
8. *Spiritual dimensions of dying in pluralist societies*, Grant et al, British Medical Journal, 25 Sep 2010 <http://www.scotland.gov.uk/Resource/Doc/924/0106421.pdf> or BMJ archive at <http://www.bmj.com/content/by/year>
9. *Personalisation: a rough guide (SCIE report 20)*, S Carr, Social Care Institute for Excellence, revised 2010 <http://www.scie.org.uk/publications/reports/report20.asp>
10. *Briefing 60: Mental Capacity Act 2005*, COT/BAOT, 2007 (COT members can access this briefing online at <http://www.cot.org.uk/english-and-welsh-policy-legislation-and-finance/briefing-60-mental-capacity-act-2005>)
11. *Personal Care Consultants Update: MCA 2005*, C Wall, Personal Care Consultants Ltd, 2007
12. *End of life care strategy: quality markers and measures for end of life care*, DH, 2009 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_101681
13. *Mental Capacity Act (2005) code of practice*, Department for Constitutional Affairs, 2007 <http://www.justice.gov.uk/guidance/protecting-the-vulnerable/mental-capacity-act/index.htm>

Key documents and strategies

End of life care strategy: promoting high quality care for all adults at the end of life, Department of Health (DH), 2008 <http://www.endoflifecareforadults.nhs.uk/publications/eolc-strategy>

Supporting people to live and die well: a framework for social care at the end of life, National End of Life Care Programme (NEoLCP), 2010 <http://www.endoflifecareforadults.nhs.uk/publications/supporting-people-to-live-and-die-well-a-framework>

Common core competences and principles for health and social care workers working with adults at the end of life, NEoLCP/Skills for Health/Skills for Care/DH, 2009 http://www.endoflifecareforadults.nhs.uk/eolc/files/NHS-EoLC_Core_competences-Guide-Jul2009.pdf

End of life care strategy: quality markers and measures for end of life care, DH, 2009 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_101681

Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own, DH, 2008 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085345

Our health, our care, our say: a new direction for community services, DH, 2006 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_4127552

Transforming community services: ambition, action, achievement transforming end of life care, DH, 2009 <http://www.dh.gov.uk/en/Healthcare/TCS/index.htm>

Report to the National Allied Health Professional Advisory Board on the outcomes of the modernising allied health professional careers programme, DH, 2011 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_124801

Framing the contribution of allied health professionals: delivering high-quality healthcare, DH, 2008 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_089513

End of life care Quality Standard, National Institute for Health and Clinical Excellence (NICE), publication due Nov 2011

College of Occupational Therapists core documents

Professional standards for occupational therapy practice, College of Occupational Therapists (COT), 2007 <http://www.cot.co.uk/library-publications/cot-publications/standards-and-strategy>

Code of ethics and professional conduct, COT, 2010 <http://www.cot.co.uk/library-publications/cot-publications/standards-and-strategy>

Occupational therapy core skills

Briefing 23: Definitions of core skills for occupational therapy, COT/British Association of Occupational Therapists (BAOT), 2009 (COT members can access this briefing online at <http://www.cot.org.uk/various-aspects-of-ot/briefing-23-definitions-and-core-skills-occupational-therapy>)

Occupational therapy defined as a complex intervention, J Creek, 2003

Advance care planning

Capacity, care planning and advance care planning in life limiting illness: a guide for health and social care staff, NEOFPC, 2011 <http://www.endoflifecareforadults.nhs.uk/publications/pubacpguide>

Advance decisions to refuse treatment: a guide for health and social care professionals, NEOFPC/National Council for Palliative Care, 2008 <http://www.endoflifecareforadults.nhs.uk/publications/pubadrtguide>

Planning for your future care: a guide, NEOFPC/National Council for Palliative Care/University of Nottingham, 2009 <http://www.endoflifecareforadults.nhs.uk/publications/planningforyourfuturecare>

Making a will (Directgov guidance on wills including links to Citizens Advice Bureau guide to making a will and Age Concern fact sheet) http://www.direct.gov.uk/en/Governmentcitizensandrights/Death/Preparation/DG_10029800

Mental capacity

Mental Capacity Act (2005) code of practice, Department for Constitutional Affairs, 2007 <http://www.justice.gov.uk/guidance/protecting-the-vulnerable/mental-capacity-act/index.htm>

Briefing 60: Mental Capacity Act 2005, COT/BAOT, 2007 (COT members can access this briefing online at <http://www.cot.org.uk/english-and-welsh-policy-legislation-and-finance/briefing-60-mental-capacity-act-2005>)

Best interests at the end of life: practical guidance for best interests decision making and care planning at end of life (relating to the Mental Capacity Act (2005) England and Wales), C Hutchinson/J Foster, East Lancashire PCT/Central Lancashire PCT, 2008 <http://www.endoflifecareforadults.nhs.uk/publications/bestinterestseolguide>

Specific tools and assessments

Preferred priorities for care (PPC) <http://www.endoflifecareforadults.nhs.uk/tools/core-tools/preferredprioritiesforcare>

Gold Standards Framework (GSF) <http://www.goldstandardsframework.nhs.uk>

About the AusTOMs for occupational therapy (information page), Unsworth/Duncombe, LaTrobe University website http://www.latrobe.edu.au/austoms/OT_sc.htm

Distress thermometer, UK Oncology Nursing Society (UKONS) website <http://www.ukons.org/downloads/index.html>

Personalisation, including personal health budgets

Personalisation: a rough guide (SCIE report 20), S Carr, Social Care Institute for Excellence, revised 2010 <http://www.scie.org.uk/publications/reports/report20.asp>

Personalisation & person centred services (information pages on personalisation, including direct payments) on COT website <http://www.cot.co.uk/personalisation-person-centered-services/personalisation-person-centred-services>

Personal health budgets (information page) on DH website <http://www.dh.gov.uk/en/Healthcare/Personalhealthbudgets/index.htm>

Reablement

Reablement: the added value of occupational therapists (position statement), COT, 2010 <http://www.cot.co.uk/position-statements/reablement-added-value-occupational-therapists-0>

Other useful resources

The College of Occupational Therapists Specialist Section – Independent Practice (COTSS-IP) online <http://www.cotss-ip.org.uk>

Living and dying with dignity: the best practice guide to end-of-life care for people with a learning disability, Mencap, 2008 <http://www.mencap.org.uk/page.asp?id=9753>

Out-of-hours toolkit, Macmillan Learn Zone (online learning resources for professionals) www.macmillan.org.uk/learnzone

Can you see me? (DVD), National Council for Palliative Care (NCPC), 2010 (DVD available from NCPC at <https://www.committedgiving.uk.net/ncpc/publications/>)

Condition-specific publications such as *End of life care in advanced kidney disease: a framework for implementation*, NEoLCP/NHS Kidney Care, 2009 <http://www.endoflifecareforadults.nhs.uk/publications/eolcadvancedkidneydisease> (See NEoLCP website for further examples: <http://www.endoflifecareforadults.nhs.uk/>)

NHS Choices (patient information) <http://www.nhs.uk/aboutNHSChoices>

Admiral Nurses® <http://www.dementiauk.org/what-we-do/admiral-nurses/>

Cruse Bereavement Care <http://www.crusebereavementcare.org.uk>

The ten essential shared capabilities: a framework for the whole of the mental health workforce, R Hope, DH/National Institute for Mental Health England/Sainsbury Centre for Mental Health Joint Workforce Support Unit/NHS University, 2004 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4087169

Spiritual dimensions of dying in pluralist societies, Grant et al, British Medical Journal, 25 Sep 2010 <http://www.scotland.gov.uk/Resource/Doc/924/0106421.pdf> or BMJ archive at <http://www.bmj.com/content/by/year>

Useful websites

National End of Life Care Programme (NEoLCP) <http://www.endoflifecareforadults.nhs.uk>

College of Occupational Therapists (COT) <http://www.cot.co.uk>

National Council for Palliative Care (NCPC) www.ncpc.org.uk

Dying Matters Coalition www.dyingmatters.org

Help the Hospices <http://www.helpthehospices.org.uk>

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