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Occupational therapy

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Guidance for professionals, managers and decision-makers

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For more information about HOPE (the College of Occupational Therapists Specialist Section for HIV/AIDS, Oncology, Palliative Care and Education), please contact the College of Occupational Therapists, 31-43 Wimpole Street, London W1G 9QD.
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Introduction

"I need to be independent. That’s the main thing. I haven’t got to have someone come in and wash me and things like that. I can still do that for myself."

Aims of the guidance

What is the contribution of occupational therapy in the care of people with cancer? That is the simple question this document aims to answer. It is guidance in its loosest sense – not a set of strict guidelines that occupational therapists or those who commission their services must follow. The document is a general description of what occupational therapists can and do accomplish for people with cancer, designed to guide and support those who are involved with commissioning or providing cancer services.

The publication aims to demonstrate the potential of occupational therapy using as its basis the expert consensus of the profession supported by references to literature documenting the occupational therapy contribution. It is targeted at cancer network managers and tumour groups, with the aim of improving appropriate referral and encouraging best practice, and at occupational therapists and their teams.

Background

The publication has been produced by HOPE – the occupational therapy specialist section for HIV/AIDS, Oncology, Palliative Care and Education. HOPE is affiliated to the College of Occupational Therapists.

Occupational therapists and other rehabilitation professionals have long been aware of the contribution they can make to helping people with cancer live fulfilled lives, but until recently their role has not been widely appreciated. However, since the publication of the Calman Hine report in 1995 and the ensuing implementation of a national Cancer Plan, there has been a growing awareness among other professions of the importance of rehabilitation in the care of people with cancer.

The change has not been solely due to centralised moves to improve cancer services in the UK. Over the past two decades, the implementation of the Disability Discrimination Act (1995), the increasing currency of social models as opposed to medical models of disability, and the increasing strength and influence of the hospice movement have made all the more apparent the importance of health professionals whose first priority is improving quality of life. Current moves towards community-based care, and reducing hospital admission times, has further reinforced the value of occupational therapy.

In the field of palliative care, there has been a gradual and vital realisation that rehabilitation does not simply mean getting people functioning independently again. It means affixing peoples’ lives – no matter what stage of illness they are at – by providing them with physical, social and emotional opportunities, and a sense of control. This found expression in the National Council for Hospice and Specialist Palliative Care Services document “Fulfilling lives”. Cancer services, however, have been slower in understanding the full potential of rehabilitation services.

In 2002, the NHS Modernisation Agency testified to the role of occupational therapy in the critical care setting. In its report on the role of allied health professions in critical care it said that critical care was all too often seen only as

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the act of saving life, and therefore the role of occupational therapists could be overlooked. "The lack of recognition of the role in critical care makes it difficult to access resources appropriate to meet the needs of the patient," it said. It was against this background that HOPE began to plan this document – to capitalise on the momentum and pin down and publicise the exact contribution of occupational therapy in the field of cancer and palliative care. The organisation originally envisaged publishing a series of documents, each looking at particular types of cancer beginning with breast cancer and lung cancer. It compiled information from specialist practitioners and literature to form an expert consensus. The practitioners contributed their thoughts at three workshops, and the College of Occupational Therapists contributed a review of relevant literature. Forty seven specialist occupational therapy practitioners have helped develop this document.

So many common elements emerged for both breast and lung cancer, that it was decided that there should be this one core document for all cancers, and then additional accompanying sheets that could spell out some of the specialist issues for occupational therapy and particular cancers.

*The relevance of this guidance today*

This HOPE and College of Occupational Therapists guidance comes at a particularly important time. The contribution of occupational therapy (OT) is not always understood by managers and policy makers, and there is evidence that current standards of provision are variable. A HOPE questionnaire of palliative care providers in 2001 showed that only 14% of services employed more than one full-time occupational therapist. The average number of OT hours per palliative care service ranged between 0 and 98, with the average size of a palliative care unit being 12 beds plus home care services for patients in the community.

This cannot continue. The provision of quality rehabilitation for people with cancer has become a matter of national priority. The National Institute for Clinical Excellence (NICE) has issued new service guidance, "Supportive and Palliative Care Services", intended mainly for those who commission cancer services. This spells out the requirement for consistent and quality rehabilitation services in oncology and palliative care across cancer networks. It means that occupational therapists will have to coordinate and communicate across service boundaries to improve patient care.

Underpinning this is the Department of Health’s first Allied Health Professions Cancer Strategy for England and Wales (2004). This vital document sets out what will be needed to deliver the standards defined in the NICE guidance. For the first time, the role of occupational therapy is being set in cancer standards, and services will have to be developed to fulfil the requirements of policy.

At the same time, many commissioners, particularly Primary Care Trusts need good, concise information to guide them in decision-making. They need to know more than ever the value they are getting for their money. And, with the advent of Patient Choice, they need to be able to demonstrate to patients the quality of treatment options that are available to them.

This guidance aims to provide them with that information.

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2 Guidance on Cancer Services: Improving Supportive and Palliative Care for Adults with Cancer: NICE 2004
3 Due to be published during 2004
“The occupational therapist encouraged me to do things I wouldn’t have done on my own. So you don’t just sit there and think ‘I can’t do anything’. It’s making you feel more the whole person instead of thinking about your…the tumour. Do you know what I mean? It enriches your life.”

What is occupational therapy?

An occupational therapist uses specific activities to limit the effects of disability and promote independence in all aspects of daily life.

Occupational therapy has recently been defined by the College of Occupational Therapists as follows:

“The occupational therapist focuses on the nature, balance, pattern and context of occupations and activities in the lives of individuals, family groups and communities. It is concerned with the meaning and purpose that people place on occupations and activities and with the impact of illness, disability or social or economic deprivation on their ability to carry them out. The main aim of occupational therapy is to maintain, restore, or create a match, beneficial to the individual, between the abilities of the person, the demands of her/his occupations and the demands of the environment, in order to maintain or improve the client’s functional status and access to opportunities for participation.”

How do occupational therapists work in oncology?

Some occupational therapists are part of specialist teams working in cancer centres, cancer units on general medical units and in the community. Others work in the field of palliative care – that is, the active total care of people whose cancer does not respond to curative treatment.

Like other rehabilitation professionals, occupational therapists aim to improve quality of life, so that people's lives will be as comfortable and productive as possible and they can live as independently as possible. This applies even if life expectancy is short. Because people with cancer can experience very rapid changes in their illness and care setting occupational therapists working with these people need to be particularly responsive to changing need. They respond quickly and plan...
Occupational therapists have a role to play at all stages of the cancer pathway (see diagram) from diagnosis to palliative and terminal care. Many health professionals in oncology nowadays assess the functional status of their patients using performance scales. Some doctors in lung cancer, for example, use performance grading systems, for example, ECOG Performance Status\(^{10}\) (Oken et al., 1982) to help judge which treatments are appropriate at a particular time. Occupational therapists have a different emphasis – they see such grades of ability as changeable, working with patients to make them as able as possible. This is the crux of what they contribute.

**Where do occupational therapists work in oncology?**

Occupational therapists promote the well-being and independence of people with cancer in various settings:

- in their homes
- in hospital (acute or community)
- in nursing and residential homes
- in day care hospices
- in in-patient hospices

As people move between home, hospitals and specialist care, they should have access to occupational therapy services at any stage and in all sectors. This should be a “seamless service” – a concept that fits in very well with occupational therapists’ holistic outlook.\(^{11}\)

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\(^{11}\) From Interface to Integration: a strategy for modernising occupational therapy services in local health and social care communities. London, College of Occupational Therapists, 2002
Chapter 2

Using this guidance

"It makes me feel good that I actually feel I’ve achieved something. You know, just because you’ve got an illness doesn’t mean to say we’re confined to, say, sitting and reading a book. I like to be able to use my hands as much as I can.”

How the guidance is arranged

The following chapter (chapter 3) presents an overview of occupational therapy interventions for people with cancer – looking at the key principles of occupational therapy that are applied whatever the symptom, whatever the setting.

Then the bulk of this publication (chapter 4) is guidance on what occupational therapy can do for specific symptoms associated with cancer. There are many possible ways of documenting the occupational therapy contribution in this field. An alternative arrangement would have been to explain occupational therapy core skills and then provide a list of how they can be applied in caring for people with cancer. However, this would take occupational therapy as the starting point, not the person with cancer. This document aims to demonstrate how occupational therapists respond to real patient needs – symptoms in their loosest but most real sense.

This inevitably means there will be some overlap and repetition in the lists of what occupational therapists can contribute. Many of the occupational therapy interventions for, say breathlessness, will be very similar to those for fatigue. Indeed, it is in some ways artificial to itemise all the symptoms separately anyway because people with cancer don’t just have one symptom – they have many. The way an occupational therapist responds will depend on the complex interplay of symptoms and how they affect a person’s quality of life.

However, the guidance is arranged like this for easy reference – to demonstrate at a glance the difference occupational therapists can make to a wide range of conditions and people.

HOPE is also publishing a series of information sheets dealing with particular cancers – looking at the policy context, any specific clinical issues that arise for that type of cancer, and the relative importance and interplay of symptoms that may be particularly important. Fact sheets on breast and lung cancer are inserted into the flap at the back of this publication and additional sheets can be found at the HOPE website.

What groups of patients and settings are covered?

This main document covers people with all types of cancer and on all parts of the cancer pathway from diagnosis onwards – treatment, end of treatment, long-term monitoring and
follow up, relapse, continuing treatment, cure, palliative care and terminal care. It also covers all settings in which occupational therapists work – in hospitals, hospices, nursing and residential homes, and people’s own homes.

The additional HOPE information sheets dealing with occupational therapy and specific cancers are obviously more focussed.

### Expert testimony

Throughout the following sections, small extracts from the literature accompany the accounts of the OT contribution to different symptoms. These are included to provide further expert backing to the points being made. They are usually not exact quotations from the articles but provide a summary of the pertinent points made in the article. The full references for the articles quoted are provided in the appendix at the back of this document.

### Other important information

One thing has to be made explicit about this guidance. An occupational therapist will not do anything unless it is with the person with cancer’s full agreement. It is easy to create the impression in guidance such as this that occupational therapy has a set agenda – a list of things they expect to do, and to which the person with cancer somehow is expected to conform. Nothing could be further from the truth. An occupational therapist’s starting point is always the experiences of the people they are working with – the person with cancer and their family/carer – and their choices and priorities drive any interventions that take place. Occupational therapists work in partnership with people with cancer and help them find new options to improve the quality of their lives.
Chapter 3

The guidelines 1 – General points for all interventions

"It’s their encouragement to try things. Otherwise I’d have been so depressed, because I can’t use this hand. Even though I can’t do all of it in the way I used to, it’s still very satisfying. It’s started me off again, doing things at home. I was feeling so frustrated before.”

At its simplest, the key outcome of occupational therapy intervention is quality of life. For many people with cancer helped by occupational therapists, one of the most important means to achieving this will be independence. However, for people who are receiving palliative care, this may not always be the first priority. Quality of life may have far more to do with affirming life – providing people with physical, social and emotional opportunity, and a sense of control in their own lives.

To achieve these objectives, occupational therapists apply their core skills to all interventions. This applies as much to cancer as any other condition. They use these skills to empower people to make choices, achieve a personally acceptable lifestyle, and maximise health.

These skills are:

- Enabling people to maximise their physical, emotional, cognitive, social and functional potential

- Anticipating the effects of disability through education and therapeutic intervention
- Enabling people to achieve a quality of life by preparing them for a return to work, or developing opportunities in leisure, education, training and voluntary work
- Advocating for people on access matters
- Providing practical advice and support for families and carers
- Changing their input as the needs of people change
- Forming partnerships with others to develop services for people.

Occupational therapists’ starting point will always be the choices and priorities of the person with cancer. This will guide all interventions and decisions.

Occupational therapists are quite systematic about the way they apply these core skills. The next chapter illustrates the way they can apply them to help specific symptoms, but it is worth noting here the process they invariably use in addressing all these problems. They will work through the following sequence:

1. Information gathering
2. Initial assessment
3. Identifying abilities and needs
4. Goal setting
5. Action planning
6. Action
7. Ongoing assessment
8. Revision of action
9. Outcome measurement
10. Discharge/End of intervention
11. Review

Adapted from Core Skills and a Conceptual Framework for Practice, a College of Occupational Therapists position statement, 1994
Adapted from Occupational Therapy Defined as a Complex Intervention, College of Occupational Therapists, April 2003
In all interventions with people with cancer, occupational therapists will need to plan ahead, and anticipate the possibility of changes in the person’s condition or circumstances. Sometimes change or deterioration can happen quickly or unexpectedly and occupational therapists will need to be able to react to that. Continuous review is essential to ensure that the occupational therapist is still working towards the priorities of the individual, and that priorities are still realistic and achievable.

There are other common threads that are woven throughout occupational therapists’ work with people with cancer. Here are three themes of special relevance, which will be found throughout the succeeding chapter about how occupational therapists approach specific symptoms.

**Lifestyle management**
The occupational therapist can:
- work with people with cancer and family/carers to achieve balance in life
- help them assess what priorities are most important to them – including social and spiritual priorities
- help them find occupation which is meaningful to them
- take into account the influences of culture
- provide a crucial link between care in hospital and living at home.

**Fatigue management**
The occupational therapist can:
- recognise that fatigue affects people’s ability to function and be independent
- provide information and advice to people with cancer and family/carers about strategies to manage their fatigue and conserve energy
- help them understand the need to adjust to change, and accept some dependency and fluctuation
- help them establish realistic expectations and goals
- use reduced energy levels as an opportunity for the person to establish what is important to them, and what their priorities should be
- help them adapt their lifestyle to meet their changed energy levels, providing equipment and adapting the environment where necessary
- help people acknowledge their values, and their role within their family and the community
- help them reflect on their current and past achievements to underpin self-worth
- help them adapt to these roles changing
- help people explore their feelings, recognise who they are and what is important to them

One further point is worth noting. On a totally pragmatic level, all occupational therapy interventions, by virtue of aspiring to make people more independent, have the potential to bring cost benefits to the NHS and voluntary sector.

- By providing preventative advice and treatment they can head off complications which are likely to require further referrals and admissions
- By helping make people more physically competent, they can reduce use of Accident and Emergency services – for example, by helping someone with lymphoedema take measures to protect their limbs from injury or by teaching someone with breathing difficulties how to cope with panic attacks.
Occupational therapists improve the quality of survival of people with cancer, so that during the period of survival they will be able to lead as independent and productive lives as possible at a minimum level of dependency regardless of life expectancy.

*(Dietz, 1981)*

Researchers and clinicians should give as much attention to the development and maintenance of psychological well-being in the face of serious illness as they do to the aetiology and treatment of psychiatric symptoms.

*(Folkman and Greer, 2000)*

Client-centred practice is an approach to providing occupational therapy which embraces a philosophy of respect for, and partnership with, people receiving services.

*(Law et al., 1995)*

In working with people who are terminally ill, occupational therapists value an individual's remaining life, help a client live in the present, recognise an individual's right to self-determination, and acknowledge and prepare for the approaching death.

*(Bye, 1998)*

Occupational therapy intervention at the supportive and palliative care stages centres around improving quality of life through the remediation of occupational role dysfunction. Engagement in meaningful activities, be they craft, recreation or work-related, assist in improving self-concept and attain task mastery. The occupational therapist is able to use the developing therapeutic relationship to assist the person with cancer and his or her family to adjust to role changes.

*(Strong, 1987)*

In terminal illness, the person’s physical and social environment must be adapted according to changing abilities, needs and choices. One of the dominant roles of the occupational therapist is to help the person maintain independence and integrity and some control of the environment.

*(American Occupational Therapy Association, 1986)*

Occupational therapists have a unique role in maintaining and increasing independence. Occupational therapists also help people gain greater autonomy and control of their environment through the provision of aids and therapeutic groups.

*(Dawson, 1982)*

Occupational therapists have skills in continuous assessment and evaluation. They can be flexible in changing treatment and goals to ensure meaningful life.

*(Flanigan, 1982)*

An individual can benefit from occupational therapy intervention at any stage of an illness from primary diagnosis through attempts at curative treatment, to palliation and finally terminal illness.

*(Penfold, 1996)*

People with fears about functional decline can be helped with therapeutic goals and rehabilitation throughout the trajectory of malignant disease. Occupational therapy allows people to execute the fine motor tasks required for self-care, and restores autonomy at home.

*(Cheville, 2001)*
This chapter, the heart of these guidelines, itemises the contribution of occupational therapy (OT) in helping people with specific symptoms. The division between different symptoms is designed to provide easy reference, but it is also to some extent artificial. People with cancer experience a range of symptoms often simultaneously. While using this chapter, it is worth bearing in mind that a survey of hospital and hospices found that on average, people were suffering from seven symptoms at the same time. The 12 most common symptoms, in descending order of frequency, were weakness, dry mouth, anorexia, depression, insomnia, pain, swollen legs, nausea, constipation, vomiting, confusion and dyspnoea.

The symptoms itemised in this chapter are those most commonly encountered by occupational therapists in their work with people with cancer. They are (listed in approximate order of how commonly encountered):

• Pain
• Fatigue
• Nausea / vomiting / sore mouth / dysphagia
• Constipation / diarrhoea / urinary problems
• Breathlessness and cough
• Insomnia
• Tissue viability / skin integrity (pressure problems)
• Weight loss (anorexia)
• Neurological problems
• Cognitive deficits
• Anxiety and depression

"When you’ve got cancer, there’s an awful side to it that’s like a downhill slope. You know, people are very ill, and it can be very depressing. The physio and occupational therapy side of it is a bit more go for it – you know, get out there and do it.”

• Fluid retention (lymphoedema, oedema, ascites)
• Body image (including hair loss, surgery lymphoedema)

**Pain**

Pain may affect a person’s ability to care for themselves, to work or to participate in fulfilling activities. This may cause emotional distress to both the person with cancer and their family/carers, affecting their wellbeing and relationships. The main treatments for pain are pharmacological, but OTs have an important role in helping people cope with the impact of pain, and addressing some of its emotional aspects.

The occupational therapist can:

• Assess the impact of pain on self-care, work, leisure activities and social roles
• Analyse problems and solutions

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Work with the person and family/carers to adapt and practise self-care, work, leisure activities and social roles within the person’s functional abilities and pain parameters

• Work with the person to identify goals and priorities
• Collaborate with the person about lifestyle management, including pacing, planning and prioritising, anxiety management, relaxation skills, ergonomics, fatigue management and working within pain tolerance
• Assess whether equipment and environmental adaptation are needed to meet the person’s needs
• Liaise with the multiprofessional team to ensure optimum pain management
• Provide regular review to assess changes in condition and function.

This aims to:
• Increase the individual’s control over their pain
• Maximise independence
• Promote psychological wellbeing and adjustment
• Maintain the individual’s activities and roles
• Support family and carers
• Facilitate close liaison within the multiprofessional team
• Improve quality of life.

Successful pain management can be achieved through coordinated efforts of team members of the cancer care team. Occupational therapy is vital to the pain management service and can help modify perceptions of pain and individuals’ lifestyles.

(Lloyd and Coggles, 1988)

Fatigue can have a devastating effect on people’s ability to maintain normality in their lives. It can:

• Affect a person’s ability to carry out normal activities of daily living: self-care and leisure
• Cause emotional and physical distress to the person and family/carers
• Reduce cognitive ability
• Affect psychological wellbeing
• Affect relationships

The occupational therapist can:

• Identify with the person the factors affecting fatigue
• Assess self-care, work, leisure activities and roles
• Work with the person and family/carers to adapt and practise self-care, work and leisure activities within the person’s functional abilities
• Work with the person to identify their goals and priorities
• Educate the person and family/carers regarding pacing, planning, balancing and prioritising activities, and energy conservation techniques
• Liaise with community and support services
• Teach relaxation techniques
• Teach assertiveness techniques to avoid overtiredness
• Assess whether equipment and environmental adaptation are required to suit the person’s needs (for example, wheelchairs and bath aids).

This aims to:
• Promote psychological wellbeing and adjustment
Improving quality of life
Maximise independence
Increase the person’s control over their fatigue
Maintain the person’s activities and roles
Facilitate close liaison with the multiprofessional team
Allow the person and their family/carers to understand the effects of fatigue
Support family and carers
Enhance understanding of symptoms and reduce friction in relationships

**Occupational therapy intervention in cancer**

> Occupational therapy has a role in educating both patient and carers about energy conservation, lifestyle changes, leisure activities, and alternative means of carrying out activities of daily living. *(Lloyd and Cogges, 1988)*

The patient with a deteriorating condition needs to exercise control and find meaning in life. He or she should be encouraged to conserve energy for activities that are important to him/her in the areas of self-care and leisure. *(Holland, 1994)*

Pre-existing mobility problems place cancer patients at high risk from fatigue and weakness. Weakness is a serious safety concern and may have impact on ability to perform at work and home. Patients need information, and to plan day to day activities and set priorities for energy use. Occupational therapists can also help with mobility and safety aids, environmental modifications and finding appropriate ways to perform tasks. *(Nail and Winningham, 1995)*

**Nausea/Vomiting/Sore Mouth/Dysphagia**

These symptoms have many social, emotional and physical effects. They will

- Cause eating, drinking and digestive disturbances
- Affect meal and drink preparation
- Reduce the social aspect of eating meals and involvement in family life
- Disturb daily routine and sleep patterns
- Alter roles in the home

The *occupational therapist can*:

- Address the difficulties of meal/drink preparation and explore alternatives (for example, using ready meals to avoid long cooking times and cooking smells)
- Advise on seating and positioning for dysphagia
- Advise on the practical implications of the symptoms (for example, on laundry and hygiene)
- Teach relaxation techniques to help reduce nausea and vomiting
- Liaise with the multiprofessional team about mouth care
- Provide education and support to help with the psychological aspects of these symptoms
- Increase the understanding of family/carers, who may find it hard to have normal feeding routines disturbed

This aims to:

- Reduce nausea and vomiting
- Reduce anxiety levels associated with food and meal times
- Facilitate improved relationships and reduce stress regarding meal preparation and lack of consumption/reduced dietary intake.
Interviews with working women with breast cancer reveal the importance of establishing a daily occupational routine including household chores such as preparing meals. Resuming their daily occupational routine serves as a source of satisfaction and a source of motivation that distracts them from the anxiety associated with their lives. In a clinical situation, occupational therapists and their clients work together to develop goals and plan intervention strategies to facilitate the clients participation in meaningful occupation.

(Vrkljan and Miller-Polgar, 2001)

CONSTIPATION/DIARRHOEA/URINARY PROBLEMS

These symptoms will cause social isolation, distress, dressing problems, hygiene difficulties, fatigue, psychological problems. Treatments such as radiotherapy can cause severe diarrhoea.

The occupational therapist can:

- Assess the person’s ability to access toilet facilities, looking at appropriate equipment, transfer, practice etc.
- Assess and adapt the environment as appropriate, addressing issues of hygiene and the problems of fatigue that may accompany frequent toilet visits.
- Advise about appropriate clothing.
- Investigate domestic facilities and ensure they are adequate to manage laundry and hygiene, and refer for financial assistance to obtain bathroom adaptation or washing equipment if appropriate.
- Liaise with the multiprofessional team, including a continence advisor, about causes contributing factors, possible treatment and management.

- Give advice about community facilities, such as the RADAR toilet scheme, Shopmobility etc, to promote engagement and increase confidence in the person’s normal social activities.

This aims to:

- Increase independence in going to the toilet.
- Increase the confidence of the person and their family/carers about managing toileting problems.
- Decrease anxiety and stress.
- Increase confidence in resuming social activities.

The community occupational therapist has an important role in relation to the provision of equipment, adaptations and advice regarding home care, and the need for skilled assessment.

(Pushpangadan and Burns, 1996)

BREATHELESSNESS AND COUGH

Like fatigue, breathlessness (dyspnoea) and continued coughing can affect a person’s productivity and ability to participate in self-care and leisure. It can cause emotional and physical distress to the person and family/carers and affect relationships.

An occupational therapist can:

- Assess how shortness of breath is affecting a person’s activity.
- Assess and analyse activities, daily living, the environment, mobility needs, positioning in bed and seating.
- Examine solutions.
- Provide advice on communicating effectively for example by writing.
- Advise on lifestyle management, and pacing activity.
• Advise on anxiety management and energy conservation
• Teach coping mechanisms and relaxation exercises for episodes of breathlessness
• Provide new equipment, and adapt equipment, such as wheelchairs
• Advise family and carers on handling the person and equipment.

This aims to:
• Improve the person’s quality of life
• Improve independence and ability
• Improve confidence and control
• Reduce the need for medication and dependence on bottled oxygen
• Reduce fear and anxiety
• Reduce psychological dependency on family/carers and others.

Patients with respiratory distress tend to experience high levels of anxiety. The team approach helps patients maintain as much control over their environment as possible. Occupational therapy has a role in this team helping the patient maintain a sense of control, encouraging coping, increasing engagement in meaningful leisure pursuits and providing with exercise programmes.  
(Centers, 2001)

Multi-dimensional assessment is necessary. Some symptoms respond to pharmacological interventions, others are better managed by expressive/supportive counselling, occupational therapy and physiotherapy. The intensity of dyspnoea significantly correlates with anxiety. Education of patients and families is required so that they can anticipate episodes of increased dyspnoea.  
(Roberts, 1999)

INSOMNIA

Poor sleep quality can cause great distress and fatigue to the person with cancer, worsening their symptoms and exhausting family and carers. Some people with cancer choose to sleep upright in a chair, because breathing is harder when they lie down. Others may have disturbed sleep patterns because they nap during the day. A good night’s sleep can bring comfort to the person with cancer and their family/carers.

An occupational therapist can:
• Examine daily routines and assist with lifestyle management
• Ensure the person is active throughout the day
• Assist with posture and positioning
• Assist with mobility and transfers
• Provide advice and equipment enabling bed mobility and transfers
• Teach relaxation techniques

A multiprofessional breathlessness clinic offers sessions run by a physiotherapist, occupational therapist and nurse practitioner. The occupational therapist focuses on energy conservation and gives a clear description of the aims of treatment and the techniques taught.  
(Stent, 2001)
• Provide family and carers with advice about encouraging good sleep, and getting sleep themselves
• Address environmental problems that may be preventing sleep.

This aims to:
• Improve quality of life
• Lower anxiety
• Increase productivity
• Reduce the risk of falling, which can be caused by night wandering or sleep deprivation
• Reduce feelings of depression and low self-esteem (which is linked to sleep deprivation).

Because hypnotic medications can have risks such as dependence, psychologic interventions such as stimulus control and cognitive therapy are the treatment of choice for sleep disturbances in the treatment of cancer

(Sarvard and Morin, 2001)

Occupational therapy as a holistic discipline confronts the debility of clients with the belief that doing must be purposeful and have meaning, thereby engaging the mind and spirit.

(Brindle, 1999)

Tissue Viability / Skin Integrity

People with cancer can remain immobile for long periods. This can cause the skin to break down, which in turn causes discomfort in lying and sitting. Some cancer treatments can also make the skin more vulnerable to breakdown.

Occupational therapists have a role in both preventing the problems associated with pressure to the skin, and helping the person engage in activities when they have pressure problems.

An occupational therapist can:
• Assess the risk of pressure problems, or assess current pressure problems
• Assess the person’s pressure care needs in relation to their activity
• Liaise with other members of the team on how to manage pressure problems, examining issues such as wound care, medicines and nutrition
• Provide advice on posture, pressure relief, and appropriate seating
• Assist with bed mobility and transfers
• Advise on lifestyle management, for example pacing activities, posture, sitting position
• Advise on finding appropriate clothing and where to find it.

This aims to:
• Prevent pressure ulcers
• Maintain independence
• Improve quality of life, and lessen emotional distress, for the person and their family/carers
• Relieve pain and improve comfort
• Lessen the burden on family and carers by reducing laundry, the need for manual handling, and the need for home intervention by outside agencies
• Allow the person to take part in desired activities
• Reduce the professional cost associated with treating pressure ulcers.
Occupational therapists can and do make a positive contribution to patient care, in providing carer support and equipment, symptomatic treatment for physical manifestations such as oedema and pain, and contributions to day care programmes. Prevention of pressure ulcers and hospital falls are examples of adverse outcomes relevant to occupational therapists.

(Brandis, 2000)

Occupational therapy goals include achieving independence in self-care, functional transfers, independent living skills maintaining skin integrity and increasing independence as progress is made. Meal preparation, cleaning, laundry, energy conservation and work simplification may also be necessary.

(Tuel et al., 1992)

**WEIGHT LOSS (ANOREXIA)**

Weight loss occurs in about 70% of people with advanced cancer, most commonly with lung, gut and ovary tumours. It sometimes occurs despite a reasonable food intake. People’s previous eating routine may not fit in with their illness, or their illness may make independent eating difficult. Weight loss leads to associated problems of fatigue, weakness and reduced mobility and reduces people’s ability to perform daily living activities.

An occupational therapist can:

- Assess and address issues surrounding meals, their timing and preparation

- Assess and address associated problems of fatigue, weakness and pressure (see earlier sections)

- Provide equipment and feeding aids where required

- Liaise with doctors and dieticians about the best ways to help the person and their family/carers.

This aims to:

- Support the person and family/carers by providing practical strategies

- Improve quality of life and independence

- Raise self-esteem

- Help reduce anxiety to the person and family/carers who prepare food.

Occupational therapy has a role in educating patient and family/carers, energy conservation, lifestyle change, self-image, leisure activities, self-maintenance, home and community management.

(Lloyd and Cogges, 1988)

Three working women with breast cancer were interviewed about the importance of establishing everyday routines during and after treatment. Establishing a daily occupational routine, including visiting friends and performing household chores such as preparing meals, became vitally important.

(Vrklan and Milin-Polgar, 2001)
**NEUROLOGICAL PROBLEMS**

Cerebral metastases can cause difficulty managing daily living activities and occupations. There will be deterioration and/or fluctuations in people's ability to perform activities such as washing, dressing, feeding and going to the toilet, and this causes a particular burden for family and carers. Tumours affecting the spinal cord cause a wide range of symptoms.

The person may experience weakness or paralysis, changes in function, vertigo, sensory deficits, frustration, shock, anger, anxiety, pain, fatigue, depression, balance problems. Nerve damage (neuropathy) can cause similar problems. (See also cognitive deficits below)

A **n occupational therapist** can:
- Assess and analyse risks to the person's safety
- Assess and analyse how well the person performs Activities of Daily Living (ADL) and leisure activities
- Help the person find ways to perform ADL, leisure activities and maximise independence
- Assess the person's environment and adapt it to suit their needs safely
- Provide rehabilitation
- Provide wheelchairs and seating
- Provide positioning advice and pressure care
- Provide advice on manual handling, transfers and mobility
- Provide assistive aids and equipment
- Provide lifestyle advice and teach adaptive techniques
- Provide advice, education and support to family and carers
- Provide regular review to take into account fluctuations in the person's condition, and to help the person cope with deterioration
- Help communication between the person, family carers and professionals through joint sessions
- Help people and their family carers adjust and set realistic goals
- Provide splinting for hands with neuropathies

**This aims to:**
- Maintain the person's safety
- Maximise the person's independence and quality of life
- Maintain the person's previous lifestyle
- Maintain the person at home for longer periods
- Facilitate discharge, reduce the likelihood of hospital re-admission
- Reduce the risk of complications such as pressure ulcers, poor posture, falls etc
- Reduce care costs associated with complications
- Help the person and family carers cope to adapt, and cope with possible deterioration.

**Occupational therapy** is an integral part of care plan for patients with metastatic disease. Interventions include daily living skills, adjustment to disability, energy conservation, adapting environment. The functional perspective of the OT can be easily distinguished from the framework of other professions. In a chronic disease like metastatic cancer, the OT perspective broadens the focus of care.

(Romsaas and Rosa, 1985)
Cancer diagnosis and treatment can have profound effect upon hand function, presenting a challenge to occupational therapists who specialise in oncology or hand therapy. Return or improvement of hand function is common after cancer treatment, meaning that restorative treatment goals in hand therapy are often appropriate. Hand therapy intervention includes gentle active range of motion, positioning and splinting for comfort and instruction in one-handed activities of daily living. *(Cook and Burkhardt, 1994)*

In a study, activities of daily living were used to assess quality of life in brain tumour patients. Patients made significant gains in functional status during rehabilitation. *(Huang et al., 2001)*

Occupational therapy has a role to play in improving vertigo and balance through graded exercise and adapting the environment and activity. Patients have improved greatly in functional areas after receiving occupational therapy. Occupational therapists have a role in providing adaptive equipment and work simplification techniques to solve the vestibular symptoms seen in these patients. *(Cohen, 1994)*

### COGNITIVE DEFICITS

Patients with cognitive deficits due to cerebral tumours or metastases have difficulty managing daily living activities and occupations. There may be problems with memory and sequencing, and a deterioration or fluctuation in abilities. This can cause a particular burden for family/carers. (See also neurological problems above)

**An occupational therapist can:**

- Assess risks to the person's safety
- Assess how well the person performs Activities of Daily Living (ADL) and leisure activities
- Help the person find ways to perform ADL, leisure activities and maximise independence
- Assess the person's environment and adapt it to suit their needs
- Assess the person's cognition
- Help the person and their family/carers use memory aids
- Provide advice, education and support to family and carers
- Provide regular review to take into account fluctuations in the person's condition, and to help the person cope with deterioration
- Help the person and their family/carers understand and have confidence in the aims of treatment

**This aims to:**

- Maintain the person's safety
- Maximise the person's independence
- Maintain the person at home for longer periods
- Prevent or reduce hospital re-admission
- Help family/carers cope with a person whose cognitive ability is deteriorating

Brain tumour patients make functional gains and significant changes in their functional status during the course of their rehabilitation. *(Huang et al., 2001)*
People with advanced disease have fears relating to functional decline. Therapeutic goals and rehabilitation have value throughout the trajectory of malignant disease, giving specific attention to motor and sensory deficits, cerebellar and cognitive dysfunction. Appropriate physical and occupational therapy techniques should be considered for all advanced cancer patients experiencing functional decline.

(Cheville, 2001)

Occupational therapists have skills in continuous assessment and evaluation, and can be flexible in treatments and goals to ensure meaningful life to the end. Helping a person prepare for the death, and thus adapt to loss of function, is part of the occupational therapist’s role in health care of the terminally ill.

(Flanigan, 1982)

Occupational therapists are an integral part of care planning for patients with metastatic disease. Their functional perspective broadens the focus of care. Evaluation and treatment related to independent living, sensorimotor components, therapeutic adaptations, can effectively address many of the problems documented in metastatic cancer.

(Romsaas and Rosa, 1985)

ANXIETY AND DEPRESSION

Cancer and its treatments may induce feelings of hopelessness, worthlessness and panic. A quarter of people with cancer experience depression at some stage during their disease. Having cancer can lower people’s self-esteem and cause them to question their belief system.

In turn, anxiety and depression can diminish people’s concentration, ability to assimilate information and motivation to carry out activities.

An occupational therapist can:

- Explore the anxiety and assess its impact on daily living activities and leisure
- Identify goals which increase a person’s sense of control
- Implement an anxiety management programme
- Implement a fatigue management programme
- Implement a lifestyle management programme
- Involve the person in purposeful activity
- Refer on to other professionals where necessary
- Help the person and their family/carers understand and have confidence in the aims of treatment

This aims to:

- Reduce anxiety
- Give the person control and choices
- Help the person to resume their normal roles
- Improve a sense of wellbeing and quality of life
- Improve relationships

A group of cancer patients felt re-humanised when dealt with as whole people – body mind and spirit. Many of them feared hospitalisation and taking on the role of patient. The emphasis was on taking back responsibility for one’s own life and finding ways of coping that are suitable to the individual, recognising that these may differ widely.

(Oldham, 1989)
Patients with a deteriorating condition need to continue to exercise control and find meaning in life. They may feel isolated and need socialisation and verbal and non-verbal communication. *(Holland, 1984)*

**FLUID RETENTION (LYMPHOEDEMA, OEDEMA, ASCITES)**

The swelling and pain associated with fluid retention causes difficulties with mobility and activities, dressing, flexibility balance, exercise tolerance and body image. Finding clothes that are large enough or fasten properly may be a problem. Some types of fluid retention can also cause sensory deficits.

**An occupational therapist can:**
- Assess mobility, transfers, self-care, dressing, meal preparation, body image, leisure and work roles, pressure problems, fatigue, relationships, sexuality
- Address issues arising from assessment
- Teach techniques to help the person adapt their lifestyle – work, leisure, social roles, relationships, activities of daily living
- Provide advice on safety issues
- Provide advice on energy conservation
- Help the person take account of fluctuations in their condition
- Help communication between the person, family, carers and professionals through joint sessions.

**This aims to:**
- Maintain or improve quality of life
- Help the person to be independent, or make sense of their functional limitations
- Increase the person’s feelings of self-worth

**Help the person resume normal roles**
- Help the person minimise limb damage, for example when preparing meals
- Facilitate a return to work.

**General health, attitude and lifestyle all affect lymhoedema and its response to treatment.** *(Dennis, 1993)*

**BODY IMAGE (INCLUDING HAIR LOSS, SURGERY, LYMPHOEDEMA etc)**

Cancer and its treatments can cause a physical change to body shape because of surgery but also hair loss, lymhoedema, weight loss and other changes.

These can affect a person’s body image, and reduce their sense of self-esteem and wellbeing. This in turn can lead to social isolation and a loss of roles in society.

**An occupational therapist can:**
- Increase self-confidence
- Address self-care issues
- Provide equipment where necessary
- Advise on, and adapt, clothing where necessary
- Help the person access assertiveness training and cognitive behavioural therapy
- Teach relaxation and anxiety management techniques
- Set realistic goals and use graded social activities to maximise independence
- Refer on to other agencies, professionals or support groups
- Help communication between the person, family, carers and professionals through joint sessions.
This aims to:
- Improve quality of life
- Increase confidence
- Increase engagement in desired roles
- Reduce stress
- Help the person resume normal roles.

Occupational therapy has a role in education (both patient and family/carers), energy conservation (eg. alternative means of carrying out ADL), counselling, self-image, leisure activities, self-maintenance, home and community management. *(Lloyd and Coggles, 1988)*

**BONE METASTASES**

Bone metastases (secondary tumours in the bones) cause pain and reduce mobility and range of movement. They can also increase the likelihood of postural problems and neurological problems. They can make a person more fearful of activity so affect all occupational performance areas.

An occupational therapist can:
- Provide precautionary and preventative information about protecting vulnerable bones
- Assess risk and provide home safety advice
- Help plan lifestyle changes to protect bones and improve mobility
- Provide wheelchairs and equipment (for example for bathing as a preventative measure against fractures)
- Provide advice to the person, family/carers and caring staff on manual handling issues
- Provide psychological support
- Advise on posture, seating, positioning and pressure care

This aims to:
- Advise on energy conservation issues
- Help communication between the person, family carers and professionals through joint sessions

This aims to:
- Help people adapt and return to normal routines
- Improve quality of life
- Improve relationships
- Give people greater control over their lives
- Reduce anxiety and depression.

Occupational therapy is an integral part of care plan for patients with metastatic disease. Interventions include daily living skills, adjustment to disability energy conservation, adapting environment. The functional perspective of occupational therapy can be easily distinguished from the framework of other professions. In a chronic disease like metastatic cancer, its perspective broadens the focus of care. *(Romsaas and Rosa, 1985)*

Occupational therapists working in a palliative care unit can observe, listen and work with people with lung cancer and metastatic breast cancer to achieve their particular aims, to ensure that they have the optimum quality of life. *(Armitage and Crowther, 1999)*
References


Appendices


