



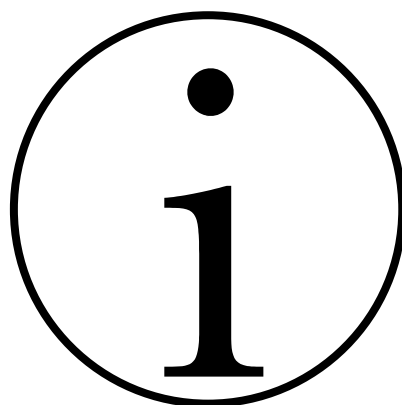
The effectiveness of physiotherapy in the palliative care of older people

EB 04

April 2002

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Executive Summary

- Palliative care focuses on the physical, psychological and spiritual care of patients with progressive diseases, aiming to provide the best quality of life for the patient and their carers. It requires close multi-professional working to ensure that needs are identified and met.
- The publication of the *National Service Framework for Older People*, the *Cancer Plan* and the *Draft National Plan and Strategic Framework for Palliative Care* all provide opportunities for physiotherapists to improve the care for these patients and their carers.
- One quarter of people will die of and one third of people will develop cancer at some point in their lives. Cancer is primarily a disease of older people. However, palliative care is not just for patients with cancer.
- The number of symptoms in older people with progressive diseases may be higher and expressed against a background of co-morbidity. Elderly patients are less likely to receive aggressive therapy.
- There is a lack of specialist palliative care services for patients with cancer and non-malignant conditions. The needs specific to elderly patients need to be identified and met appropriately.
- While it may appear to an outsider that the physiotherapist is working with dying people they are working with living patients, improving their quality of life.
- The role of physiotherapists in palliative care is primarily defined by expert opinion, which is not backed up by good quality evidence. However, an absence of research evidence does not mean that a service or treatment is ineffective, just that we don't know for certain yet. This has highlighted the need for high quality research in this field, using appropriate methodologies.
- There is some evidence for manual lymph drainage in patients with lymphoedema, rehabilitation by a multidisciplinary team and interventions for breathlessness. This is predominantly derived from research on a general population. It may therefore not be applicable to an elderly population.

1.0 Introduction

1.1 The National Service Framework for Older People

The National Service Framework (NSF) for Older People (England) was launched on 28 March 2001 (Department of Health, 2001). The framework presents eight standards which focus on: rooting out age discrimination; person-centred care; intermediate care; general hospital care; stroke; falls; mental health in older people and promoting an active healthy lifestyle in older age. The NSF will impact on physiotherapy and provide important opportunities for developing services centred on the needs of older people, by setting standards of service delivery for implementation at a local level.

The Government is to invest an extra £1.4 billion in services for older people in England by 2004 in order to improve the health and social care services for this sector of the population. The framework aims to ensure:

- High quality care and treatment, regardless of age
- That older people are treated as individuals, with respect and dignity
- Fair resources for conditions which most affect older people
- Easing of the financial burden of long term residential care

The Chartered Society of Physiotherapy (CSP) has produced a Policy Briefing on the NSF It provides an overview of the content of the NSF for older people (England); considers the impact of each of the NSF standards on the profession and the delivery of physiotherapy services as well as highlighting the opportunities available to the profession; and makes recommendations for action (CSP, 2001a).

The NSF rightly asserts that older people have the right to top quality healthcare and challenges the healthcare professions to deliver this so that older people can live full and active lives, with minimal pain and disability and optimal independence and dignity. Delivering this will be a daunting task because older people are the largest consumers of healthcare, the prevalence of multiple pathologies increases with age and the number of people living longer has increased and will increase further over the next 2–3 decades. In addition, this will have to be performed with finite healthcare resources, necessitating the best use of available resources.

Although the NSF does not make explicit any standards concerning the palliative care of older people, it does refer to intermediate care. In addition, standard four is directly relevant (Department of Health, 2001).

Box 1: NSF for Older People Standard four

Standard Four: General hospital care

Aim

To ensure that older people receive the specialist help they need in hospital and that they receive the maximum benefit from having been in hospital.

Standard

Older people's care in hospital is delivered through appropriate specialist care and by hospital staff who have the right set of skills to meet their needs.

1.2 Other Relevant NHS Policy Initiatives

The *Cancer Plan* (Department of Health, 2000a) and *Draft National Plan and Strategic Framework for Palliative Care* (NCHSPCS, 2000a) have recently been published and examine areas for development over the next few years. Physiotherapists have welcomed the *Cancer Plan*, but are worried that the profession has only been mentioned in one standard (breast cancer care) and the rehabilitation of cancer patients has not been sufficiently highlighted (Friend, 2001). The CSP is preparing a position statement on oncology and palliative care, which will be available during 2002.

1.3 Purpose of this Report

The CSP is committed to supporting physiotherapists in maximizing the opportunities provided by the NSF and the Cancer Plan to improve patient care. This report is one aspect of the Society's activities in this area. Feedback from previous reports produced by the CSP, to support the mental health and coronary heart disease NSFs, suggests that physiotherapists are using these reports to:

- Inform service reviews and planning
- Develop business cases
- Inform Continuing Professional Development (CPD) activities, including qualifying programmes and postgraduate courses
- Develop research areas
- Submit topics for research priorities
- Inform briefing papers
- Provide evidence to commissioners
- Raise the profile of physiotherapy

This report is one of four commissioned to support physiotherapists implementing the Older People's NSF. They are:

- Effectiveness of falls prevention and rehabilitation strategies in older people: implications for physiotherapy.
- The effectiveness of physiotherapy in the palliative care of older people.
- The clinical and cost effectiveness of physiotherapy in the management of older people with common rheumatological conditions.
- The clinical and cost effectiveness of physiotherapy in the management of older people following a stroke.

A report on the clinical effectiveness of physiotherapy in mental health, produced by the CSP to support physiotherapists implementing the NSF on Mental Health, is also relevant to physiotherapists implementing the NSF for Older People (Donaghy and Durward, 2000). The Society has also produced a position statement on intermediate care and rehabilitation (CSP, 2001b).

Physiotherapists can use these reports and the position statement, alongside the NSF, to develop business plans, ensuring that physiotherapy is at the forefront of delivering improvements in services for older people.

While the NSF refers to England, Frameworks and action plans for the other Nations will draw on the same evidence base, but local application and context may vary, affecting how services are delivered.

1.4 Scope of the Report

This report focuses on the problems experienced by the older palliative care patient, whether caused by the disease process or the treatment, not specifically on the disease process itself. It covers palliative care related to cancer and non-malignant disease. There were few citations directly relating to palliative care in the elderly. Where these were available, they have been used, if not general palliative care literature on the area has been used, with the caveat that it may not be possible to transfer conclusions based on work on a general population to an older one. As much of the evidence drawn upon is not specific to the older population (over 65 years) this report will also be of interest to physiotherapists working with any adult with cancer or non-malignant disease. Details of the studies discussed in the report are contained in Appendix 1.

1.5 Searching the Evidence

An extensive literature search was conducted that included, but was not limited to, the following key words : systematic review(s), review(s), clinical trial(s), controlled trial(s), randomized controlled trial(s), meta-analysis, physiotherapy, physiotherapist(s), physical therapist(s), physical therapy, rehabilitation, Palliative care, palliative treatment, hospice, terminal care, terminal illness, elder*, aged, middle age*, old people, older people, old person*, older person*, post menopaus*, clinical effectiveness, cost benefit analysis, economic evaluation.

The following sources were used for the search: Cochrane Library, DARE, MEDLINE, EMBASE, CINAHL and AMED. Also the newsletter of the Association of Chartered Physiotherapists in Oncology and Palliative Care (ACPOPC) was hand searched for relevant articles. Where possible, systematic reviews of the literature have been used to inform the area under discussion and if that was not possible RCTs, observational and qualitative studies have been used.

2.0 Palliative Care in Older People

2.1 Definition

Palliative care is "the active total care of patients and their families by a multi-professional team when the patient's disease is no longer responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families."(WHO, 1990).

Higginson (1999) sees palliative care as a "person centred approach concerned with physical, psychological and spiritual care in progressive disease."

Palliative care:

Affirms life and regards dying as a normal process

Neither hastens or postpones death

Provides relief from pain and other distressing symptoms

Integrates the psychological and spiritual aspects of care

Offers a support system to help patients live as actively as possible until death

Offers a support system to help carers cope during the patient's illness and in their own bereavement (WHO, 1990).

2.2 Levels of Need

Franks et al (2000) have reported on the level of need for palliative care as assessed by disease specific mortality. They estimate that pain control may need to be provided for 2,800 patients per million (p/m) population dying from cancer each year and for 3,400 p/m with non-cancer terminal illness. Using health service usage as an indicator of need, 700-1800 p/m with cancer and 350-1400 p/m with non-cancer terminal illness would require a support team or specialist home care nurse.

In England at present there are:

1320 day care places per 100,000 population

21 home care nurses per million population
51 specialist in-patient beds per million population
8 hospital palliative care support team nurses per million population (Department of Health, 1999).
The percentage of patients gaining access to specialist palliative care services who have a non-cancer diagnosis is only 4.3% for both in-patient and home care, whereas it could be expected that the percentage gaining access would be between 25 and 50%, if access reflected need (NCHSPCS, 2000a).

3.0 Multi-Professional Working

3.1 Specialist Palliative Care Teams

3.1.1 Definition

The Working Group for Palliative Care (1998) has set out guidelines, to provide commissioners and providers of palliative care services with goals to improve the quality of care. They distinguish between the *interdisciplinary* and *specialist* palliative care teams.

Interdisciplinary teams

"The identity of the team supersedes individual personal identities. Members share information and work interdependently together to develop goals. Leadership is shared among team members depending on the task in hand. Because the team is the vehicle of action, the interaction process is vital to success." (Lowe, 1981)

Special Palliative Care Teams

"The specialist palliative care team is a team of flexible membership which assesses, plans implements and evaluates palliative care services for patients and carers with more complex and intractable problems and needs. Team members are experienced in palliative care or have undertaken education (to diploma level at a minimum) which is appropriate to their role and are able to share specialist expertise." (Working Group for Palliative Care, 1998).

The special palliative care team can include any of the following professionals: doctor, nurse (including specialist palliative care nurse), physiotherapist, occupational therapist, social worker, chaplain/pastoral worker, dietician, pharmacist, speech and language therapist, radiographers – diagnostic and therapeutic, complimentary therapists, other health care professionals (Working Group for Palliative Care, 1998).

3.1.2 The Evidence

Two systematic reviews have examined the evidence for specialist palliative care teams. Hearn and Higginson (1998) found that there was some evidence that, compared to conventional care, specialist teams improve satisfaction, identify and deal with more patient and family needs and can reduce the overall cost of care by reducing the time patients spend in acute hospital settings. Of the 18 studies identified, only 5 were randomised, 5 were comparative and 8 observational. Salisbury et al (1999) identified 86 papers concerned with the impact of different models of specialist palliative care on patients' quality of life. They found it difficult to make firm conclusions as there were few comparative trials of reasonable quality.

3.2 Complications of Medical Treatment and Problems Affecting Patients

Physiotherapy in palliative care has to be considered in amongst many other treatments and as part of the total management of the patient. Situations that will affect the physiotherapist's assessment and treatment of the patient may be as follows (Gillham, 1995; Sheehan and Forman, 1997):

- **The patient's pain.** Pain should be seen as a "total pain", i.e. physical, psychological, emotional and spiritual (Mackey and Sparling, 2000). Active physiotherapy should be delayed until a pain relief regime has successfully been established.
- **Delivery of drugs other than by the oral route.** Some drugs may be delivered subcutaneously or via the spinal route. Physiotherapists must be aware of the complications of these routes and any limitation it may have on rehabilitation.
- **Side effects of drugs.** These can include nausea, vomiting, dizziness, increased weight, an increased risk of secondary infection, risk of osteoporosis or proximal myopathy, and constipation.
- **Consequences of radiotherapy.** Guidelines for physiotherapists whose patients are undergoing radiotherapy have been produced (Brooks, 1998). Physiotherapists need to be aware that peripheral neuropathy can be a consequence of radiotherapy.
- **Surgery.** This may involve excision, reconstruction, colostomy, drainage of abscess or the insertion of cannulae. Orthopaedic surgery may be required to fix pathological fractures. Neurological surgery may include cordotomy or decompression.
- **Anorexia-cachexia-asthenia.** This is a common cause of suffering and contributes to psychosocial distress.
- **Increased risk of pressure sores.** Rapid weight loss in patients with advanced cancer results in the protective fat in the subcutaneous tissue and muscles becoming atrophied. This stresses the importance of pressure care.
- **Psychological status.** Potential for impaired ability to process and retain information (Robinson, 1996).

Information on chemotherapy response in the aged is unreliable, but toxicity may be enhanced. Many elderly patients will have reduced bone marrow reserve and renal function and also be on a variety of drugs for co-morbidities. Biological and chronological ages often differ because of genetic make-up and past lifestyles. Patients should be assessed for therapy on their ability to benefit not their chronological age (Osoba and Macdonald, 1997).

4.0 Role of Physiotherapy in Palliative Care

4.1 Aims of Treatment

Physiotherapy aims to "optimise the patient's level of physical function and takes into consideration the interplay between the physical, psychological, social and vocational domains of function..... The physiotherapist understands the patients underlying pathological condition, but this is not the focus of treatment. The focus of physiotherapy intervention is, instead, the physical and functional sequelae of the disease and/or its treatment, on the patient." (Fulton and Else, 1997; p817).

Physiotherapy aims to:

- Maintain optimum respiratory function
- Maintain optimum circulatory function
- Prevent muscle atrophy

- Prevent muscle shortening
- Prevent joint contractures
- Influence pain control
- Optimise independence and function
- Education and participation of the carer (Fulton and Else, 1997).

Early referral is advisable to ensure early implementation of rehabilitation goals, especially those which are preventative or restorative. The reasons a patient may be referred are encompassed in the criteria for referral to a physiotherapist (Working Group for Palliative Care, 1998).

Patient has any of the following:

- Dyspnoea or other respiratory symptoms, such as cough or excessive secretions
- Lymphoedema or oedema of mixed cause
- Central or peripheral neurological symptoms, which may require referral to a specialist neurological physiotherapist

Patient requires any of the following:

- Portable nebulizers or instruction in the correct use of inhaler devices
- Treatment to improve, maintain or manage the deterioration of exercise tolerance and muscle strength
- Treatment to maintain or improve joint range of movement and soft tissue flexibility
- Gait re-education and/or provision of walking aids / equipment to maximise independence in mobility and / or transfers
- Adjuvant, non-pharmacological pain management, including the use of transcutaneous electrical nerve stimulation (TENS) to support pharmacological intervention in the management of nausea and vomiting and pain
- Stress and anxiety management, for example, through relaxation and/or massage therapy

In addition, patients, carers or health professionals require advice and training on appropriate, safe and legal moving and handling techniques.

4.2 Service Provision

The Association of Chartered Physiotherapists in Oncology and Palliative Care (ACPOPC) is the clinical interest group representing physiotherapists working in this area.

In the year 1999/2000 there were 246 members of ACPOPC. Members work in a variety of settings, and often more than one, that mirror the diversity of settings for palliative care in general (see table 1). It is not clear how many of these therapists are members of specialist palliative care teams. There may also be physiotherapists working in the speciality who are not members of ACPOPC. Also, members work with all ages, not just older people. Many physiotherapists working with other specialities, such as respiratory medicine and the care of older people are routinely involved in the care of palliative care patients.

Table 1: Number of members of ACPOPC in different work settings

Work Place	1999/2000
Community	64
Day centre	78
General wards	26
Hospice	129
Lymphoedema Clinic	82
Oncology Unit	62
Other	28
Palliative Care Unit	48
Radiotherapy ward	33
Research	14
Surgical ward	25

In a survey of 40 palliative day care centres in North and South Thames Regions, Higginson et al (2000) found that 30 had physiotherapists, in which two were working as volunteers. Twenty centres provided physiotherapy daily, 11 up to once per week and 9 less than once per week. The focus of 13 of the 40 centres was described as social or mostly social and 19 as equally medical and social. There are no comparative statistics across the country.

4.3 Physiotherapy Treatment Approaches

The general principles of physiotherapy are discussed by a number of authors (Fulton and Else, 1997; Working Group for Palliative Care, 1998; Gillham, 1995; O’Gorman, 1993) and can be summarised as follows:

- Commence treatment as soon as possible after assessing the patient’s physical function. Take into account that the patient’s stamina may be reduced. Little and often is the principle. Ongoing assessment and modification of goals is essential.
- Consideration of multipathology by identifying actual and potential limitations to function, including pain and other problems of a musculoskeletal, neural, respiratory or circulatory nature.
- Modification of general principles e.g modification of treatment principles for a cerebrovascular event to be used in a patient with cerebral metastases.
- Consider the whole person by identifying realistic and achievable goals, negotiated with the patient, carers and interdisciplinary team.
- Consider the safety of the patient and carers by providing education and training on the safe movement and handling of patients.
- Assess for, provide and support the use of mobility aids, nebulizers, TENS etc.
- Adjust treatment programmes to suit the capabilities of the patient so as not to make any deterioration obvious to them as a result of their physiotherapy: do not take the patient off treatment while they are aware.
- Be prepared to listen to the patient, carers, team members and other health professionals regarding the patient’s functional status and potential.

Gillham (1996) considers four areas of difference for physiotherapists working in palliative care.

1. Developing a different way of thinking: many areas of clinical practice encourage the physiotherapist to think curatively. This may not be possible in palliative care and physiotherapists may require a shift

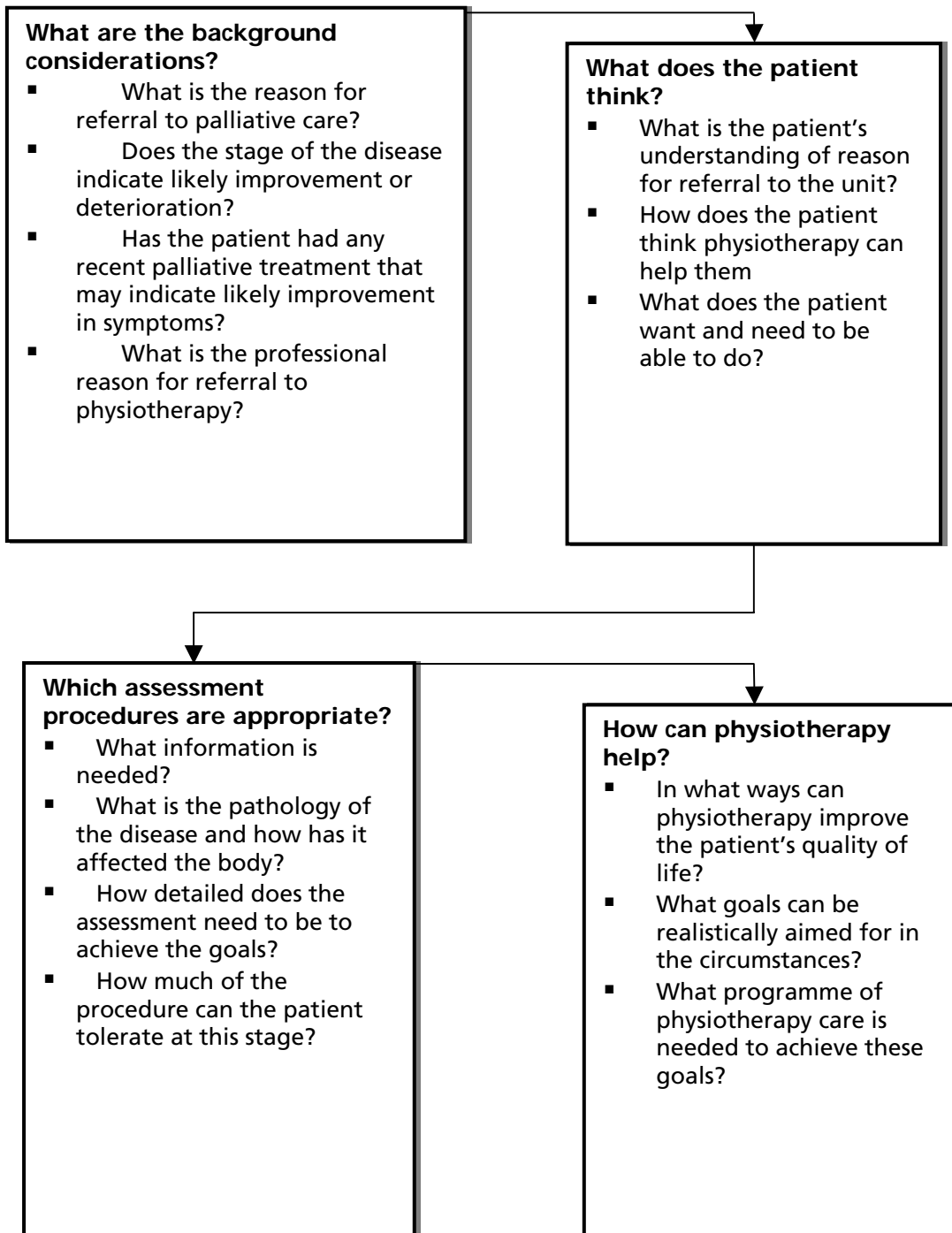
in perception. It may appear to an outsider that the therapist is working with dying people, whereas they are working with living patients, improving their quality of life.

2. Fostering a different image: a common image of physiotherapists is that of someone who pushes people in to doing things they don't want to. Patients may have this perception and the therapist needs to work to create an image that, through encouragement and enabling, will achieve highly beneficial results.
3. Coping with the pain and the pleasure: health professionals working in palliative care recognise that deterioration will feature more starkly in this area of work than in others. It is also likely to end in the death of the patient. Patients may also have unrealistic expectations about what physiotherapy can do for them. These stresses should be acknowledged and balanced against the satisfaction experienced when goals are reached and patient morale is high.
4. Moving towards a counselling approach: physiotherapists can spend a considerable amount of time relating closely to patients and may be drawn in to situations involving difficult questions. Undergraduate training may not have provided for these situations. Physiotherapists working in palliative care may choose to extend their training into counselling skills. This can help their capacity for listening and reflecting and allow them to improve the quality of their care. Clinical reasoning in palliative care should be modified by the patient's goals, be realistic and identified by the patient themselves, coupled with a calculated professional input from the physiotherapist.

Figure 1 provides an algorithm for decision-making about physiotherapy in advanced malignant disease.

Figure 1: Making decisions about physiotherapy in advanced malignant disease
Reprinted with permission from 'Physiotherapy with older people.' Pickles B, Compton A, Cott C, Simpson J, Vandervoort A. Figure 2, page 314, © 1995 by permission of the publisher WB Saunders.

Thinking through the situation



One qualitative study (Martlew, 1996) has examined the effect of physiotherapy on 10 patients' perceptions of their illness, relevance and benefit of physiotherapy and factors contributing to quality of life. It was

found that physiotherapy had improved the quality of all the interviewees' lives through offering positive psychological support and 8 of the 10 had improved quality of life through improved function. There was no description of the type of physiotherapy employed.

4.4 Massage

Two studies have examined the effect of massage or aromatherapy in palliative care (Corner et al, 1995; Wilkinson et al, 1999). They conclude that massage with or without essential oils can have a positive effect on anxiety. Corner et al (1995) notes that the massage can provoke strong emotional reactions and become a semi-counselling session. It is not clear if this may have a confounding effect on the results.

4.5 Electrophysical Modalities

Transcutaneous Electrical Nerve Stimulation (TENS) is the only electrical modality currently recommended for use in the presence of active neoplastic disease. However, the use of other electrical modalities (ultrasound, interferential, continuous short-wave diathermy, pulsed short-wave diathermy) may be of benefit in the palliative stage of disease when applied over normal tissue.

The use of TENS is discussed in detail by Thompson and Filshie (1997). They state that there is an extensive world literature on TENS, most of it supporting the view that this is a useful form of analgesia, particularly for chronic pain. However, they accept that there are a small number of controlled trials and that there may be a placebo response to TENS therapy. McMillan and Dundee (1991) discuss the role and application of TENS in controlling sickness after chemotherapy.

4.6 Complementary Therapies

Acupuncture, reflex therapy, the Alexander technique, and aromatherapy are all modalities used in palliative care. The contribution of these modalities is gaining recognition in many fields of health care, although evidence of their effectiveness is lacking. Their use in palliative care has been described by a number of authors (Leng, 1999; Penson, 1998; Vickers, 1996 ; Wilkinson et al, 1999).

5.0 Rehabilitation in Palliative Care

5.1 Definition and Scope

The National Council for Hospice and Specialist Palliative Care Services (NCHSPCS) has recently published an occasional paper examining the role of rehabilitation in palliative care (NCHSPCS, 2000b).

"Rehabilitation in palliative care has a strong emphasis on speed of response and careful forward planning to take account of deterioration. Staff need to be able to deal with uncertainty – far more so than in chronic care – and have to constantly adapt to potentially distressing situations.

Because of these special circumstances, staff may need to be more prepared to blur their roles and cross professional boundaries that those working in mainstream rehabilitation."

Is rehabilitation appropriate in patients requiring palliative care? It may not be the first word that comes to mind (Doyle, 1997a). It may conjure up ideas of restoring and regaining abilities previously lost or active and tiring hard work. Patients may be considered too ill for rehabilitation (Gillham, 1995).

The purpose of rehabilitation in palliative care is to:

"improve the quality of survival, so that patients lives will be as comfortable and productive as possible and he/she can function at a minimum level of dependency regardless of life expectancy." (Dietz, 1981)

Gillham (1995) cites Dietz (1981) in recommending the use of the word rehabilitation in the treatment of cancer patients. Patients are distinguished by the goals they may set for themselves:

- Preventative goals where disability is likely to occur and the treatment provided is designed to keep disability to a minimum.
- Restorative goals when patients can be expected to return to normal.
- Supportive goals where the disease is controlled, but continued support is needed.
- Palliative goals when the patient has advanced disease.

Gillham (1995; 1996) suggests an alternative paradigm, active readaptation. This encourages the patient to readapt to a new set of circumstances as they gradually lose abilities and function. "Active" emphasises that activity is necessary for reassessing, readjusting and coming to terms with new techniques and equipment.

Fulton (1994a) discusses a framework for the rehabilitation of patients with cancer based on Habeck et al's (1984) seven principles.

5. Comprehensive care is provided to address the needs of the whole person.
6. A team approach is used to achieve co-ordinated interdisciplinary care.
7. The unit of care includes both the patient and the family.
8. Goals for rehabilitation are derived from the effects of medical problems in accordance with prognostic expectations.
9. Intervention occurs as soon as the likelihood of disability is anticipated.
10. Rehabilitation needs must be reassessed on a continuing basis and met throughout all phases of care.
11. Education is a major component of the rehabilitation process.

Doyle (1997b) proposes that rehabilitation in palliative care is allowing the patient to return to a degree of usefulness and less dependence on others that results in the ability to function again as a person. These may be simple activities of daily living, using the lavatory, shaving, or it may be creative activity, painting, music or being addressed with respect. Whatever the case rehabilitation in palliative care is *"never easy, often challenging, always rewarding."* Doyle (1997b; p817)

5.2 The Evidence

Four studies have examined the effect of rehabilitation or physiotherapy on a general population of patients needing palliative care. Three are observational (Yoshioka, 1994; Marciniak et al, 1996; Cole et al, 2000) and one is a small qualitative study (Mackey and Sparling, 2000). None looks at specific physiotherapy techniques and the qualitative study (Mackey and Sparling, 2000) examines areas of patient's lives that might benefit from physiotherapy i.e. routine physical activities, including social activities. All three use differing outcome measures. Two used the Functional Independence Measure (FIM); one using just the motor component (Marciniak et al, 1996) and one (Cole et al, 2000) the motor and cognitive components. All had a mixed cancer population. Two (Marciniak et al, 1996; Cole et al, 2000) showed that rehabilitation significantly improved the FIM motor scores over the period of admission, irrespective of whether patients were receiving chemo- or radiotherapy at the same time as their rehabilitation. Yoshioka (1994) found an improved Barthel

score in 239 Japanese patients and the more fully patients discussed the therapy programme, the more effective the programme was judged to be.

Morasso et al (1999) examined the met and unmet needs of 89 patients admitted for palliative care. They showed that 62.1% of their study population had unmet needs in occupational functioning i.e. the need to spend time usefully. Unmet needs in personal care were found in 14.6% (26.3% of women). Patients with unmet needs were more likely to show psychological and symptom distress. This agrees with Mackey and Sparling's (2000) small qualitative study that concludes that self-identity and sense of control appear to be linked to the performance of routine, familiar activities.

It is hard to draw conclusions from these few studies, but there are some indications that rehabilitation can be helpful in patients with cancer, particularly if it is aimed at those areas of life where patients want to maintain their independence either in personal care or general useful and social activity. Only Yoshioka's study (1994) gave any indication of the type of treatment given to these patients.

6.0 Cancers and their Consequences

6.1 Prevalence of Cancers

One quarter of people in England will die of cancer and one third will develop cancer at some point in their lives (Department of Health, 2000a). The incidence of cancer deaths varies widely across the UK from 183 deaths per year per 100,000 population in Kensington, Chelsea and Westminster up to 353 in Isle of Wight (NCHSPCS, 2000a).

Cancer is primarily a disease of older people with greater than 50% of cancers in the United States of America (USA) occurring in people aged over 65 (Cleary and Carbone, 1997). Donnelly et al (1995) found the median age for patients with advanced lung cancer was 64 years, 61 years in renal cancer and 70 years in prostate cancer (in a group of 1000 patients).

Studies to date, primarily from the USA, indicate that:

- Elderly patients are less likely to receive aggressive therapy
- They are less likely to have alternative therapies presented to them
- They are less likely to receive adjuvant therapy (Roy and MacDonald, 1997)

6.2 Bone Metastasis and Pathological Fracture

Skeletal metastases can potentially occur with any malignancy, but most commonly in breast cancer, myeloma, cancer of the bronchus and prostate. The long bones are particularly at risk. Collapse of individual vertebrae may occur, causing excruciating pain and potential risk of spinal cord compression must be considered. Orthopaedic stabilisation may be carried out in osteolytic bones to prevent fracture, to reduce spinal compression or in the case of fracture to ensure early mobilisation. Radiotherapy is usually carried out to aid pain relief (Gillham, 1995; Galsko, 1997). This needs to be taken into account by physiotherapists when planning treatment goals.

6.3 Breast Cancer

Standards of care for patients with breast cancer have been published by Norwegian physiotherapists (Bohn, 1997). They present a holistic view of the care of patients with breast cancer, describing the process as follows:

- A caring respectful attitude for the woman's needs and limitations.

- Individual advice and counselling.
- Information about the function of the lymphatic system and its significance as well as guidelines for activity.
- Encouragement that helps the woman take some personal responsibility for activity and rehabilitation.

It is important from the outset to give the woman the opportunity to express her feelings about breast cancer. Anxiety and fear may prevent her from being able to understand and benefit from any form of patient education.

Concurrent with treatment, the woman should receive counselling about activity and be shown how to exercise at home. Activity should be within the pain threshold and chosen in relation to the individual's needs and abilities. This can include the following interventions:

- Careful mobility exercises for the shoulder joint, resistance limited to the weight of the arm.
- Relaxation exercises for the shoulder region.
- Respiratory exercises.
- Light massage.
- Gentle hydrotherapy excluding swimming during the first weeks.

6.3.1 The Evidence

Friedenreich and Courneya (1996) have reviewed the literature on exercise and rehabilitation in patients in the early stages of breast cancer. The NHS Centre for Reviews and Dissemination note that the systematic review has major methodological flaws and Friedenreich and Courneya's conclusion, that some evidence exists that exercise rehabilitation has a beneficial effect on the physiologic and psychological well being of patients with breast cancer, should be viewed with caution (DARE database <http://nhscrd.york.ac.uk/online/dare/961575.htm>).

The evidence for physiotherapy in patients with breast cancer is concentrated around those younger patients in the active stage of their disease. There is no research evidence for physiotherapy in older patients with advanced disease.

7.0 Non Malignant Conditions

In their study based on the Regional Study of Care for the Dying (RSCD), Addington-Hall et al (1998) found that half the non-cancer sample had died from circulatory disease and nearly 25% from respiratory disease. They estimate that 71,744 people who die from non-malignant disease in England and Wales each year may require specialist palliative care. This would entail at minimum a 79% increase in caseload if specialist palliative services were to be made available to non-cancer patients.

O'Brien et al (1998) looks at the symptoms common to malignant and non-malignant conditions and reviews the care of patients with advanced respiratory, cardiac and neurological disease. The symptoms were categorised as:

Physical: Pain, Breathlessness, Anorexia, Immobility, Constipation

Social: Loss of employment, Role change, Fear for dependants

Psychological: Depression, Fear and anxiety, Uncertainty, Guilt

Existential: Religious, Non-religious, Meaning of life, Why

Many of the problems already discussed in this report will also be encountered in patients with non-malignant conditions.

The National Service Framework (NSF) for Coronary Heart Disease (CHD) (Department of Health, 2000b) has set standards for the palliative care of patients with advanced CHD (Standard 11) and Taylor (2000) has reviewed the effects of exercise training on patients with chronic heart failure. She concludes that exercise can reverse the effects of reduced exercise tolerance with a concomitant improvement in quality of life.

8.0 Relief for Specific Symptoms

8.1 Introduction

The management of pain and other symptoms may be particularly problematic in an older population, but there is no evidence to suggest that older patients suffer less than younger ones (Roy and MacDonald, 1997). The number of symptoms itemised by older patients may in fact be higher (Cleary, 1997; Sheehan and Forman, 1997; Roy and Macdonald, 1997) and often expressed against a background of co-morbidity.

8.2 Pain Management

Bernabei and colleagues (1998) found that between 25% and 40% of patients with cancer in nursing homes had daily pain and this was inversely associated with age. This incidence is lower than in other studies and may be due to the reporting only of daily pain. Sheehan and Forman (1997) and Cleary and Carbone (1997) review the incidence and alleviation of pain in the elderly patient receiving palliative care. They conclude that the prevalence of pain in people over 60 years of age is twice that in the younger age group, with the predominant cause of pain being musculoskeletal, with 80% of people over 65 suffering from arthritis. Approximately 33% of patients with metastatic disease report that pain interferes with activities of daily living. Pain also has a significant impact on the carer when they feel unable to relieve the patient's pain.

Pain is also likely to be a problem in patients who are dying from non-cancer related causes.

Common causes of pain associated with cancer (Sheehan and Forman, 1997):

- Unrelated to the cancer e.g. spinal stenosis, arthritis etc.
- Directly initiated by the cancer e.g. infiltration of organ, compression on peripheral nerves
- Resulting from treatment e.g. radiotherapy, surgery

Assessment of pain in the elderly may be complicated by disease processes that affect the patient's ability to communicate (Cleary and Carbone, 1997). Sheehan and Forman (1997) discuss in some detail the assessment of pain in the elderly and state that an appropriate tool should be used that includes physical, psychological and functional components.

Non-pharmacologic techniques for treating pain can include relaxation, distraction, positioning, mobility, TENS (as discussed previously), heat or cold and massage. Rhiner et al (1993) found that patients experiencing chronic cancer pain preferred heat, massage and physical treatments to cognitive methods of pain reduction. Massage for pain relief can have an effect on complex behavioural patterns as well as the simple perception of pain, although this is mainly derived from empirical work (Lund, 2000).

Elderly patients in a small qualitative study (Duggleby, 2000) describe psychological pain as being the worst and, in part, was related to the loss of function, described as "...not being able to move like me." Strategies described for decreasing the pain were divided into things others do and things done by themselves. These second strategies included heat, positioning and activities like walking and knitting.

It would appear that a distinct proportion of patients receiving palliative care will be in some degree of pain. Some are receiving physiotherapy, although this may not be for pain management, and patients seem to need to keep active to fend off the worst aspects of the pain. Physiotherapy may have a role in this area, but at present there is little evidence to show how this should best be delivered.

8.3 Lethargy, Fatigue, Muscle Weakness and De-conditioning

Asthenia is defined as general weakness combined with mental or physical fatigue. It may be caused by chemotherapy, radiation therapy, medications, anaemia, tumour, malnutrition, infection, metabolic abnormalities or psychiatric factors (Sheehan and Forman, 1997). It has only been recently recognised as a problem in its own right (Neuenschwander and Bruera, 1997). Curt et al (2000) states that cancer related fatigue is the most important untreated symptom in cancer today. In a telephone survey of 379 patients who had undergone chemotherapy, 30% experienced fatigue on a daily basis and 91% of those experiencing fatigue reported that it prevented a "normal" life (Curt et al, 2000). Guidelines for the evaluation and management of fatigue have been published (Portenoy and Itri, 1999).

Fatigue in the elderly is also a common symptom not associated with cancer or its treatment and there may be treatable causes such as anaemia, diarrhoea, renal failure, hypothyroidism, hypercalcaemia or depression (Gillham, 1995; Cleary and Carbone, 1997).

Brown (1999) reviews the differences between weakness and fatigue noting that the two terms are often used synonymously and are likely to be part of a larger symptom complex. Patients may use the term interchangeably to mean either an objective difficulty in doing something or a subjective feeling of tiredness. It would seem essential that health care professionals working with patients requiring palliative care understand what the patients mean by their use of the words fatigue, tired, weak, lethargic etc and fit that in to the objective examination of muscle weakness and loss of function

Many patients in the palliative phase of their disease may have spent many weeks in bed. As a result there may be bone loss and hypercalcaemia resulting in increased risk of fracture, muscle atrophy and shortening, joint contractures, respiratory function changes, peripheral mononeuropathy and circulatory changes (Fulton and Else, 1997).

Many patients with advanced cancer are deconditioned. Weakness may also be due to proximal muscle weakness as a side effect of some drugs, nerve compression by a tumour, spinal cord compression, systemic failure, infection or paraneoplastic syndrome (a tumour that produces toxins that put neurones out of action resulting in paralysis) (Gillham, 1995).

Common physiotherapy approaches are:

- Maintenance exercises
- Bed mobility exercises
- Active, active assisted and passive exercises.
- Breathing control and Forced Expiratory Technique
- Positioning
- Provision of appropriate mobility aids
- Pacing of activities by adapting activities of daily living (decreasing housework, allowing others to help), re-arranging time schedules and concentrating energy on important activities
- Education and participation of the carer.

The carer will need to find a balance between increasing the amount of rest to alleviate the asthenia, which may in turn increase the dependency and reduce the exercise tolerance. (O'Gorman, 1993; Fulton and Else, 1997; Neuenschwander and Bruera, 1997).

Three studies (Porock et al, 2000; Scialla et al, 2000; Schwartz, 2000) examine the role of exercise rehabilitation in cancer patients with fatigue. Scialla et al (2000) looked retrospectively at 110 patients receiving multidisciplinary rehabilitation as inpatients while Schwartz (2000) and Porock et al (2000) looked at a small number of patients receiving home based exercise programmes. The results in all three cases found that patients benefited from the intervention, but the lack of randomisation and relatively small numbers mean that firm conclusions cannot be drawn.

Little research has been done to evaluate the relationships between subjective complaints of weakness and fatigue and objective measures of strength and function and these merit further study. The role of exercise as an intervention remains uncertain and should be further evaluated (Brown, 1999).

8.4 Neurological Impairment and Disability

There may be damage to the peripheral or central nervous system in patients who are in the palliative phase of their disease. This commonly results in disorders of movement (Fulton and Else, 1997).

Malignant cord compression is a rare, but serious complication of cancer seen in palliative care. It is a medical emergency. Neurological symptoms can develop rapidly and delays in diagnosis and treatment can lead to irreversible paralysis. The physiotherapist is in a good position to be aware of the possibility and recognise the early signs. It is most commonly associated with cancers of the lung, breast, unknown primary, lymphoma, myeloma, sarcoma, prostate and kidney (in descending order). Prompt palliative treatment such as radiotherapy or surgery may reverse the condition and patients who are ambulatory before treatment are likely to remain so. If paraparesis has developed, approximately 50% of patients will regain the ability to walk and survival may be lengthy. If paraplegia has developed, then only 5% will regain ambulation and survival will be short (Gillham, 1995; Caraceni and Martini, 1997).

Physiotherapy treatment of those patients with a good prognosis, involving exercises to improve function and muscle power, can be successful in increasing mobility. Those patients who are paraplegic will have many other problems associated with a short prognosis, poor quality of life, recurrent infection, bowel disturbance and musculoskeletal pain to complicate their management (Gillham, 1995; Caraceni and Martini, 1997).

Intracranial metastases have been found at autopsy in about 25% of patients who die of cancer (Posner et al, 1978). The primary sites being most commonly lung, breast and melanoma. It is usually a sign of advanced disease. If untreated, survival is about one month, two months if steroids are used. Whole brain radiotherapy can extend life for 3-6 months. Surgery is reserved for those patients who have only one deposit. It is important to recognise that the aim of treatment may not be the same as for a patient with a cerebrovascular event and techniques which would be used to decrease spasticity may be rejected in favour of early ambulation with walking aids (Gillham, 1995).

8.5 Lymphoedema and Swelling

The distinction needs to be made between lymphoedema and postural, cardiac, renal or venous oedema (O'Gorman, 1993), and lipoedema (Todd, 1999). Lymphoedema occurs in a limb as a result of damage to the lymphatic drainage caused by the tumour, surgery or follow up radiotherapy. Thirty percent of patients with mastectomy for breast cancer will develop lymphoedema. Swelling of the legs may occur following operations for tumours low down in the pelvis. There is also an increased risk of local infection due to the locally compromised immune system.

Lymphoedema and its management have been reviewed (Gillham, 1994; Regnard et al, 1997; Todd, 1998).

The aims of conservative treatment are:

- Reducing the risk of acute inflammatory episodes
- Limiting capillary filtration
- Stimulating lymph formation
- Improving lymph transport capacity (Todd, 1998).

Indications and contraindications for bandaging and hosiery exist as shown in Box 2 (Regnard et al, 1997).

Box 2: Bandaging and Hosiery	
Bandaging	Hosiery
Indications Fragile or damaged skin Limb too large to fit hosiery Distorted limb shape Pain in site of oedema Contraindications Ratio of posterior tibial : brachial artery pressures less than 0.8 Ventricular failure Recent peripheral vein thrombosis Caution with Microcirculatory problems Absence of sensation	Indications Intact skin Patient able to fit and remove it Limb size and shape allow fitting Contraindications and cautions As for bandaging

Hosiery can be used to apply external support or compression. External compression is used when the aim of treatment is to reduce swelling or to maintain reduced limb size. Support is used when a reduction in limb size is not anticipated or necessarily desirable. Exercise programmes should be used to maintain mobility and range of movement in the affected limb. Self-massage can be used if deemed appropriate. Three times weekly out patient massage, multi-layered compression bandaging and exercise for 2-3 week periods as an in-patient may be necessary (also known as complex physical therapy [CPT]) (O’Gorman, 1993;

Gillham, 1994, 1995; Mortimer et al, 1997; Todd, 1998).

Gillham (1994) looks in detail at the changes in the delivery of manual lymph drainage (MLD) that need to be examined by physiotherapists caring for patients with lymphoedema.

A systematic review of conservative management of lymphoedema in patients with breast cancer concluded that the evidence base for these interventions was poor, but that compression garments appear to reduce limb size after 6 months. The addition of pneumatic pumps or electrical stimulation does not improve the results. Complex physical therapy was supported by two non-randomised studies, but the modified form was as effective as the full form (Megens and Harris, 1998). These results should be viewed with caution due to poor methodological quality in the selected studies.

Four comparative studies have examined the role of MLD in treating lymphoedema. Matthews and Smith (1996) compared full versus modified CPT in mixed conditions. They found that both forms of CPT effectively reduced limb volume and they attribute the maintained improvement to the 24 hour/day use of pressure bandaging or hosiery. Johansson and colleagues (1998) compared MLD to sequential pneumatic compression (SPC) in breast cancer and found that both MLD and SPC reduced limb volume, but there was no significant difference between the two treatments. Johansson et al (1999) looked at low stretch compression bandaging (CB) versus MLD + CB in breast cancer and found that both CB and MLD + CB reduced limb volume, with the % difference being significant (p=0.04). Both interventions reduced heaviness and tension, but only MLD +

CB reduced pain. Mortimer (1999) compared MLD to self-administered massage (SAM) in breast cancer and found that MLD reduced limb volume ($p=0.12$) whereas SAM had no significant effect.

An observational study by Todd (1999) examined the effect of CPT on patients with lymphoedema in two centres over a period of six months, finding reduced limb volume, improved skin condition, improved functional movement in patients with lower limb oedema, but not arm oedema, a reduction in reports of acute inflammatory episodes and improved physical and psychological well being after treatment.

Woznewski et al (2001) followed 208 women with lymphoedema over their treatment with CPT and SPC, finding that all patients had a reduction in lymphoedema, but the reduction was greatest in those patients with minimal or moderate oedema (43% reduction in minimal, 33% in moderate and 19% in severe oedema).

There seems to be some evidence that MLD is effective in controlling lymphoedema, particularly in patients with breast cancer and when used in conjunction with compression bandaging or hosiery. These studies were primarily conducted on a younger group of patients and the patients were not in the palliative stage of their disease.

These conclusions are not generalisable to elderly patients receiving palliative care, but there is no other evidence available at present.

8.6 Ascites

Swelling in the abdominal cavity can be caused by ascites; the accumulation of fluid within the peritoneal cavity caused by pressure on the venous or lymphatic systems.

Patients with ascites feel heavy, uncomfortable and bloated. There are mechanical problems with mobility and patients may need to be taught a variety of techniques to enable them to maintain their independence. After the fluid is tapped, breathing exercises may help to reinflate the lower part of the lungs (Gillham, 1995).

Corner (1998) attempted to discover whether the raising of intra-peritoneal pressure through the wearing of an abdominal binder and breathing exercises could reduce the re-accumulation of ascites. They found that intra-peritoneal pressure was raised significantly by the breathing exercises and the binder, but due to procedural problems in the research, were unable to show an improvement in ascites.

8.7 Dyspnoea

There is usually a physiological basis for breathlessness in patients in the palliative phase of their disease (Fulton and Else, 1997) although many causes of breathlessness originate outside the respiratory system; cardiac disease, metabolic acidosis or psychological factors (Gillham, 1995; Birks, 1997). The pathophysiology of dyspnoea is comprehensively reviewed by Birks (1997) and reviews of breathlessness, cough, and lung cancer have been conducted (Michie, 1994; Davis, 1997; Rawlinson, 2000).

As with pain, the individual is the only one who can accurately judge the presence and severity of dyspnoea (Sheehan and Forman, 1997). Approximately 41% of palliative care patients may have dyspnoea and 46% of those describe it as being of moderate to severe intensity (Curtis et al, 1991). Age has a strong effect on lung capacity. Lung volumes in normal elderly people can be expected to fall to a quarter of the values for young, healthy adults (Ahmedzai, 1997).

Sheehan and Forman (1997), Birks (1997) and Hough (2001) discuss non-pharmacologic techniques that may be effective for the treatment of dyspnoea. They include:

- Accurate assessment
- Bedside fan or open window

- Positioning
- Pursed lip breathing
- Oxygen therapy
- Relaxation therapy
- Breathing retraining
- Energy conservation / pacing

Assessment of the breathless patient has been examined in detail by Corner and O'Driscoll (1999) and an assessment tool specifically for use in palliative care has been developed and evaluated (see appendix 2). Physiotherapy for the breathless patient is covered by Brown (1997), the Association of Chartered Physiotherapists in Respiratory Care (ACPRC, 1997) and Hough (2001).

Nebulizer therapy is now commonly offered by most UK hospices (Johnson et al, 1990). The Effective Health Care Bulletin on the management of lung cancer (University of York, NHSCR, 1998) discusses the management of breathlessness citing two RCTs (Corner et al, 1996; Bredin et al, 1999) in its conclusion that counselling and breathing retraining by nurses can reduce anxiety and enhance patients ability to cope. The intervention strategy was based on rehabilitation techniques used in chronic pulmonary disease and consisted of:

- Detailed assessment of breathlessness and factors that ameliorate or exacerbate it.
- Advice and support for patients and their families on ways of managing breathlessness.
- Exploration of the meaning of breathlessness, their disease, and feelings about the future.
- Training in breathing control techniques, progressive muscle relaxation, and distraction exercises.
- Goal setting to complement breathing and relaxation techniques, to help in the management of functional and social activities, and to support the development and adoption of coping strategies.
- Early recognition of problems warranting pharmacological or medical intervention.

The results from both studies show that patients do benefit from a rehabilitative approach and are able to increase their functional level and ability to perform activities of daily living. The drop-out rates from both studies were high, but this might be expected in a population with a limited life span. Physiotherapists were not involved in the design or conduct of either study although are well placed to apply the findings and advise others.

9.0 Outcome Measures and Quality of Care

Fulton (1994b) and NCHSPCS (1995) have examined some of the outcome measures available to healthcare professionals working in the field of palliative care. No study has compared the use of measures in patients with advanced cancer to provide information on which are the most suitable and valid (Higginson and Hearn, 1994). The Support Team Assessment Scale (STAS) and the more recent Palliative Care Outcomes Scale (POS) are discussed by Higginson (Romer, 2000). The POS is available free to registered users via the web (www2.edc.org/lastacts/archives/archivesJan00/POSCover.asp)

Standards for good practice in palliative care have been published by NCHSPCS (1997) and NHSE Trent (Manifold and Coleman, 1997). An example of standards and audit used at St Catherine's Hospice, Crawley has been published (ACPOPC, 1995). Guidelines for good practice have been published by ACPOPC (1993).

10.0 Overall Strength of the Evidence

10.1 Clinical Effectiveness

Twenty-eight studies were found relating in some way to the provision of physiotherapy to a palliative care population; 5 systematic reviews, 8 randomised controlled trials, 2 comparative studies, 9 observational studies, 3 qualitative and one case report. In some cases the connection was not regarding physiotherapy per se, but highlighted areas of concern for patients that might be helped by physiotherapy. The only area of physiotherapy intervention to be studied in any depth has been that of lymphoedema and manual lymph drainage. Nurses have also instigated many of the studies. There have been few studies examining the effect of physiotherapy or rehabilitation specifically on an elderly population, although the mean age of the participants in many studies was over 65.

In general the evidence base for the role of physiotherapy in palliative care is lacking. There have been few studies of any power looking at specific interventions. It is accepted that conducting research in palliative care is difficult given ethical and procedural problems. Outcomes such as the quality of care and quality of life, including quality of death and best resolution of bereavement, are hard to measure. Thus, many studies exclude quality of life as an outcome variable, or only include patients who can complete questionnaires (Higginson, 1999). There are ethical and practical difficulties in obtaining evidence on systems of care that are intended for a population that may not survive to follow up.

10.2 Cost Effectiveness

No evidence was found on the cost effectiveness of physiotherapy in palliative care. Todd (1999) has calculated the costs of providing a lymphoedema service, including costs of service provision, garments and equipment and patient costs.

11.0 Recommendations for Research

The NHS R&D Strategic Review of Ageing and Age-associated Disease and Disability (NHS R&D, 1999) concludes that if the current rates of disability continue, there will be two million more people aged over 65 sufficiently disabled as to require assistance with activities of daily living by 2031. They note 23 specific topic areas that will need to be addressed, cancer being one. Their conclusion is that there is ageist discrimination in the quality of care provided for older cancer sufferers in the UK. In their summary of recommendations they conclude that:

- The optimal management of service delivery and waiting lists for interventions that reduce or prevent disability should be a research priority.
- The cost-effective provision of rehabilitation for older people throughout the NHS should be a research priority.
- Best practice for the management of distressing symptoms needs to be developed and implemented for both terminal and non-terminal illness.

Based on the evidence reviewed in producing this report further research is required on physiotherapy interventions for older people in the palliative care stage of their life for a variety of conditions.

Useful Organisations and Websites

Age Concern

www.ageconcern.org.uk/

Age Concern England

Astral House

1268 London Road
London SW16 4ER
Tel: 020 8765 7200

Age Concern Scotland

113 Rose Street
Edinburgh EH2 3DT
Tel: 0131 220 3345

Age Concern Cymru (Wales)

4th Floor, 1 Cathedral Road,
Cardiff CF11 9SD
Tel: 029 2037 1566

Age Concern Northern Ireland

3 Lower Crescent
Belfast BT7 1NR
Tel: 028 9024 5729

American National Hospice and Palliative Care Organization

www.nhpco.org/
1700 Diagonal Road
Suite 300
Alexandria
VA 22314
USA

Association of Palliative Medicine

www.palliative-medicine.org.uk

Bandolier Palliative Care and Supportive Care

www.jr2.ox.ac.uk/bandolier/booth/booths/pall.html

BMJ Collected Resources of Palliative Medicine

www.bmj.com/cgi/collection/palliative_medicine

British Lymphology Society

www.lymphoedema.org

CancerBACUP

www.cancerbacup.org.uk/
3, Bath Place
Rivington Street
London EC2A 3JR
Telephone: 020 7696 9003
Fax: 020 7696 9002

Cancer Research Campaign

www.crc.org.uk/
10 Cambridge Terrace
London
NW1 4JL
Tel: 020 7224 1333
Fax: 0207487 4310

Cochrane Collaborative Review Group in Pain, Palliative and Supportive Care (PaPaS)

www.jr2.ox.ac.uk/Cochrane
Editorial Office
Pain Relief Unit
The Churchill Hospital
Oxford OX3 7LJ UK
Tel: 01865 225762
Fax: 01865 225400

Department for Health England: National Service Framework for Older People:

NSF for Older People Implementation Team
Department of Health
133-155 Waterloo Road
London SE1 8UG
Tel: 020 7972 3000
Fax: 020 7972 4863
Email: nsf-for-older-people@doh.gsi.gov.uk

Main website: www.doh.gov.uk/nsf/olderpeople.htm
NSF Standard 4 good practice examples website:
www.doh.gov.uk/nsf/oldergeneralhospital.htm

Department for Health England: Cancer

Main website: www.doh.gov.uk/cancer/index.htm
Cancer R&D: www.doh.gov.uk/research/rd1/strategicresearch/cancer/cancerresearch.htm
The NHS Cancer Plan: www.doh.gov.uk/cancer/cancerplan.htm

Edmonton Palliative Care Program Assessment Tools
www.palliative.org/pc_assess.html

European Association of Palliative Care

www.eapcnet.org
The EAPC Head Office
Istituto Nazionale Dei Tumori
Via Venezian 1
20133 Milano
ITALY.
Tel: +39 02 2390 3390
Fax: +39 02 7060 0462.
E-mail: eapc@istitutotumori.mi.it

A non-governmental organisation recognised by the Council of Europe

Growth house

www.growthhouse.org/

International gateway to resources for life-threatening illness and end of life care.

Halley Stewart Library, Department of Palliative Care and Policy, King's College London

www.kcl.ac.uk/kis/schools/kcsmd/palliative/library.htm

Halley Stewart Library
St Christopher's Hospice
51-59 Lawrie Park Road
Sydenham
London SE26 6DZ
Tel: 020 8778 9252
Fax: 020 8776 9345

The Halley Stewart Library at St Christopher's Hospice is a unique specialist library covering a wide variety of subjects related to hospice and palliative care, death, dying and bereavement.

Help the Aged

www.helptheaged.org.uk/

Head Office:
207-221 Pentonville Road
London
N1 9UZ
Tel: 020 7278 1114
Fax: 020 7278 1116

Scotland:
Heriot House
Heriothill Terrace
Edinburgh
EH7 4DY
Tel: 0131 556 4666
Fax: 0131 557 5115
Northern Ireland:
Ascot House
24-30 Shaftesbury Square
Belfast
BT2 7DB
Tel: 02890 230 666
Fax: 02890 248 183

Wales Office:
Room 123
CSV House
Williams Way
Cardiff
CF10 5DY
Tel: 02920 415 711
Fax: 02920 415 700

Hospice Information Service

www.hospiceinformation.co.uk
The Hospice Information Service at St Christopher's Hospice
51-59 Lawrie Park Road,
London SE26 6DZ
Tel: 020 8778 9252
Fax: 020 8776 9345
E-mail: info@his2.freeserve.co.uk

Providing information on hospices and palliative care services for both professionals and the public. Through publications, research and professional links, the service encourages networking and provides a worldwide resource for all those engaged in palliative care.

Innovations in End-of-Life Care

www2.edc.org/lastacts/
An international journal and online forum of leaders in end-of-life care

Institute of Cancer Research
www.icr.ac.uk/index.html

Marie Curie Cancer Care

www.mariecurie.org.uk/

General enquiries e-mail: info@mariecurie.org.uk

Marie Curie Cancer Care Head Office:

89 Albert Embankment

London

SE1 7TP

Tel: 0207 599 7777

Scotland:

29 Albany Street

Edinburgh

EH1 3QN

Tel: 0131 456 3700

Wales:

Raglan Chambers,

63 Frogmore Street,

Abergavenny

Monmouthshire NP7 5AN

Tel: 01873 30 3000

Northern Ireland:

60 Knock Road,

Belfast BT5 6LQ

Tel: 028 9067 1210

National Council for Hospice and Specialist Palliative Care Services NCHSPCS

www.hospice-spc-council.org.uk

First Floor, 34-44 Britannia Street

London

WC1X 9JG

Tel: 020 7520 8299

Fax: 020 7520 8298

Council is the umbrella and representative body for hospice and palliative care in England, Wales and Northern Ireland.

National electronic Library for Health (Cancers)

www.nelc.org.uk/

Scottish Partnership Agency for Palliative and Cancer Care

www.palliativecarescotland.org.uk/

Scotland's national umbrella and representative body for palliative care. The SPA aims to improve and extend the care and support available in Scotland for people with progressive conditions such as cancer particularly towards the end of their lives.

St Christopher's Hospice

Physiotherapy Department

51-59 Lawrie Park Road

London

SE26 6DZ

Tel: 020 8768 4608

A team of physiotherapists specialising in all aspects of palliative care.

Acknowledgements

The CSP commissioned and funded the report. Kay Mowle Clarke, research officer ACPOPC, is thanked for advice and guidance. The Library at Exeter Hospice is thanked for help in finding many of the papers and books needed. Judy Jolliffe reviewed the literature and drafted the report. Tracy Bury managed the production of the report, assisted in the drafting of the text and carried out the editing. Anna Sewerniak, CSP Senior Information Officer, carried out the searches. Thanks are also due to the reviewers and colleagues who provided helpful comments on an earlier draft: Ruth Tigue, Val Young, Liz Jordan, Kay Mowle-Clarke, Jane Norris, and Rosemary Oddy.

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Appendix 1

The Evidence Base for Physiotherapy and Rehabilitation

The evidence base: physiotherapy / rehabilitation

Study	Bernabei et al, 1998, USA
Type of study	Retrospective, cross-sectional
Intervention	Objective; to evaluate the adequacy of pain management in elderly and minority cancer patients admitted to nursing homes
Number patients/studies	13,625 patients aged >65 mean age 81 (73-89) Patients with cancer admitted to nursing homes.
Population	Daily pain and analgesic treatment
Outcome measures	25-40% of patients with cancer experience daily pain. Arthritis was present in 11% of 65+, 17% of 75+ and 25 % of 85+. The prevalence for osteoporosis was 4%, 7% and 9% and for recent # was 10%, 14% and 18%. Age inversely associated with pain. As age increased patients were less likely to be given analgesics
Results	Study has limitations in that patients are only assessed for daily pain and was based on observation by the nursing home staff, if patients could not complete the questionnaire. The use of analgesics relates to the first 7-15 days in the nursing home only.
Study	Bredin et al, 1999, UK
Type of study	RCT
Intervention	8 week intervention by specialist nurse. Range of activities including breathing control, activity pacing, relaxation and psychosocial support
Number patients/studies	119 recruited results on 103 I=51, mean age 68 (41-82) C=52, mean age 67 (41-83) Patients with small cell, non-small cell carcinoma or mesothelioma who have completed 1 st line treatment.
Population	Visual analogue scales measuring distress due to breathlessness, breathlessness at best and worst, WHO performance status scale, HAD Scale, and Rotterdam symptom checklist.
Outcome measures	I improved significantly at 8 weeks in 5 of 11 items assessed; breathlessness at best, WHO performance status, levels of depression and 2 Rotterdam symptom checklist measures (physical symptom distress and breathlessness)
Results	16 patients died during course of study, 28 withdrew. The authors conclude that the completion and results of this study are an achievement in the field of palliative care considering the difficulties of randomising very ill patients.
Study	Cole et al, 2000,
Type of study	Retrospective cohort
Intervention	Comprehensive inpatient rehabilitation
Number patients/studies	108 male, 92 female., mean age 71 +/- 11.5. Mixed cancers:

Population	Breast (32), BRN (32), GI (21), GU (32), gynaecologic (12), head and neck (12), PIN(13), lung (33), other (12). Patients also divide as to functional impairment; Aesthenia (82), CNS dysfunction (34), orthopaedic (610 and post op (23). FIM
Outcome measures	Scores in each group showed significant improvement in motor function; patients with post operative or orthopaedic problems making greater gains than those with •sthenia or CNS problems. There was no effect on the FIM scores if patients were undergoing radio-or chemo-therpay. FIM cognitive scores improved significantly in all groups except PIN.
Results	
Study	Corner et al, 1995, UK
Type of study	RCT
Intervention	2 treatment groups; 1 (17)– massage with blend of essential oils 2 (17)– massage with carrier oil + matched control group (18),
Number patients/studies	47 m women, 5 men mean age 47.8 Mixed cancers; Breast (24), gynae (10), BRN (8), Sarcomas, head & neck or lung (10). 10 in palliative care phase
Population	Interview, HAD Scale, QoL & symptom distress scale
Outcome measures	Massage with or without essential oils has a positive effect on anxiety. This may be enhanced by the use of essential oils, but study too small to draw firm conclusions.
Results	Control group not randomised. Effects of massage lasted 3-4 days and sessions were cumulative, with peak effect at 4 sessions. Massage provoked emotional release and increased communication. Could this be a confounding factor.
Study	Corner et al, 1996, UK
Type of study	RCT pilot
Intervention	Weekly sessions with a nurse research practitioner over 3-6 weeks using counselling, breathing retraining, relaxation and teaching coping and adaptation strategies.
Number patients/studies	34 randomised, results on 20. I=11, mean age 55. C=9, mean age 69 Patients with advanced small cell and non-small cell carcinoma.
Population	Visual analogue scale ratings of breathlessness, distress caused by breathlessness, functional capacity, ability to perform ADL, HAD Scale.
Outcome measures	Improvement in median scores on all measures observed in I, with exception of depression. C scores remained static or worsened. Significant improvement observed in breathlessness at best (p<0.02), Breathlessness at worst (p<0.05), distress caused by breathlessness (p<0.01), functional capacity ([p<0.02) and ability to perform ADL (p<0.03).
Results	High drop out due to disease process. Randomisation was stopped in response to medical and nursing staff requests who felt they had observed a clear benefit for the intervention.
Study	Corner 1998, UK
Type of study	RCT

Intervention	Breathing exercises and abdominal binder
Number patients/studies	8 Patients with malignant ascites
Population	QoL, time between drainage
Outcome measures	Breathing exercises and abdominal binder increased intra-peritoneal pressure.
Results	Procedural problems meant study could not be completed.
Study	Duggleby, 2000, USA
Type of study	Qualitative
Intervention	Hospice care
Number patients/studies	5 men, 6 women aged > 65 Mixed cancers; Lung (5), rectal (2), uterine, breast, transitional cell and brain (1 each).
Population	Constant comparative analysis
Outcome measures	Patients described the site of pain, a hierarchy of pain (differentiated into physical and psychological pain) and strategies used to reduce it. Strategies to reduce pain included heat, positioning and activity.
Results	Limitations; study based in rural Texas with predominately white, protestant and English speaking participants. Co-morbidity may have influenced the findings.
Study	Friedenreich and Couneya, 1996
Type of study	Systematic Review
Intervention	Rehabilitation/ Treatment involving moderate exercise programmes
Number patients/studies	9 studies – 4 RCTs, 3 quasi-experimental, 2 retrospective. Patients with breast cancer, mixed stages.
Population	Physiological parameters, quality of life measures.
Outcome measures	Authors found that exercise has a positive effect on physiologic and psychologic function including functional capacity, body fat, nausea, fatigue, locus of control, mood states, self-esteem and quality of life. See comments
Results	Authors state that there is some evidence that exercise rehabilitation has a beneficial effect on patients with breast cancer, but that the studies included had numerous methodological limitations. The Centre for Reviews and Dissemination (York) found several major methodological flaws in the systematic review and conclude that the authors cannot state that exercise rehabilitation is beneficial to cancer patients.
Study	Hearn and Higginson, 1998, UK
Type of study	Systematic review
Intervention	A systematic review of the literature on whether specialist palliative care teams improve outcomes for cancer patients
Number patients/studies	18 studies; 5 RCTS, 5 comparative 8 observational Patients with cancer in mixed settings.
Population	Varied
Outcome measures	Improved outcomes seen in the amount of time spent at home, satisfaction, symptom

	control, reduced number of inpatient hospital days, reduction in overall cost and likelihood of patients where they wished to for those receiving palliative care from a multiprofessional palliative care team.
Results	Thorough review of the literature on specialist palliative care teams.
Study	Johansson et al, 1998, Scandinavia
Type of study	RCT
Intervention	Part 1- 2 weeks SPC all patients Part 2 – 2 weeks (MLD) 45 min/day or SPC 2 hours/day.
Number patients/studies	28; results presented on 24; SPC (12) and MLD (12).
Population	Women with previously treated breast cancer and unilateral arm lymphoedema
Outcome measures	Arm volume, mobility, strength and subjective assessment. Part 1 –7% reduction in arm volume. Part 2 – 15% reduction MLD, 7% reduction SPC. All patients reported reduced tension & heaviness in part 1, only MLD reported further decrease of tension and heaviness.
Results	Not in palliative care phase. No significant difference between treatments.
Study	Johansson et al, 1999, Scandinavia
Type of study	Controlled trial
Intervention	Part 1-2 weeks Low stretch compression bandaging (CB) all patients and then Part 2- one week CB alone or CB + MLD
Number patients/studies	38 women CB 18, CB + MLD 20. Age range 37 – 83.
Population	Arm lymphedema post mastectomy treatment.
Outcome measures	Arm volume + subjective assessment Part 1 – mean reduction of 26% in arm volume. Part 2 – 11% reduction in CB+MLD, 4% reduction in CB alone. CB and CB+MLD reduced heaviness and tension, CB+MLD reduced pain.
Results	Patients not in palliative phase CB alone has effect on lymphoedema, MLD adds positive effect.
Study	Mackey and Sparling, 2000, USA
Type of study	Qualitative
Intervention	Hospice care
Number patients/studies	4 women
Population	Terminal care
Outcome measures	Grounded theory 4 recurrent themes; social relationships-particularly the family, spirituality – based on religion or internal beliefs, acceptance of mortality & meaningful physical activity linked to their lives.
Results	Self-identity and sense of control appear to be linked to the performance of routine, familiar activities. To further maximise meaning for patients who are dying, while maximising endurance and conserving energy, physical therapists may foster continuity of those physical activities that have held meaning in patient's lives.
Study	Marciniak et al, 1996, USA
Type of study	Retrospective cohort
Intervention	Comprehensive inpatient rehabilitation

Number patients/studies	159, mean age 56.7+/- 17.1, range 17-88. Mixed cancers; PIN (72), breast (14), spinal cord (16), other (57). 27% of patients had 2 medical disorders, 21% had 3, 11% had 4 and 4% had 5 or more.
Population	FIM motor score – 13 items covering self-care, mobility, locomotion & sphincter control.
Outcome measures	146 patients with complete data; significant functional gains made from admission to discharge (p<.001). Neither presence of metastatic disease nor ongoing radiation therapy had a poor effect on functional outcome.
Results	This study looked at motor and cognitive function, examined separate cancer categories and looked at functional impairment.
Study	Martlew , 1996, UK
Type of study	Qualitative
Intervention	Unstructured interview.
Number patients/studies	10 patients receiving physiotherapy at a day hospice. Not detailed
Population	Concepts arising from interviews
Outcome measures	All patients felt that physiotherapy fitted into the hospice programme and had been a positive psychological support. 8 felt physiotherapy had contributed to an improvement in function.
Results	A small qualitative study. Difficult to generalise to a broader population.
Study	Matthews and Smith, 1996, Australia
Type of study	Controlled study
Intervention	Full Foldi< Technique of Complex Physical therapy for lymphoedema (LDM for 5 days/week for 4 weeks, compression with low stretch bandages, skin care, exercises and education or Modified version of this therapy (LDM twice/week for 4 weeks, compression with temporary pressure garments, skin care, exercises and education. All patients wore pressure garments after treatment finished.
Number patients/studies	24 female, 1 male. 5 receiving full programme. 15 modified programme. Median age 63 (full), 60 (modified) Patients with lymphoedema of a limb.
Population	Circumference of< affected and contralateral l. limb Follow up at end of treatment, 13 weeks, 26 weeks and 52 weeks.
Outcome measures	41% reduction in lymphoedema at end of treatment, maintained over following year form either programme.. Benefits cited by patients; improvement in use of limb, reduction in weight and pain.
Results	Both forms of treatment effective. Continued improvement attributed to compression garments. Full programme required 30 hours of therapist time, modified programme required 13.5 hours of therapists time.
Study	Megens and Harris, 1998, Canada
Type of study	Systematic review
Intervention	Physical therapy management of lymphoedema
Number patients/studies	13 studies; 1 small RCT 5 non RCT with comparison group or cross over design 7 one group pretest/post test. Participants who had been treated for breast cancer and who had secondary

Population	lymphoedema in at least one upper extremity Studies graded as to level of evidence (Sackett) Level 2 – 1 Level 3 – 5 Level 5 - 7
Outcome measures	Compression garments appear to reduce limb size after 6 months of use (grade B evidence). Complex physical therapy in full or modified form is effective as are combination treatments (grade C evidence)..
Results	None of the conclusions are supported by numerous, definitive studies and caution should be exercised when considering the results. It is not clear whether any of these patients were in the palliative phase of their disease.
Study	Morasso et al, 1999, Italy
Type of study	Prospective cohort
Intervention	Palliative care
Number patients/studies	89, mean age 64.8 +/- 11.1 Mixed cancers; Lung (20), breast (16), pancreas (8), stomach (10), colorectal 910), GU (10), other (14), unknown 91).
Population	Index of Independence of Daily Living (ADL), SDS, PDI
Outcome measures	62.1 % of patients had unmet needs in occupational functioning (the need to spend time usefully). 14.6 % had unmet needs in personal care (but this was 26.3 % of women and 5.9% of men). Women also had significantly higher needs in the areas of emotional support and communication.
Results	Patients with unmet needs had higher levels of symptom and psychological distress. Limitations; the use of a semi-structured interview may not have given patients the opportunity to explore the issues as seen by them.
Study	Mortimer, 1999, UK
Type of study	Randomised cross over
Intervention	Daily manual lymphatic drainage (MLD) for 1 hour or self administered massage (SAM) for 20 minutes/day.
Number patients/studies	31 women Stable breast cancer-related oedema of > 3 months.
Population	Excess limb volume, QoL, movement and function.
Outcome measures	MLD significantly reduced limb volume. SAM did not have any significant effect on limb volume. MLD significantly improved emotional function, dyspnoea, sleep disturbance. MLD showed a significant improvement in pain, discomfort, heaviness, fullness, bursting and hardness.
Results	Patients were not in palliative care phase and study did not compare equivalent times of massage i.e one hour each.
Study	University of York, NHSCRD 1998
Type of study	Systematic review
Intervention	Comprehensive review of the various interventions for lung cancer
Number patients/studies	Not detailed as no meta analysis
Population	*****
Outcome measures	Section on management of breathlessness concludes that counselling and breathing

Results	retraining by nurses can enhance patients ability to cope. Bredin 1999 and Corner 1996 the only two RCTs cited.
Study	Porock et al 2000, Australia
Type of study	Prospective cohort; pre & post test
Intervention	Duke Energising Exercise Plan (DEEP) over 2 weeks.
Number patients/studies	6 female, 3 men, mean age 59.87 +/- 9.7, range 51-77. Mixed cancers; bowel (4), pancreas (2), melanoma (1), breast (1), oral (1) with life expectancy greater than 1 month.
Population	MFI, , SDS, HADS, Quality of Life Scale (QoLS) + diary.
Outcome measures	Fatigue did not change over the period of the study, but patients were more active at the end of the study. QoL scores improved and qualitative comments from the patient's diaries showed satisfaction in increasing activity.
Results	Missing data and a small population make it hard to draw any firm conclusions about the role of exercise in these patients, but further research is warranted.
Study	Saddison and Vaneck 1993, USA
Type of study	Case report
Intervention	Physiotherapy in early stage, then stellate ganglion blocks, anti depressants and continued physiotherapy
Number patients/studies	49 year old woman Right modified radical mastectomy and subsequent reflex sympathetic dystrophy
Population	Pain. Range of motion,
Outcome measures	Patient improved after blocks, but was still receiving physiotherapy after 2 years.
Results	
Study	Salisbury et al, 1999, UK
Type of study	Systematic review
Intervention	Impact of different models of specialist palliative care on patient's quality of life.
Number patients/studies	86 papers; 22 descriptive, 27 comparative Views from patients receiving palliative care or surviving spouses/partners.
Population	Various systems of measuring QoL.
Outcome measures	Overall conclusion is that there is little robust evidence that any form of organisation of specialist palliative care offers significant advantage in terms of QoL.
Results	Need for larger studies and reliable, valid QoL tools,
Study	Sciolla et al, 2000, USA
Type of study	Retrospective cohort Patients aged > 60 years.
Intervention	In patient multi disciplinary rehabilitation
Number patients/studies	110, mean age 75.3 (95% CI = 73.8-76.8), range 60-90. BRN< (16), lung (19), breast (22), < GU (21), GI (11), PIN (5), gynae (6), head & neck (4), other (6). All patients had asthenia plus one of 4 other problems; asthenia only (48), orthopaedic (41), CNS dysfunction (16), postoperative problems (5).
Population	FIM motor & cognitive
Outcome measures	Mean total FIM improved from 70.5 to 88 (p<0.001), from a level indicating pathological fatigue to a level where patients required only moderate assistance with self care. These results were independent of cancer diagnosis or ongoing treatment.

Results	Limitations; confounding factors may have led to the patient's recovery
Study	Todd , 1999, UK
Type of study	Prospective, observational
Intervention	Complex physical therapy (CPT)
Number patients/studies	96 recruited, results on 83 – 80 female, 3 male. Mean age 57
Population	Patients with lymphoedema, 80.5% with malignancy, 65% with breast cancer. Limb volume, skin condition, functional movement, acute inflammatory episodes, HHQ, HADs, costs.
Outcome measures	HHQ increased physical & psychological well being. No decrease in anxiety & depression (HADs). Improvement in limb volume, skin condition, leg movement, acute inflammatory episodes.
Results	Study piloted condition specific tools. Population dependent on local service provision and referral patterns.
Study	Wilkinson et al, 1999, UK
Type of study	RCT, but no control group
Intervention	2 groups each receiving 3 full body massages over 3 consecutive weeks. Group 1 (46) – carrier oil + Roman chamomile oil Group 2 (57) – carrier oil only.
Number patients/studies	78 female, 9 male mean age 53.5 Mixed cancers; Breast (43), lung (10), head and neck (8), cervix (7), lymphoma (5), colorectal 95), other (9). Reasons for referral; Anxiety (51), pain (28), depression (8)
Population	Rotterdam Symptom Checklist (week 1 & 4), State Anxiety Inventory (before 7 after each massage), Trait Anxiety Inventory (week 4), semi-structured questionnaire (week5).
Outcome measures	Massage with or without essential oils appears to reduce levels of anxiety
Results	16 dropout
Study	Wozniowski et al, 2001, Poland
Type of study	Prospective, observational
Intervention	CPT including SPC, elastic hosiery and SAM.
Number patients/studies	208 women aged 17 –83 (mean 50.8). Lymphoedema; 90% upper limb, 10% lower limb.
Population	Volume or circumference
Outcome measures	Average reduction in swelling of 19 – 43%, depending on severity of oedema, those with minimal or moderate oedema achieving a greater % decrease.
Results	Original MLD technique modified
Study	Yoshioka, 1994 , Japan
Type of study	Prospective, cohort
Intervention	Physical therapy – mostly ADL exercises re transfers & locomotion, sitting balance and positioning.
Number patients/studies	301 results presented on 239; 96 male, 143 female, aged 60 or over (mean 61.7). Terminal cancer – stomach (54), lung (43), breast (38), rectum (28), uterus (23), liver

	(21), colon (18), ovary (11), pancreas (10) , other (55).
Population	Barthel mobility index (max score 47) & questionnaire to relatives of 169 patients.
Outcome measures	Barthel score increases from mean 12.4 to 19.9. 88% pts wanted a wheelchair, 98% satisfied with hospice care, 78% satisfied with rehab.
Results	The more fully patients discussed the therapy programme, the more effective the programme was judged to be. Japanese setting may not be generalisable to UK.

Glossary

ADL = activities of daily living
BDI = Beck depression inventory
BRN = blood related neoplasm
C= control group
CB = low stretch compression bandaging
CNS = central nervous system
CPT = Complex Physical Therapy
CRD = Centre for Reviews and Dissemination, York
DARE = Database of Abstracts of Reviews of Effectiveness
FIM = Functional Independence Measure
GI = gastrointestinal
GU = genitourinary
I= intervention group
HAD Scale = Hospital anxiety and depression scale
HHQ = Hunters Hill Questionnaire
MFI = Multidimensional Fatigue Inventory
MLD/LDM = manual lymph drainage
PDI = psychological distress inventory
PIN = primary intra cranial neoplasm
ROM = range of movement
QoL – quality of life
SAM = self administered massage
SDS = symptom distress scale
SPC = sequential pneumatic compression
TENS = transcutaneous nerve stimulation