

National Standards for Rehabilitation of Adult Cancer Patients

Welsh Assembly Government

TABLE OF CONTENTS

1.	INTRODUCTION TO THE CANCER STANDARDS	3
2.	METHODOLOGY	4
3.	FORMAT	5
4.	INTRODUCTION TO THE NATIONAL STANDARDS FOR REHABILITATION OF CANCER PATIENTS	6
	Strategic context.....	6
	Epidemiology	8
	The relationship between the Standards for Rehabilitation of Cancer Patients and existing National Cancer Standards	10
5.	STANDARDS	
	Topic: Organisation - the Cancer Network Rehabilitation Advisory Group (CNRAG)	13
	Topic: The Cancer Rehabilitation Practitioners.....	17
	Topic: The Care Pathway.....	19
	APPENDICES	21
	APPENDIX 1 – Literature to support clinical evidence for rehabilitation.....	22
	APPENDIX 2 – Cancer Rehabilitation Practitioners to support cancer site MDTs and community teams	24
	APPENDIX 3 – Levels of care	25
	APPENDIX 4 – Recommended model of rehabilitation and support	26

1. INTRODUCTION TO THE CANCER STANDARDS

- 1.1 National Cancer Standards define the core aspects of the service that should be provided for adult cancer patients throughout Wales. The Standards should be used in conjunction with other requirements for example from the Health and Safety Executive, NHS, Royal Colleges and the National Institute for Clinical Excellence [NICE] recommendations and guidelines that cover patient care, facilities and staff. Local Health Boards may provide or aim to provide additional services and work to more rigorous and/or wide-ranging standards. This should be encouraged.
- 1.2 The National Standards for Rehabilitation of Cancer Patients take account of NICE guidance¹. In some cases the new standards are developmental and will be challenging. It is recognised that such changes take time and resource to implement and it will therefore be important that the process of implementation is planned to start as soon as possible. Local Health Boards will need to work with their Cancer Networks/Clinical Programme Group (CPG North Wales) to plan and deliver the service changes required.
- 1.3 The Cancer Information Framework Strategy Group² will need to define the information requirements arising from these new standards.
- 1.4 Healthcare Standards for Wales set out the Welsh Assembly Government's common framework of healthcare standards to support the NHS and partner organisations in providing effective, timely and quality services across all healthcare settings³. The Healthcare Standards are used by Healthcare Inspectorate Wales (HIW) as part of their processes for assessing the quality, safety and effectiveness of healthcare providers and commissioners across Wales. The National Standards for Rehabilitation of Cancer Patients Standards contribute to the achievement of the Healthcare Standards for Wales and establish a basis for continuous improvement, promoting the effective delivery of care in the rehabilitation of cancer patients. These Standards will be mapped to the revised Healthcare Standards once published.

¹ Improving Supportive and Palliative Care for Adults with Cancer (2004) NICE.

² Cancer Information Framework Strategy Group (2010)

³ Healthcare Standards for Wales (2005) Welsh Assembly Government

2. METHODOLOGY

- 2.1 The Cancer Services Co-ordinating Group [CSCG] was tasked to develop standards for rehabilitation for adults living with or after cancer. A core group of the CSCG's Nursing and Allied Health Professional Cancer Advisory Group [NAHPCAG] has led this work and sought to ensure that those involved in providing rehabilitation services have had input to the process. The core group included input from the regional cancer networks and, as observers, from the Assembly Government's Therapy Adviser and Lead Nurse for Cancer Jan Smith and Denise Richards respectively. Final editing was undertaken by Sue Acreman (chair), Beryl Roberts, Iain Mitchell and Jane Hanson.
- 2.2 The core group commenced work in March 2008 and took account of the evidence base, the existing Welsh Assembly Government guidance on chronic disease management, the development of cancer specific rehabilitation measures by the Department of Health⁴ and a framework for rehabilitation developed by the Scottish Executive⁵. Sian Clifton, Lecturer at Cardiff University undertook the literature review (Appendix 1).
- 2.3 To support a more inclusive approach national, network and local events were held. Nationally, workshops were held as part of the March 2008, October 2008 and March 2009 Cancer Learning Network Events with a full day workshop on Living with Cancer; Survivorship and Rehabilitation in Wales also in March 2009. These events resulted in opportunities for input from a wide audience of patients, and professionals from both NHS and voluntary sector providers.
- 2.4 A three month consultation was conducted prior to final changes and submission to the Assembly Government.

⁴ Rehabilitation Measures Manual of Cancer Services National Cancer Peer Review Programme (2008). Department of Health

⁵ Co-ordinated, integrated and fit for purpose: A Delivery Framework for Adult Rehabilitation in Scotland (2007). Scottish Executive,

3. FORMAT

- 3.1 The standards are presented as a series of three Topics. The first of these covers organisation, the second the practitioners and the third the care pathway. Within each Topic, a Rationale is presented that provides the context to the specific standards that follow.
- 3.2 It will be necessary to develop an all Wales audit tool to monitor the implementation of these standards across all sectors.
- 3.3 Throughout the standards when the term “person/ patient with cancer” is used this is an overarching term which refers to the individual adult with cancer and also their significant others including family, dependants and carers as central to the whole rehabilitation process.
- 3.4 Throughout the standards the following abbreviations are used:
- AHP - Allied Health Professional— professions that include Dietetics; Speech and Language Therapy; Physiotherapy; Occupational Therapy
 - CNRAG - Cancer Network Rehabilitation Advisory Group
 - SPCT - Specialist Palliative Care Team

4. INTRODUCTION TO THE NATIONAL STANDARDS FOR REHABILITATION OF CANCER PATIENTS

Strategic context

- 4.1 These standards inform the development of site specific rehabilitation pathways which are integral to all services. They are intended to identify the rehabilitation needs that underpin many of the deliverables identified in the Welsh Health and Social Care policies in particular Designed to Improve Health and the Management of Chronic Conditions in Wales⁶. The Welsh Assembly Government's cancer policy Designed to Tackle Cancer⁷ has a specific policy aim to improve rehabilitation services for people "that match or surpass the best in Europe in terms of quality" and to achieve this will require the organisation and effective planning of services.
- 4.2 The NICE guidance Improving Supportive and Palliative Care for Adults with Cancer states that '*Rehabilitation attempts to maximise patients ability to function, to promote their independence and to help them adapt to their condition. It offers a major route to improving their quality of life, no matter how long or short the timescale. It aims to maximise dignity and reduce the extent to which cancer interferes with an individuals physical, psychosocial and economic functioning*'.⁸ In addition, the NAHPCAG working definition included the recognition that, '*Rehabilitation in cancer can be preventive, restorative, supportive and palliative*'.
- 4.3 Rehabilitation for cancer patients should not be regarded as an isolated stage or form of therapy but be integrated within NHS and social care. The existing site specific National Cancer Standards apply to all patients receiving cancer rehabilitation.
- 4.4 A continuum is described as a link between two or more stages that blend into each other seamlessly so that it is impossible to identify the transition from one stage to the next. Table 1 summarises the Cancer Continuum. Best practice in rehabilitation requires support, assessment and intervention as necessary at each stage in this continuum.

⁶ Designed to Improve Health and the Management of Chronic Conditions in Wales (2007) Welsh Assembly Government

⁷ Designed to Tackle Cancer in Wales 2008-2011 Strategic Framework (2008). Welsh Assembly Government

⁸ Improving Supportive and Palliative Care for Adults with Cancer (2004), NICE.

Table 1 The Cancer Continuum - Phases in Cancer Care

Prevention/ Health promotion	Detection	Diagnosis	Treatment	Living with cancer/ Survivorship	End of life care	
Smoking cessation	Cancer screening	Tumour staging	Chemotherapy Surgery Radiotherapy	Long term follow up	Palliative care	
Diet	Awareness of cancer signs and symptoms	Patient counseling and decision making	Symptom management Psychosocial care	Late effects management	Spiritual issues	
Physical activity				Psychological coping	Hospice care	
Sun exposure				Health promotion	Bereavement care	
Virus exposure				Rehabilitation, survivorship and palliative care can run throughout these phases in cancer care and will be different for each patient		
Alcohol use						

4.5 NICE have described the domains of care in cancer rehabilitation⁹. Each assessment of a patient’s rehabilitation needs should consider each of these domains as and when they progress through their cancer journey. The domains are as follows;

Physical - such as optimising functional ability and management of symptoms such as breathlessness or fatigue

Nutritional – optimising nutritional status to ensure maximum benefit from physical programmes; management of nutrition related symptoms

Psychological – from recognising signs of psychological distress to accruing knowledge and skills to deal with certain levels of distress

Informational – written, audio and visual information

Practical – activities to enhance daily living; returning to work

Spiritual – finding personal value; identifying personal meaning; seeking, finding and maintaining hope; being able to express emotions

Social – relationships; socialising hobbies and pastimes

Financial – paying the rent or mortgage; loss of earnings; travel and other insurance

⁹ Improving Supportive and Palliative Care for Adults with Cancer (2004) NICE.

- 4.6 The voluntary sector provides significant support for patients living with and after cancer and has published patient surveys that add to the understanding of patient views and concerns. Recent surveys highlight issues around both a lack of awareness amongst patients that cancer is classified as an actual disability and the difficulties encountered in returning to work. Comprehensive assessments covering the key domains as described above will need to be undertaken by both NHS and voluntary sector providers of care and will be expected in future to identify such issues.
- 4.7 It is important that each patient is able to self manage their condition, symptoms and side effects wherever possible with the ability to access specialist care should their needs become complex. Patient self management needs to be supported regardless of where patient care is managed across the continuum (Table 1). The emphasis for rehabilitation must always be on well informed, patient centred and patient identified care. As a result, the cancer rehabilitation team will need to be flexible, share expertise and work across boundaries as necessary.

Epidemiology

- 4.8 The population of Wales is aging and the prevalence of cancer is therefore increasing as cancer is predominantly a disease of the older people. Additionally, earlier diagnosis and more effective treatments have resulted in more people living with their cancer. As a result, cancer is classified as a chronic life threatening illness rather than a terminal disease¹⁰.
- 4.9 Cancer survival continues to improve in Wales, with overall survival rates increasing from 24% 30 years ago to the current level of 46%. By the end of 2006 a total of 116,086 people that had been diagnosed with cancer in the previous twenty years, 1987-2006, were either cured or living with their cancer. This gives a prevalence rate of 3,914 per 100,000 people in Wales and accounts for 3.9% of the population¹¹.

¹⁰ Disability and Rehabilitation action plan 2006-2011 (2006). World Health Organisation

¹¹ Cancer in Wales, 1992-2006: A Comprehensive Report. (2008). Welsh Cancer Intelligence and Surveillance Unit, Velindre NHS Trust, Cardiff

4.10 As cancer survival continues to improve in Wales and across the UK, the challenge is for each individual living with or after cancer to achieve ‘as healthy and active a life as possible for as long as possible’¹². Rehabilitation of those individuals coping with long term effects of treatment needs to be an integral part of the care provided.

¹² National Cancer Survivorship Initiative (2010) Department of Health

The relationship between the Standards for Rehabilitation of Cancer Patients and existing National Cancer Standards

4.11 These new standards have been developed and based on NICE service guidance in-line with all other published National Cancer Standards.

4.12 It is recognised that certain aspects of rehabilitation post treatment will be best centred on oncology services and if these requirements are already covered in the various National Standards for specific cancer sites they are not restated as part of standards for rehabilitation. The two standards below are taken from the Topics on Patient Centred Care and Multi Disciplinary Team (MDT) Working and are examples of generic standards applicable to all cancer site standards.

- Standard 3.2 - Written information in a language and format appropriate to the patient should be offered to each new cancer patient. This should cover;
 - a) General background information about the specific cancer
 - b) Detail of treatment options, specific local arrangements including information about the MDT and support services and whom the patient should contact if necessary
 - c) Details of local self help/support groups and other appropriate organisations
- Standard 4.x - Patients found to have significant levels of anxiety and or depression should be offered prompt access to specialist psychological or psychiatric care capable of providing level 3 or level 4 psychological interventions as defined in the NICE Supportive and Palliative Care Guidance

4.13 Certain cancer site specific standards include a requirement for AHPs to be members of the core MDT and all include AHPs as part of the extended MDT membership. The National Standards for Head and Neck Cancer Services include the following three standards;

- Standard 3.7 - The MDT to ensure that patients are assessed for ongoing support following treatment for head and neck cancer
- Standard 3.8 - There should be access to an appropriate local support team in the community as recommended by NICE service guidance to provide rehabilitation and after care for all patients. The team should include specialists with experience in head and neck cancer

- Standards 4.2 - The core MDT should include the following specialists all with expertise in head and neck cancer a) surgeons with the majority of their work involving head and neck cancer b) clinical oncologists c) restorative dentists d) radiologist/s e) pathologist/s f) palliative care physician/nurse – member of the specialist palliative care team g) speech and language therapist/s h) dental hygienist i) dietician/s j) specialist nurse/s k) an MDT co-ordinator

4.14 The Standards for Rehabilitation of Cancer Patients should also be read in conjunction with the National Cancer Standards for Specialist Palliative Care which recognises the need for information on local services. Specifically, standard 5.2 requires that the agreed referral pathway must provide explicit information on how to access services not directly provided by the SPCT including psychological support services, spiritual care, family and carer support services and complimentary therapy services.

4.15 These standards principally apply to the non pharmacological interventions provided by AHPs and nurses, though a pharmacological approach can be used alongside other interventions. However, it is important to remember that rehabilitation has to be a team undertaking to acknowledge the domains of care, with the emphasis on the appropriate involvement of the professions determined by the rehabilitation needs at the time to bring about an improvement in patient care and a positive outcome. Appendix 2 details the variety of professionals which may be required for effective, patient-centred cancer rehabilitation.

4.16 These new Standards for Rehabilitation of Cancer Patients apply to adults and do not include the needs of children and young people as these will be covered by the National Cancer Standards for Children and Young People with Cancer.

4.17 The standards are intended to set a high level framework for the development of rehabilitation within the context of specialist care provided led by cancer MDTs and chronic disease management provided in the community. As a result, providers of care will be required to assess and address the rehabilitation needs of cancer patients as necessary along the patient care pathway.

4.18 There are a number of resources available to support implementation of these standards. Passing the Baton, A Practical Guide to Effective Discharge Planning was launched in 2008 by the National Leadership and Innovation Agency for Healthcare. Use of this toolkit will support individualised discharge care plans, tailored to individual patient needs. Whilst this takes a generic approach it could easily be adapted to the specific needs of cancer patients.

4.19 Work on rehabilitation care pathways has recently been published by the Department of Health and is a very useful resource for the work now required to support rehabilitation of cancer patients led by the Regional Cancer Networks in Wales¹³.

¹³ National Cancer Rehabilitation Pathways. Department of Health 2010

Topic: Organisation - the Cancer Network Rehabilitation Advisory Group (CNRAG)

Objective 1: Regional Cancer Networks to develop a Cancer Network Rehabilitation Advisory Group (CNRAG) such that they bring together those planning and providing cancer rehabilitation with an open and transparent management structure, to ensure that all aspects of cancer rehabilitation are developed, coordinated and delivered to an agreed uniform standard of care in line with best practice.

To formalise and identify existing service provision of cancer rehabilitation, gaining approval that it is an essential component throughout the continuum of cancer care.

To ensure that all cancer rehabilitation interventions delivered throughout the Network will be assessed as relevant to the person receiving the intervention using an initial screening and ongoing assessment process of need, to be delivered by the most appropriate team members to achieve optimum results.

Rationale

There should be a single cancer network rehabilitation advisory group (CNRAG) with a specified professional membership. In North Wales the cancer clinical programme group equates to a cancer network. Patients should be represented on the CNRAG to ensure their views are considered as should the third sector where possible. Rehabilitation is integral to all the cancer standards and will be reviewed as part of the overall review of the National Cancer Standards in 2010¹⁴. Network level patient groups are now established with training available to enable individuals to participate effectively and contribute to development of services. The evaluation and review of services will be lead through the CNRAG.

The number of patients in Wales with rehabilitation requirements is not fully known and it would be useful to stratify these individuals' needs into risk categories to quantify the scale of both self management and complex specialist rehabilitation required. The stratification will be led by the CNRAG.

¹⁴ Designed to Tackle Cancer in Wales 2008-2011 Strategic Framework (2008). Welsh Assembly Government 2

The CNRAG should be recognised as the primary source of opinion within the Cancer Network on issues relating to cancer rehabilitation and for co-ordination consistency and leadership across the Network on issues relating to service and workforce development, education and training strategies and tumour site specific and specialist palliative care cancer rehabilitation guidelines.

The CNRAG will receive and act upon the findings of the National Cancer Standards self assessment monitoring reports that relate to rehabilitation.

The Chief Executives of the Local Health Boards will remain the accountable officers for the quality of care provided across their organisations. Where a team provides care to more than one organisation, clear agreements will be required between organisations about how clinical governance requirements are to be fulfilled. In relation to team working, the recommendations made at the team meeting are advisory, and the responsibility for clinical decisions and actions always rests with the senior responsible clinician under whose care the patient is at that point of the journey.

Existing individuals and teams of Allied Health Professionals, Nurses and other professionals provide elements of cancer rehabilitation as part of their role. It is vital that, through implementation of the Rehabilitation Standards, all such teams can recognise and formalise rehabilitation to ensure that the needs of all patients and their significant others are addressed by the most appropriate professional at an appropriate time.

Standard

1.1 Each Cancer Network board should agree a single named lead and deputy for cancer rehabilitation across the network, who should be a registered member of one of the following professions:

- Dietetics
- Lymphoedema*
- Occupational Therapy
- Physiotherapy
- Speech and Language Therapy

The Cancer Network Board should agree the responsibilities of and support for the Cancer Rehabilitation lead role.

1.2 The CNRAG should be developed to include patient/user representation and also membership from as a minimum each of the following professions with deputies nominated for each professional member:

- Dietetics
- Lymphoedema
- Occupational Therapy
- Physiotherapy
- Speech and Language Therapy
- Nursing
- Psychology
- Social Work
- Patient information specialist

The CNRAG terms of reference should be agreed by the Cancer Network Board.

1.3 The CNRAG should undertake a baseline survey of the provision of cancer rehabilitation services within the network regardless of provider and to include patient experience measurements. The survey should be repeated on a regular basis as agreed by the CNRAG with findings reported to the Cancer Network Board/Clinical Programme Group (North Wales)

- | | |
|-----|--|
| 1.4 | A model for community-based rehabilitation taking account of the findings of the baseline survey should be developed and form the basis of a rehabilitation Service Development Plan (SDP) that is a component part of the Cancer Network SDP. Aspects of integrated models and frameworks currently being tested for the management of chronic conditions in Wales should be considered. |
| 1.5 | The CNRAG should support the cancer site MDTs and community based services to develop the care pathway so that each patient's rehabilitation needs are assessed and met as they move along the cancer continuum from diagnosis to the treatment episode in secondary or tertiary care and back to community-based and /or third sector care. The CNRAG should provide opinion on all aspects of rehabilitation for co-ordination, consistency and leadership across the eight domains of care. |
| 1.6 | The CNRAG should agree an education and training programme to meet the levels of rehabilitation interventions required |
| 1.7 | The CNRAG should maintain a directory listing details of rehabilitation services including the level of service provided (Appendix 3) which should be included in the Cancer Network Directory. |

* Whilst lymphoedema is a service it is included here as it is principally provided by specialist physiotherapists or nurses.

Topic: The Cancer Rehabilitation Practitioners

Objective 2: Objective Cancer rehabilitation should be delivered by competent, capable practitioners supported by well informed support agencies and carers.

Rationale

Cancer rehabilitation needs to be provided by the person with the necessary capabilities, competencies and experience, according to the level of rehabilitation required, taking into account the range of expertise across professional groups ensuring that care is patient focused. A key feature of patient focused care is MDT work, with the development of a core delivery system that brings together the workforce from all appropriate care providers.

Cancer rehabilitation involves the patient having access to a wide range of the Health and Social Care Workforce whose combination of skills will enable patients' needs to be met. Thus rehabilitation should be considered as a core role for each cancer site specific MDT and community based team providing care for cancer patients. A suggested list of professionals who provide cancer rehabilitation is at Appendix 4.

A key worker/navigator is important for patients to be able to refer to when needed. The key worker may change over time and as a patient moves from hospital based care and follow up to home or community based care. The choice of key worker will depend on each patient's needs. For patients undergoing initial or follow up treatment the cancer site MDT are best placed to agree the key worker. For cancer patients also having to deal with other diseases the GP/primary care team may well be the most appropriate to co-ordinate care. For those at the end of life a member of the palliative care team may be the most appropriate key worker.

Planners should ensure a comprehensive rehabilitation service is available in all care settings. Current evidence needs to be built upon in order to develop rehabilitation in cancer care appropriately. A programme of audit, defining performance against the Cancer Standards will provide the Cancer Networks, CNRAG, health planners, the Welsh Assembly Government and the public with the information needed to maintain and improve rehabilitation for cancer patients. Professionals need to be able to work across organisational and professional boundaries, and care packages should be organised to enable patients to access services as

and when they need them, in order that rehabilitative care is responsive to patient need within diverse care settings.

Standard	
2.1	Cancer rehabilitation should be a core consideration of all cancer MDTs whether cancer site specific, specialist palliative care or community based to ensure that patients at any stage from diagnosis to end of life are identified, referred and assessed for rehabilitation measures as necessary.
2.2	Cancer rehabilitation practitioners should fully involve each patient in their rehabilitation needs assessment and resulting interventions/support
2.3	Cancer rehabilitation practitioners should be grouped according to experience and training using the four level model described in NICE’s Improving supportive and palliative care for adults with cancer (Appendix 4).
2.4	From diagnosis patients should be allocated an experienced key worker or navigator by the clinical team managing the patient. The key worker will be the most appropriate health or social care professional involved with the patient at any stage along the cancer continuum. When the key worker changes both the person handing over and the person stepping in to the role must be jointly responsible for passing on essential details of the care plan and contact points. This applies whatever level of care is provided.
2.4	The CNRAG through the cancer rehabilitation specialists will review the use of staff resources and recommend new service models as necessary.

Topic: The Care Pathway

Objective 3: Patients with rehabilitation needs should be identified, referred, assessed and treated promptly in line with best practice guidelines.

Rationale

Cancer and its treatments can result in symptoms that significantly impact upon the patient's ability to live well within their illness, and symptoms rarely occur in isolation. Consequently these patients may have multifaceted problems. Standardisation of protocols for screening and referral, across the Cancer Network, will enable assessment and treatment to be performed in a consistent manner and will assist the workforce in gaining greater expertise by concentrating on well defined protocols.

Early identification of cancer rehabilitation needs can improve quality of life, maximise independence and reduce the burden on the NHS through self management. It is important that patients are given information on what symptoms to watch out for particularly after treatment so that they can be referred promptly for assessment and treatment.

A screening tool will assist in identifying those cancer patients who may require more in depth assessment of their needs and this should be followed up by prompt referral to the necessary professionals who can provide the care. Subsequent to the referral, the professional who conducts the assessment will determine the level of intervention required as detailed in Appendix 4

Waiting time standards for therapy services in Wales, as required by the Assembly Government, should be met however this should not prevent clinical or social prioritisation so that patients can be seen much more quickly if necessary.

Standard	
3.1	The CNRAG should agree referral guidelines which incorporate the level of practitioner able to provide each intervention. These guidelines need to integrate with and support existing care pathways already agreed with cancer site MDTs. The guidelines need to be reviewed and revised if necessary on publication of new guidelines or advice.
3.2	Written referral pathways to access cancer rehabilitation services should be drawn up by the CNRAG in collaboration with primary, secondary and voluntary sector providers which detail the patient journey from whichever point the patient accesses the system. These pathways should include clear transfer of care arrangements from inpatient and outpatient settings once a patient is transferred to their preferred location ¹⁵ .
3.3	The CNRAG should ensure that referral pathways are adhered to particularly where pathways cross care providers or Network boundaries.
3.4	Management of patients including review of procedures should follow written locally agreed policies in line with NICE service guidance and national guidelines when published.
3.5	The CNRAG should produce a written programme of audits for use by cancer rehabilitation professionals to assess adherence to policies.
3.6	Patients should be given the opportunity to participate in research to enhance the knowledge base of cancer rehabilitation.

¹⁵ Passing the Baton, National Leadership & Innovation Agency for Healthcare (2008)

APPENDICES

APPENDIX 1 – Literature to support clinical evidence for rehabilitation

This is a small selection of evidence to demonstrate AHP/ Nursing interventions in cancer rehabilitation.

Bruera, E., Sala, R., Rico, M. A., Moyano, J., Centeno, C., Willey, J., et al. (2005). Effects of parenteral hydration in terminally ill cancer patients: a preliminary study. *Journal of Clinical Oncology*, 23(10), 2366-2371.

Bruera, E., Sweeney, C., Willey, J., Palmer, J. L., Strasser, F., Morice, R. C., et al. (2003). A randomized controlled trial of supplemental oxygen versus air in cancer patients with dyspnea. *Palliative Medicine*, 17(8), 659-63

Cheema, B. S. B., & Gaul, C. A. (2006). Full-body exercise training improves fitness and quality of life in survivors of breast cancer. *Journal of Strength and Conditioning Research*, 20(1), 14-21.

Dixon, J. (1984). Effect of nursing interventions on nutritional and performance status in cancer patients. *Nursing Research*, 33(6), 330-5.

Doyle N and Kelly D (2005) 'So what happens now?' Issues in cancer survival and rehabilitation. *Clinical Effectiveness in Nursing* 9 (3-4) 147-153.

Fialka-Moser V, Crevenna R, Korpan M and Quittan M (2003) Cancer rehabilitation: particularly with aspects on physical impairments. *Journal of Rehabilitation Medicine* 35 (4) 153-162.

Gerber L (2001) Cancer Rehabilitation into the Future. *Cancer (supplement)* 92 (4) 975 - 979.

Hase, K., Kamisako, M., Fujiwara, T., Tsuji, T., & Liu, M. (2006). The effect of zaltoprofen on physiotherapy for limited shoulder movement in breast cancer patients: a single-blinded beforeafter trial. *Archives of Physical Medicine and Rehabilitation*, 87(12), 1618-22

Hopkins K, Tookman A (2000) Rehabilitation and specialist palliative care. *International Journal of Palliative Nursing* 6 (3) 123-130.

Hunter M (1998) Rehabilitation in cancer care: a patient-focused approach. *European Journal of Cancer Care* 7 (2) 85-87.

Korstjens I, Mesters I, Gijzen B and van den Borne B (2008b) Cancer patients' view on rehabilitation and quality of life: a programme audit. *European Journal of Cancer Care* 17 (3) 290-297.

León-Pizarro, C., Gich, I., Barthe, E., Roviroso, A., Farrús, B., Casas, F., et al. (2007). A randomized trial of the effect of training in relaxation and guided imagery techniques in improving psychological and quality-of-life indices for gynecologic and breast brachytherapy patients. *Psycho-Oncology*, 16(11), 971-9

Liao, S., Huang, M., Li, S., Chen, I., Wei, T., Kuo, S., et al. (2004). Complex decongestive physiotherapy for patients with chronic cancer-associated lymphedema. *Journal of the Formosan Medical Association*, 103(5), 344-8.

Mantovani, G., Maccio, A., Madeddu, C., Gramignano, G., Lusso, M. R., Serpe, R., et al. (2006). A Phase II study with antioxidants, both in the diet and supplemented, pharmaconutritional support, progestagen, and anti-cyclooxygenase-2 showing efficacy and safety in patients with cancer-related anorexia/cachexia and oxidative stress. *Cancer Epidemiology, Biomarkers & Prevention*, 15(5), 1030-1034.

NCI. 2005. Cancer Control Continuum (Online)
<http://cancercontrol.cancer.gov/od/continuum.htm>

Pinto, B. M., Frierson, G. M., Rabin, C., Trunzo, J. J., & Marcus, B. H. (2005). Home-based physical activity intervention for breast cancer patients. *J Clin Oncol*, 23(15), 3577-3587.

Ripamonti, C. (1999). Management of dyspnea in advanced cancer patients. *Supportive Care in Cancer*, 7(4), 233-43.

Scheier, M. F., Helgeson, V. S., Schulz, R., Colvin, S., Berga, S., Bridges, M. W., et al. (2005). Interventions to enhance physical and psychological functioning among younger women who are ending nonhormonal adjuvant treatment for early-stage breast cancer. *Journal of Clinical Oncology*, 23(19), 4298-4311.

Solà, I., Thompson, E., Subirana, M., López, C., & Pascual, A. (2004). Non-invasive interventions for improving well-being and quality of life in patients with lung cancer. *Cochrane Database of Systematic Reviews*, issue 4.

Toles, M., & Demark-Wahnefried, W. (2008). Nutrition and the cancer survivor: evidence to guide oncology nursing practice. *Seminars in Oncology Nursing*, 24(3), 171-9.

Van Weert E, Hoekstra-Weebers J E H M, Grol B M F, Otter R, Arendzen J H, Postema K and van der Schans C P (2004) Physical functioning and quality of life after cancer rehabilitation. *International Journal of Rehabilitation Research* 27 (1) 27-35.

Vignes, S., Porcher, R., Arrault, M., & Dupuy, A. (2007). Long-term management of breast cancer-related lymphedema after intensive decongestive physiotherapy. *Breast Cancer Research and Treatment*, 101(3), 285-90.

Watson PG (1992). Cancer rehabilitation: An overview of cancer rehabilitation. *Seminars in Oncology Nursing* 8 (3): 167-173

Yoshioka, H. (1994). Rehabilitation for the terminal cancer patient. *American Journal of Physical Medicine & Rehabilitation*, 73(3), 199-206.

APPENDIX 2 – Cancer Rehabilitation Practitioners to support cancer site MDTs and community teams

The following is not an exhaustive list but rather an example of the range of practitioners that may be required to provide care across the 8 domains. The team will ultimately be dependent on the patient's needs.

- Chaplaincy
- Counsellors¹⁶
- Dieticians
- Doctors
- Financial/Benefits Advisors
- General Dental Practitioners
- General Practitioners
- Lymphoedema specialists
- Mental health teams
- Nurses
- Occupational Therapists
- Patients/Carers/Users
- Patient information specialists
- Pharmacists
- Physiotherapists
- Podiatrists
- Psychologists
- Researchers
- Social Workers
- Speech & Language Therapists
- Support Workers
- Therapeutic radiographers

¹⁶ To include cancer genetics

APPENDIX 3 – Levels of care

Those involved in each level¹⁷ and their functions are as follows:

Level 1 involves all those providing day-to-day care for a patient, including the patient and carer. Patients' needs are assessed using an agreed assessment tool, with basic interventions initiated or a referral made to the next appropriate level of care.

Level 2 involves all generalist AHPs. Patients' rehabilitation needs may be provided by the appropriate AHP at this level, cross-referring to AHP colleagues as necessary, or patients may be referred to a more experienced colleague, according to need.

Level 3 involves experienced AHPs with basic-level training in approaches to managing cancer. These professionals may work across a care setting, such as a Primary Care Organisation or acute NHS Trust, and will also cross-refer as necessary, delivering interventions requiring knowledge of the impact of the disease and its treatment.

Level 4 involves advanced practitioner AHPs who work predominantly or exclusively with patients with cancer and who provide expert advice and input for clearly defined rehabilitation needs. These expert AHPs will have received higher-level training in the rehabilitation needs of patients with cancer.

¹⁷ Improving Supportive and palliative care for adults with cancer (2002). National Institute for Clinical Excellence.

APPENDIX 4 – Recommended model of rehabilitation and support

Level¹⁸	Patient need example	Group providing input	Assessment	Intervention
1	<ul style="list-style-type: none"> • Simple energy conservation techniques. • Simple or first line dietary advice. • Advice to patients regarding skin care and risks of developing lymphoedema. 	<ul style="list-style-type: none"> • Patients and carers. • General nursing staff. • Therapeutic radiographers. • Assistant practitioners/ support workers. 	Recognition of needs for help and support based on assessment of function	Basic interventions including self management and care strategies initiated by generalist healthcare professionals
2	<ul style="list-style-type: none"> • Post operative physiotherapy following breast surgery. • Dietary advice for patients receiving enteral feeding. 	Generalist AHPs	Routine assessment of rehabilitation needs	Interventions provided for commonly presenting rehabilitation needs – post operative input plus management of commonly presenting side effects of treatment or functional impairment
3	<ul style="list-style-type: none"> • Post operative physiotherapy following breast surgery. • Dietary advice for patients receiving enteral feeding. 	Experienced AHPs with basic level training in cancer rehabilitation working at senior level	Specialist assessment from an experienced AHP	Interventions provided by professionals with knowledge and experience of effects of cancer treatment and aetiology; interventions requiring knowledge of the impact of the disease
4	<ul style="list-style-type: none"> • Management of a patient with spinal cord compression. • Swallowing assessment for patients having had radical head and neck surgery. • Management of severe or complicated lymphoedema 	Advanced practitioner AHPs working predominantly or exclusively with patients with cancer and with higher training as specialist practitioners	Highly specialist complex assessment from expert AHP	Highly specialist interventions for patients having radical surgery, patients with advanced disease, patients with functional impairment, Patients undergoing combination therapies and/or patients with complex end of life issues.

¹⁸ Improving Supportive and palliative care for adults with cancer (2004). National Institute for Clinical Excellence.