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Palliative Care
in partnership

Management of Symptoms in Palliative Care

The Role of Specialist Palliative Care Allied Health Professionals

March 2018

Foreword

"You matter because you are you and you matter to the last moment of your life. We will do all we can not only to help you die peacefully but also live until you die" Dame Cicely Saunders Founder of Hospice Movement 1918-2005

Each year in Northern Ireland around 15000 people die and many will have had palliative and end of life care needs. If we are to live up to the commitment given by Dame Cicely Saunders we all must play our part to meet the needs of those living with often complex palliative and end of life care needs. AHPs recognise they have a skill set that is critical to meeting those needs and are passionate that their skills are fully utilised in a consistent way across Northern Ireland.

This document aims to support all staff working with palliative and end of life patients by clearly outlining the AHP interventions that are required to address some of the symptoms that have been identified by service users and carers as being necessary to achieving better living. The document also sets out how palliative and end of life symptoms can be better managed by a range of AHP interventions to improve quality of life and again better living.

I am delighted to be able to support and promote this excellent piece of work and encourage its use to the full.

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Contents

1. Introduction and Purpose

The aim of the specialist palliative care team is to enable a person to:

“live until he dies, at his own maximal potential performing to the limit of his physical and mental capacity with control and independence whenever possible.”

Dame Cecily Saunders

The number of deaths in Northern Ireland is projected to grow significantly in the projections to 2040, (31%). Deaths are projected to be 20,261 by 2040. This is almost the same level of deaths recorded in NI in the 1920s, (PHA, 2017). Research suggests that three quarters of these people will benefit from some form of palliative care [Murtagh et al. 2014].

Living Matters, Dying Matters Strategy (2010) states:

“*Palliative and end of life care is the active, holistic care of patients with advanced progressive illness as a continuum of care that can evolve as a person’s condition progresses. This is an integral part of the care delivered by all health and social professionals, and indeed by families and carers, to those living with and dying from any advanced, progressive and incurable condition. Palliative and end of life care focuses on the person rather than the disease and aims to ensure quality of life for those living with an advanced non-curative condition”*

Rehabilitation within palliative care can assist people to live their lives whilst experiencing rapid change and deterioration (Bray and Cooper, 2005). It aims to optimise people’s function and wellbeing and to enable them to live as independently and fully as possible, with choice and autonomy, within the limitations of advancing illness (Tiberini & Richardson, 2015).

It is an approach that empowers people to adapt to their new state of being with dignity and provides an active support system to help them anticipate and cope constructively with losses resulting from deteriorating health (Tiberini & Richardson, 2015).

Whilst specialist palliative care clinicians should focus on the person as opposed to a catalogue of symptoms, it is important to demonstrate evidence based practice for the most frequently presenting symptoms for those with specialist palliative and end of life care needs.

This document outlines the definition, cause, prevalence and evidence based practice for the Specialist Palliative Care Allied Health Professional (AHP) interventions to manage each of the symptoms listed.

This document has been produced by the Specialist Palliative Care Allied Health Professionals Forum. This forum is co - chaired by Corrina Grimes, AHP Consultant and Regional Palliative Care Lead, Public Health Agency and Lesley Nelson, Specialist Palliative Care Physiotherapist, South Eastern Trust. Members include clinicians who work in Specialist Palliative Care from Dietetics, Occupational Therapy, Physiotherapy and Speech and Language Therapy (SLT) professions within acute and community settings from Hospice and HSC Trust organisations. Details of members of the Specialist Palliative Care Allied Health Professionals Forum can be found in Appendix A, with a glossary of terms in Appendix B.

The main drivers for this document were:

- To outline evidence based practice for symptom management which can be used regionally across all sectors and setting
- To ensure people with rehabilitative needs are referred in a timely manner to relevant AHP services
- To support the Regional Specialist Palliative Care Workforce Review
- To support the implementation of the regionally agreed Palliative Care Day Services model developed within the Transforming Your Palliative and End of Life Care Programme, currently being implemented by the Regional Palliative Care Programme- Palliative Care in Partnership.

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2. Specialist Palliative Care Allied Health Professionals

Allied Health Professionals (AHPs) are the only health care professionals whose primary qualification is in rehabilitation.

Specialist Palliative Care (SPC) AHPs are involved in the care of individuals with complex and unresolved needs. They are recognised as essential members of all specialist palliative care teams and their core activity is limited to the provision of specialist palliative care.

Their job plan includes the four key elements of the specialist practitioner role:

- Expert clinical practice
- Provision of formal and informal education
- Research audit and development of best practice guidelines
- Service improvement and leadership.

Specialist Palliative Care AHPs require a greater degree of training and expert knowledge. They will have undergone or be working towards a recognised post graduate qualification in palliative care.

Specialist Palliative Care AHPs:

- Work as autonomous practitioners offering holistic assessment, diagnosis and treatment
- Demonstrate an advanced clinical knowledge of the full spectrum of life limiting conditions and of complex symptoms
- Create a holistic and person centred plan that acknowledges the psychosocial impact of diminishing function and sets realistic goals that are continually adapted to individual need
- Demonstrate a high level of clinical expertise to enable the person and their carers to adapt to fluctuating clinical presentation and functional levels
- Act as an expert clinical resource to generalist and other specialist palliative care providers
- Utilise advanced communication skills to engage in a variety of highly skilled compassionate and timely communications with individuals with life limiting conditions, their carers and members of the interdisciplinary team
- Actively engage in building the evidence base to support interventions for

people with advanced progressive conditions, collaborating with all relevant research stakeholders
- Influence and promote strategic initiatives and policy development for palliative care services at local, regional and national level
- Develop, facilitate and provide education, leadership and mentorship for colleagues and other palliative care providers.

SPC Dietetics:

- **Nutritional assessment and dietary planning -** Create dietary plans that are realistic and continually adapted to individual need and expectations
- **Management of changing nutritional requirements and/or dietary intake** associated with advancing disease. Recognising psychosocial implications and impact on quality of life
- **Discuss ethical and legal issues** in conjunction with the multidisciplinary team, individuals and those important to them that may arise in relation to nutrition at end of life
- **Artificial nutrition support-** Provide advice and guidance regarding alternative feeding within the context of advanced disease.

SPC Occupational Therapy:

- **Functional rehabilitation** - to optimise independence, prevent deconditioning and encourage participation in daily activities identified as meaningful by the person
- **Environmental adaptation & prescription of equipment** - to create a safe home environment to allow the person to be as independent as possible or to reduce the burden on carers
- **Non-pharmacological symptom management** of fatigue, breathlessness and pain which impact on functional ability
- **Self-management** - education to empower individuals and their carers to cope with difficult symptoms and promote quality of life within advancing disease.

SPC Physiotherapy:

- **Functional rehabilitation -** to maintain or improve independence, reducing dependence on carers and encouraging self-management and a sense of control
- **Non-pharmacological symptom management -** interventions for pain, breathlessness, fatigue and lymphoedema
- **Exercise prescription -** individual programmes aimed at improving muscle strength and mobility within the context of advancing disease
- **Manual handling assessment -** to guide carers and other healthcare professionals in safe manual handling techniques and promote a safe environment.

SPC Speech and Language Therapy

- **Functional Rehabilitation** - to facilitate a person with a communication difficulty to maintain their personal relationships and to ensure their inclusion in end of life decision making
- **Provision of Alternative/Augmentative Communication Systems** - to assist the person to communicate as independently as possible in various environments and to reduce frustration/social isolation
- **Symptom Management** of dysphagia - to minimise aspiration risk and maximise the person’s comfort, safety and pleasure in oral intake
- **Education** to empower the person and their carers to cope with distressing, rapidly changing communication and swallowing symptoms and to address ethical/quality of life concerns with them.

Psychological and emotional support

'The gift of support that we offer can be one of the most appreciated yet one of the most neglected of our skills in primary care.'
(Thomas, 2003)

All health and social care professionals provide general psychological support to patients and carers and play a key role in psychological assessment and prevention and amelioration of distress.' (NICE, 2004)

It is widely recognised that AHPs who work in specialist palliative care provide much valued emotional and psychological support to the people they care for.

Specialist Palliative Care AHPs will have advanced communication skills training to ensure that they are able to support people in the varying levels of emotional support they may require, and indeed be aware of the avenues through which more specialist psychological support can be accessed for those who require more targeted therapeutic interventions.

The advanced communication skills of AHPs are 'essential to help a person and their family proactively plan for the future, anticipate potential functional changes, avert functional crises and adapt constructively to the spectrum of losses related to functional decline in advancing illness' (Tiberini & Richardson, 2015).

There is increasing emphasis on the benefits of early emotional support in improved mood and quality of life and coping with the demands of a non-curative illness. AHPs may be the first professional a person meets on their journey and therefore have a key role in providing this emotional and_psychological support from an early stage.

It is imperative that treating health professionals make it clear to people that attention to emotional adjustment is an integral part of care, rather than assuming a distressed person will spontaneously raise concerns (As-Brooks et al, 2014).

The relationship between AHPs and the people they care for can provide a vital link with the support services available to them.

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3. Rehabilitation in Palliative Care

Rehabilitation in palliative care aims to:

***"maximise patients' ability to function, to promote their independence and to help them adapt to their condition"* [NCHSPCS,2000].**

***"It offers a major route to improving quality their of life, no matter how long or short the timescale"* [NICE, 2004].**

Palliative care and rehabilitation services share common goals, therapeutic approaches and multidisciplinary models for care. Regardless of life expectancy, rehabilitation aims to:

- Maximise quality of life for people and their families
- Optimise physical function and emotional wellbeing to the highest extent possible
- Assist people gain control, independence and dignity
- Respond promptly and flexibly as people experience rapid changes in condition
- Have a holistic realistic approach to person centred goals, taking pace from the individual's priorities and limitations.

(Crompton, 2000; Tiberini and Richardson, 2015)

Prevalence and significance of loss of function:

People receiving palliative care experience many symptoms, with loss of physical function and fatigue repeatedly reported as being among the most distressing of these symptoms (Strömgren et al, 2006; Baile et al, 2011). Changes in function could be a primary consequence of underlying disease or due to secondary influences e.g. side effects of medical interventions, bed rest/deconditioning, cachexia, and a person's other co-morbidities or psychosocial influences. The loss of function is interwoven with the multiple losses experienced by those with palliative needs. For people with a non-curative progressive illness, loss of function and independence is a common struggle and a significant contributor to diminished quality of life (Cohen and Leis, 2002; Stromgren et al, 2006).

Maintaining function represents an important gateway to preserving independence and participation in meaningful activities that add quality of life (Bray and Cooper, 2005; Brovold et al, 2012).

It is easier to maintain function than to regain it once it is lost, therefore functional assessment is essential to proactively recognise a person's need for specialist rehabilitation input and ensure appropriate early referral to allied health professionals.

AHP Interventions:

High quality evidence supports the efficacy of rehabilitation within the palliative phase of many conditions. Interventions should be based on person-centred goal setting, parallel planning and proactive identification of functional concerns/priorities. They will incorporate elements of enablement and supported self-management (Tiberini and Richardson, 2015).

The table below lists some of the evidence to support the valuable role of rehabilitation in palliative care:

Rehabilitation in	Rehabilitation aims	Evidence
Advanced cancer	Reduce the impact of symptoms such as pain and anxiety and improve functional status Improve quality of life Increase physical activity Maintain personal care independence.	Bray & Cooper, 2005 Oldervoll et al, 2011 Lowe et al, 2009 McGrillen & McCorry, 2014 Segal et al, 2003 Bade et al, 2015 Bray & Cooper, 2005
Advanced respiratory and cardiovascular disease	Pulmonary and cardiac rehabilitation programmes	McCarthy et al, 2015
Advanced neurological conditions	Symptom management Communication issues Specialist equipment	Simmons, 2013 Khan et al, 2008 Trend et al, 2002
Older people/ people with dementia	Physical function	Crocker et al, 2013

Examples of good practice:

- An 8 week programme of exercise and education developed through partnership working between Marie Curie Belfast and Parkinson's NI for people with Parkinson's disease. Includes one hour of exercise (warm up, circuit class and cool down) and an education talk, covering the topics of; (a) Barriers to exercise (b) Fatigue management and role of OT (c) Medicine Management; facilitated by the Parkinson's Specialist Nurse and (d) Falls Prevention.
- AHP led gym based exercise groups and education programme within St Christopher's Hospice in London; a rolling programme over nine sessions, conducted within a group setting including an exercise circuit class and education. Topics for education are (a) strength stretching stamina and mobility, (b) balance and coordination, (c) home exercises, (d) fulfilling your potential, (e) breathing and pacing, and (f) falls prevention (Talbot Rice et al, 2014).
- Outpatient gym sessions within the Marie Curie Hospice Day Therapy Unit in Hampstead, London. A multi-disciplinary approach to rehabilitation with individually tailored exercise programmes (Turner et al, 2016).

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4. Fatigue

Definition:

A distressing persistent, subjective sense of physical, emotional and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning

(NCCN 2016).

Although this definition refers to cancer related fatigue it is a relevant definition for all conditions within palliative care. Fatigue is a significant symptom in all palliative care conditions with 50-60% of clients with multiple sclerosis identifying it as the worst symptom (National MS Society, 2006).

Prevalence/incidence information:

Condition	Prevalence	Reference
Cancer	32-90%	Ream, 2007
COPD	68-80%	
Heart Disease	69-82%	
Renal Disease	73-87%	
MND	44%	Gibbons et al, 2013
MS	75-95%	National MS Society, 2006
Parkinson's Disease	33-70%	Schiehser et al, 2012

Overview of interventions:

All interventions for fatigue management are based on a holistic assessment with emphasis on person centred goal setting. The assessment will involve identifying any reversible medical conditions.

The intervention should include regular review, anticipating the next phase of disease progression.

All professionals are responsible for providing education and support to the person and where appropriate their carer. Educating people about fatigue helps the development of self- management strategies and enhanced control over their illness (Berger et al 2010).

Interventions can be provided by day services or domiciliary services and in an out-patient or in-patient setting.

Intervention	Evidence base
OCCUPATIONAL THERAPY	
• Energy conservation techniques including pacing, compensatory techniques and task simplification with regard to participation in activity • Provision of equipment and/or home adaption if appropriate • Anxiety and stress management interventions including relaxation strategies • Strategies to manage cognitive impairments • Sleep management.	Borneman, 2013 NCCN, 2016 Howell et al, 2011 Twomey & Robinson, 2010 Barsevick, 2004 Lowrie, 2006 Hawthorn, 2010 Tiberini & Richardson, 2015 National Cancer Action Team, 2009
DIETETICS	
• Optimisation of nutritional intake to maintain nutritional status and /or minimise deterioration • Small amounts of high nutritional value foods and drinks in appropriate consistency at frequent intervals. • Appropriate use of nutritional supplementation • Dietary advice for management of symptoms such as iron deficiency anaemia. • Strategies to help facilitate meal • preparation • Practical advice for shopping, resting before meals etc.	Parkin & Boyd, 2011 Gandy, 2014 Berger et al, 2010 Living well with COPD, 2011 Lundholm et al, 2004 NICE, 2006
PHYSIOTHERAPY	
• Individualised exercise programmes • Energy conservation advice regarding exercise and rest • Mobility - advice and equipment • Relaxation - progressive muscle relaxation • Sleep management.	Borneman, 2013 Cramp & Bryon-Daniel, 2015 Jensen et al, 2014 Mayo et al, 2014 Lowe et al, 2009 Oldervoll et al, 2006 NCCN, 2016 Tiberini & Richardson, 2015 Howell et al, 2011

SPEECH & LANGUAGE THERAPY	
• Maximising on alert periods for oral intake, choosing the best time of day for main meal • Smaller amounts of high nutritional value in appropriate consistency at frequent intervals • Pacing through mealtime, taking breaks as required • Conserving energy for anticipated speaking situations • Use of voice amplifier if fatigue impacting on vocal volume or other Alternative/Augmentative Communication Aid (AAC) if fatigue is affecting speech intelligibility.	Solomon, 2006. Refer to dysphagia and communication section.

A good practice existing model for fatigue:

4 session individual domiciliary programme facilitated by Occupational Therapist & Physiotherapist includes trigger question within the assessment for direct referral to SLT and Dietetics.

Session 1:	Assessment and intervention - energy conservation advice, goal setting and equipment provision if required
Session 2:	Exercise - individualised advice and programme
Session 3:	Relaxation - CBT techniques and advice re sleep management
Session 4:	Review and any domiciliary follow up

As required: telephone review / on-going domiciliary intervention.

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5. Breathlessness

Definition:

A subjective experience of breathing discomfort that consists of qualitatively distinct sensations that varies in intensity. The experience derives from interaction among multiple physiologic, psychological, social and environmental factors and may induce secondary physiological and behavioural responses

(Parshall et al, 2012).

Breathlessness is a complex experience of the mind and body; it is not a one-dimensional event. Possible causes of breathlessness include:

- **Pulmonary:** Primary or metastatic tumours replacing lung tissue; obstruction of main bronchus; pleural effusion; lymphangitis carcinomatosa; mediastinal obstruction; pre-existing respiratory conditions e.g. COPD, asthma, bronchiectasis; radiation induced pneumonitis; fibrosis; chest infection; retained secretions.
- **Cardiovascular:** Superior vena cava obstruction; pericardial effusion; congestive cardiac failure; pulmonary oedema; ischaemic heart disease; pulmonary embolism; anaemia.
- **Other**: Chemotherapy; ascites; abdominal distension; weakness; anxiety resulting in hyperventilation; acidosis; pneumothorax; fractured ribs; pain; concurrent neuromuscular or neurological conditions.

Prevalence/incidence information:

Condition	Prevalence	Reference
Cancer*	46% of general cancer outpatients	Dudgeon et al, 2001
COPD	90-95%	Solano et al, 2006
Heart Disease	60-88%	Solano et al, 2006
HIV**	41%, 68% in last 3 months of life	Fantoni et al, 1996; Diaz et al, 2003
Renal Disease	11-62%	Solano et al, 2006

* Breathlessness is common in all cancer types:

- Prevalence varies by site, stage and other factors (Chan et al, 2010).
- More common/severe with primary lung cancers (90%) (Booth & Dudgeon, 2006)
- Frequency/severity increases with disease progression (Booth et al, 2006; Chan et al, 2010).

**People who are HIV positive may suffer from dyspnoea due to comorbid conditions such as pneumocystis carinii pneumonia, Kaposi's sarcoma with lung infiltration and tuberculosis.

Overview of interventions:

All interventions are based on a holistic assessment with emphasis on person centred goal setting. The assessment will involve identifying any reversible medical conditions.

The intervention should include regular review, anticipating the next phase of disease progression.

All professionals are responsible for providing education and support to the person and where appropriate their carer.

Interventions can be provided by day services or domiciliary services and in an out-patient or in-patient setting.

Interventions	Evidence Base
PHYSIOTHERAPY	
• Respiratory examination and comparison to respiratory baseline. • Breathing control techniques, including pursed lip breathing if appropriate. • Relaxed breathing techniques • Positions of ease • Airway clearance techniques including active cycle of breathing technique. • Advice re. oxygen therapy and nebulisers • Advice re correct use of a fan • Education on symptoms/trigger awareness and appropriate responses • Individual exercise and walking programmes • Provision of appropriate mobility aids • Steps / stairs assessment • Activity pacing and energy conservation	Palliative Care Dyspnoea - Clinical Knowledge Summary NICE, 2015 Bausewein et al, 2008 Booth et al, 2006 Farquar et al, 2011 Galbraith et al, 2010 Hochstetter et al, 2005 Bott et al, 2009
DIETETICS	
• Optimisation of nutritional intake to maintain good nutritional status and minimise nutritional deterioration • Dietary texture modification advice in line with SLT recommendations • Individual advice plan regarding diet and fluid modification • Appropriate use of nutritional supplementation • Strategies to help facilitate meal preparation at home • Practical advice for shopping, resting before meals etc.	Adapted from Living Well with COPD- A plan for action for life, 2011 NICE, 2006

OCCUPATIONAL THERAPY	
• Anxiety management	Palliative Care Dyspnoea - Clinical Knowledge Summary
• Relaxation techniques	
• Energy conservation re: planning, functional pacing, prioritising	
• Activity analysis (applying breathlessness management techniques to achieve meaningful activity for people)	NICE, 2015 Morgan & White, 2012
• Equipment provision/adaptations for reducing breathlessness and increasing independence	
• Care management assessments and recommendations.	
SPEECH & LANGUAGE THERAPY	
• Advice re. strategies to facilitate swallowing and communication e.g. pacing, frequent breaks for breath replenishment/rest	Refer to Dysphagia section.
• Modification of food/fluid consistency to minimise aspiration risk & maximise comfort and pleasure of oral intake.	

A good practice existing model for breathlessness:

Four sessions of an individualised domiciliary programme are facilitated by a Physiotherapist and Occupational Therapist. (Assessment includes a trigger question for onward referral to SLT and Dietetics).

Session 1:	Assessment and intervention - Breathlessness management including breathing techniques, positions of ease, pacing and mobility
Session 2:	Energy conservation for breathlessness, advice and equipment provision if required
Session 3:	Relaxation - CBT techniques and advice
Session 4:	Review and any domiciliary follow up

As required: telephone review / on-going domiciliary input.

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6. Anxiety

Definition:

A feeling of worry, nervousness, or unease about something with an uncertain outcome.

(Oxford English Dictionary)

Anxiety is a complex interaction of the mind, emotions, body and behaviour. Some anxiety is expected as a natural response but it is important to identify and treat the exaggerated response which is classified as pathological anxiety. Anxiety within palliative care can be caused by:

- Pre-existing anxiety disorders
- Anxiety due to a medical condition e.g. pulmonary embolism, infection, hypoxia etc.
- Anxiety due to substance withdrawal e.g. alcohol, steroids, opioids etc.
- Anxiety as a psychological reaction to illness/condition - multiple

It can exacerbate other symptoms, compromise adherence to treatment and have a negative impact on quality of life both for the person and those around them (Carpenter, 2014).

Prevalence/incidence information:

- Up to 30-40% of individuals with advanced cancer report anxiety symptoms that are sufficiently severe to reach clinical levels (Greer et al, 2012)
- Women, people who were more physically impaired, and younger people with advanced cancer were more likely to meet criteria for an anxiety disorder. (Spencer et al, 2010)
- Anxiety with people on haemodialysis is a factor strongly linked to suicidal ideation (Patel et al, 2012)]

Condition	Prevalence	Reference
Cancer	6-49%	Spencer et al, 2010
COPD	13-46%	Yohannes & Alexopoulous, 2014
Heart Failure	Common	Heart Failure Matters
HIV	39%	Atkinson et al, 1988
End Stage Renal Failure	27-46%	Patel et al, 2012
MND	Present	MNDA

Overview of interventions:

Compassionate, person centred care is foundational with anxiety. All information sought re condition and prognosis and concerns should be addressed fully. The MDT should work to provide a calm environment, assess understanding of information and ask about fears and concerns. It is necessary to provide the time and opportunity for people to express their concerns and for these to be expressed and addressed on an individual basis where possible.

All interventions are based on a holistic assessment. This will involve identifying any reversible factors such as pain or other symptoms, reducing stimulant drugs where possible and tackling any withdrawal.

NICE (2011) recommend a stepped approach, with initially simple, but then if required, increasing levels of intervention.

All professionals are responsible for providing education and support to the person and where appropriate their carer. Where distress is mild, often supportive listening, assistance with problem solving and sign posting may be sufficient.

All professionals need to be aware of available psychological support services and refer on when appropriate.

Interventions can be provided by day services or domiciliary services and in an out-patient or in-patient setting.

Interventions	Evidence Base
PHYSIOTHERAPY	
• Individualised exercise programmes • Breathing control techniques • Relaxation - progressive muscular relaxation • CBT techniques	Yohannes & Alexopoulous, 2014 Tiberini & Richardson 2015
DIETETICS	
• Management of anxiety related to poor appetite • Addressing concerns relating to oral intake, weight loss, muscle weakness and nutrition issues including withdrawal discussions	Delgado-Guay M et al, 2009 Carpenter, 2014 Del Rio et al, 2012 Tiberini & Richardson 2015

OCCUPATIONAL THERAPY	
• Anxiety management - psycho-education re symptom • Functional rehabilitation tasks • Relaxation and mindfulness skills training • Adapted CBT techniques • Energy Conservation re: planning, functional pacing, prioritising • Activity analysis - graded tasks • Equipment provision and adaptations for increasing independence • Facilitation of meaningful activities • Reminiscence - including review of previous achievements, coping skills and difficult situations	Greer et al 2012 NEOLCP/COT, 2011 Moorey S et al, 2009 Carpenter, 2014 AOTA, 2015 Tiberini & Richardson, 2015
SPEECH & LANGUAGE THERAPY	
• If dysphagia is present, management of a person’s anxiety related to aspiration/choking risk whilst enabling autonomous choice • Empowerment of carers/care staff involved in risk feeding through education and support • If communication difficulties are present, management of related anxiety through strategies/AAC and support for person to remain fully involved in EOL decisions.	The Oral Cancer Foundation Tiberini & Richardson 2015 Pollens, 2012

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7. Unintentional Weight Loss (Anorexia and Cachexia)

Definition:

Anorexia/cachexia syndrome is a complex metabolic process found in many end stage illnesses. This is characterised by the loss or absence of appetite (anorexia) with weight loss and muscle wasting (cachexia). This impacts significantly on quality of life, can cause anxiety and distress for the person and perhaps even more so for carers

(SPCG, 2014).

Unintentional weight loss and loss of appetite are common in people who have palliative care needs. Unintentional weight loss is a poor prognostic indicator in advanced disease (Muscaritoli et al, 2010).

The aetiology of unintentional weight loss in advanced progressive illness is very different to that of simple starvation. The negative prognostic implications of weight loss through inadequate nutrient intake are in the most part reversible through appropriate dietary interventions - advanced disease-related unintentional weight loss is not (Balstad et al, 2014). This type of weight loss, known as cachexia, has been defined by a group of international experts as follows: **‘**Cancer cachexia is a multifactorial syndrome defined by an on-going loss of skeletal muscle mass (with or without loss of fat mass) that cannot be fully reversed by conventional nutritional support and leads to progressive functional impairment. Its pathophysiology is characterised by a negative protein and energy balance driven by a variable combination of reduced food intake and abnormal metabolism’ (Fearon et al, 2011).

The expert cachexia group proposed three relevant clinical stages of cachexia in cancer: pre-cachexia, cachexia and refractory cachexia. While these stages are specifically for cancer, they are likely to be equally as relevant to other forms of advanced incurable illness, such as organ failure or progressive neurological conditions.

Prevalence/incidence information:

The prevalence of anorexia and/or cachexia in palliative conditions is shown in the following table:

Condition	Prevalence	Reference
Cancer	40 - 85%	Bosaeus et al, 2001 Hutton et al, 2006 Von Haehling et al, 2010
COPD	20-60%	King et al, 2008 Von Haehling et al, 2010
Dementia	50%	White et al, 1996
Heart Failure	5-20%	Hughes et al, 2012 Von Haehling et al, 2009
MND	20%	Worwood et al, 1998
Renal Disease	18-75%	Mak et al, 2011

Overview of interventions:

All interventions for unintentional weight loss are based on a holistic assessment with emphasis on person centred goal setting. The assessment will involve identifying any reversible medical conditions.

The intervention should include regular review, anticipating the next phase of disease progression.

All professionals are responsible for providing education and support to the person and where appropriate their carer. Educating people about unintentional weight loss helps the development of self- management strategies and enhanced control over their illness.

Interventions	Evidence Base
DIETETICS	
• Optimisation of nutritional intake to help maintain nutritional status and/or minimise nutritional deterioration • Management of aggravating factors (nausea, vomiting, pain, malabsorption, psychological distress) • Appropriate use of nutritional supplementation • Appetite stimulants • Behaviour modifications to overcome barriers to eating e.g. anxiety, depression, fear of choking • Artificial nutrition support (if appropriate) • Advance Care Planning regarding artificial nutrition support.	NICE, 2006 Arends et al, 2016 Macmillan, 2011 NICE, 2015
OCCUPATIONAL THERAPY	
• Functional activities to improve stamina, general debility & mood • Anxiety management & relaxation techniques • Body image alteration / adjustment • Pressure care management • Equipment provision including feeding aids	NCAT, 2009 Refer to Fatigue section

PHYSIOTHERAPY	
• Prevent muscle wasting and maintain muscle bulk	Cramp et al, 2015
• Maintain functional ability/mobility	Macmillan, 2011
• Reduce the risk of falls utilising balance and functional exercises	
• Exercise programmes (individual and group) delivered in conjunction with advice on pacing activities and energy conservation	Refer to Fatigue section
• Enhance cardio-respiratory status	
SPEECH & LANGUAGE THERAPY	
• If dysphagia is present, advice re. consistency modification to reduce the impact for person/care giver and therefore promote nutritional intake • If dysphagia is present, reduction of the risk of aspiration and of anxiety related to choking risk • Advice about communication strategies during mealtimes to promote oral intake.	Beirnacki & Barratt, 2001 Lubinski, 1995.

Example of good practice/existing models for unintentional weight loss:

Interdisciplinary working to ensure an appropriate plan is made to maximise nutrition in the context of declining oral intake and facilitate discussion with families regarding end of life ethical issues related to nutrition and artificial nutrition support if appropriate.

Multimodal interventions in the form of nutritional guidance and physical activity aim to prevent or reverse muscle wasting. This type of palliative rehabilitation may be more effective than monotherapy (Balstad 2014, Payne, 2012).

Dedicated specialist palliative care multidisciplinary teams are in an excellent position to offer interventions to a person and their families/carers in their last year of life and to showcase effective joint working in a domiciliary/clinic setting.

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7. Dysphagia

Definition:

Dysphagia describes eating and drinking disorders which may occur in the oral, pharyngeal and oesophageal stages of deglutition. Subsumed in this definition are problems positioning food in the mouth and in oral movements, including sucking, masticatio***n and the process of swallowing***

(RCSLT, 2016)

Potential consequences of dysphagia include choking, aspiration, dehydration, malnutrition and death.

In palliative care, the management of dysphagia is within the context of progressive disease. It is aimed at optimising function, improving comfort and eating satisfaction and promoting a positive feeding environment for the person and their carers/family members. The person is encouraged to retain choice and control in decisions related to eating and drinking as end of life approaches. The focus of intervention is on minimising risk and on maximising comfort and thereby enhancing the quality of the person's remaining life.

Dysphagia can occur as a result of the disease itself or be secondary to treatment e.g. radiotherapy or surgery.

Prevalence/incidence information:

Condition	Prevalence	Reference
Advanced malignancy	63%	Roe & Eckman, 2005
Brain tumour	63%	RCSLT, 2016
Oral Cancer	90%	
Oesophageal Cancer	90%	
Lung Cancer	43%	Brady et al, 2015
COPD	27%	RCSLT, 2016
Dementia	50-75%	
MND	90%	
Patients in last week of life	46%	Roe & Eckman, 2005
Stroke	78%	RCSLT, 2016.

Overview of interventions:

All interventions for dysphagia are based on a holistic assessment with emphasis on person centred goal setting. The assessment will involve identifying any reversible medical conditions.

All professionals are responsible for providing education and support to the person and where appropriate their carer. Educating people about dysphagia helps the development of self- management strategies and gives enhanced control over their illness.

The intervention should include regular review, anticipating the next phase of disease progression, and intervening at critical points to minimise risk and maximise comfort and quality of life, in consultation with the wider MDT.

Interventions can be provided by day services or domiciliary services and in an out-patient or in-patient setting.

Intervention	Evidence Base
SPEECH & LANGUAGE THERAPY	
• Food and liquid consistency modification • Swallow strategies and/or postures that reduce aspiration risk • Positioning and advice regarding feeding technique • Specific recommendations for a plan for feeding 'with acknowledged risk' where an MDT decision has been taken to minimise risk and maximise comfort and quality of life • Investigative procedures such as Videofluoroscopy or FEES • Management of saliva difficulties, oropharyngeal secretions and oral medication format as disease progresses in conjunction with the medical team • Advice re. oral hygiene and as end of life approaches encouragement of the use of oral hygiene by those important to the person in lieu of feeding • Maintain/improve jaw opening (if Trismus is present) via use of a Therabite regime or other exercises.	Carrau & Murray, 1998 Crary & Groher, 2003 Ekberg, 2002 Dennehy, 2006 Groher, 2012 Bowden & Davies, 2006 Elman et al, 2005 NICE, 2004 Costa Banderia et al, 2008 Dijkstra et al, 2004 Shiley et al, 2006 Scherpenhuizen et al, 2015 Rosenvinge & Starke, 2005 RCSLT, 2003 RCSLT, 2006

DIETETICS	
• Advice on foods according to texture modification recommended by SLT • Minimise unintentional weight loss through assessment and nutritional support • Specific dietary advice for individuals with palliative oesophageal stent in situ • Behaviour change skills required to attempt to overcome barriers to eating e.g. anxiety, depression, fear of choking • Consider the need for oral, enteral and parenteral nutrition • Advance care planning for nutrition and hydration • Review of nutrition in the last days of life.	NPSA, 2011 Becker et al, 2011 Bradley & Donaldson, 2000 Brody et al, 2000 Findlay et al, 2001 NICE, 2016 NICE, 2015 NICE, 2006
If there is unintentional weight loss please refer to Section 6	
OCCUPATIONAL THERAPY	
• Review of postural needs to facilitate optimal positioning for safe eating/feeding • Provision of adjustable specialised seating if required • Advice re specialised equipment to support assisted feeding • Collaboration with other professions in the development of person-centred plans for feeding and/or alternate forms of nutrition • Advice on preparation of food	CAOT, 2010 AOTA, 2011

PHYSIOTHERAPY	
• Airway clearance techniques to minimise the effects of aspiration • Positioning to prevent aspiration • Secretion and saliva management • Maintaining/optimising lung volumes • Drug therapies, including nebulisers, inhalers and oxygen therapy • Optimising mobility and physical strength training.	Elman et al, 2005 Langmore et al, 1998 McKinstry et al, 2009 Chakladar, 2012 King's College Hospital, Multi-disciplinary Working Party, 2000

Examples of good practice/existing models for dysphagia:

Interdisciplinary working to ensure an appropriate plan is made to maximise nutrition in the context of declining oral intake and facilitate discussion with families regarding end of life ethical issues related to nutrition and dysphagia and non-oral feeding if appropriate.

Dedicated specialist palliative care multi professional teams are in an excellent position to offer interventions to a person in their last year of life and to showcase effective joint working in a domiciliary/clinic setting.

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8. Communication Difficulties

Definition:

Speech, language and communication needs (SLCN) is the term given to describe the extensive range of needs related to all aspects of communication - from understanding others to forming sounds, words and sentences to expressing ideas and emotions and using language socially

(www.afasic.org.uk, 2016).

Communication is a universally recognised human right. It is an essential life skill, central to interaction… and vital for helping to reduce social isolation (Communication Matters, 2013).

The ability to communicate one's needs, thoughts, feelings and wishes is central to a person's sense of wellbeing and quality of life. It enables patients to be active participants in goal setting within the wider rehabilitation process, expressing their needs, wishes and priorities and contributing to personalised advance care plans. When communication is compromised, significant frustration and distress can result for both patients and their care givers

(Tiberini & Richardson, 2015).

Communication difficulties can be caused by a range of malignant and non- malignant conditions, and as a direct result of treatments such as radiotherapy and surgery (Eckman & Roe, 2005).

Prevalence/incidence information:

Condition	Prevalence	Reference
Brain tumour	30-50%	Davie et al, 2009
Lung cancer	43%	Brady et al, 2015
Dementia	100%	RCSLT, 2014
MND	80%	MNDA, 2016
Multi Systems Atrophy	90%	Duffy, 2013
Parkinson's Disease	90%	Tjaden, 2008.

Salt & Robertson, (1998) in a small study of 12 patients in a hospice setting, found 92% of these patients presented with a communication disorder. Schleinich et al (2008) developed a questionnaire for identifying patient priorities for rehabilitation in palliative care. Of 36 parameters included in the questionnaire, communication was rated in the top 10 of importance.

Overview of interventions:

All interventions for communication difficulties are based on a holistic assessment with emphasis on person centred goal setting. The assessment will involve identifying any reversible medical conditions.

The intervention should include regular review, anticipating the next phase of disease progression.

All professionals are responsible for providing education and support to the person and where appropriate their carer. Educating people about communication difficulties helps the development of self- management strategies and enhanced control over their illness.

Interventions can be provided by day services or domiciliary services and in an out-patient or in-patient setting.

Intervention	Evidence Base
SPEECH & LANGUAGE THERAPY	
• Provision of communication strategies to support the person's inclusion in end of life decision making and to maintain significant relationships • Advocacy and support for the person to comprehend information related to their care and to communicate their end of life goals. • Provision of appropriate Alternative or Augmentative Communication systems (AAC) • Collaboration with the Regional Communication Advice Centre (CAC) in management of complex AAC needs, and customisation/adaptation of recommended system by SLT as disease progresses • Provision of voice amplification and liaison with ENT for consideration of vocal cord medialisation procedure as palliative measure as appropriate.	Biddell & Mitchell, 2008 Tiberini & Richardson, 2015 Pollens, 2012 Communication Matters, 2013 Brady et al, 2015 NICE, 2005

OCCUPATIONAL THERAPY	
• Consideration of cognitive abilities to inform appropriateness of equipment recommendations • Interventions to consider emotional wellbeing which may impact on communication, e.g. anxiety/ depression • Scanning training • Functional positioning - both wheelchair and static seating (including taking account of need for eye contact to aid communication) • Activity analysis in relation to the person's fatigue on communication.	Polgar, 2002 Topia & Hocking, 2012 Communication Matters, 2013

Examples of good practice/existing models for communication difficulties:

The complex symptomatology of language disorders in people with cancer demands a multidisciplinary team and a co-ordinated treatment effort (Davie et al, 2009).

Communication difficulties can impact on every element of a person's care and multi-professional specialist palliative care teams are in a unique position to offer and indeed showcase best practice i.e. joint management of these people with SLT leading on maximising communicative function to enable them to participate in rehabilitation, decision making and advance care planning.

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9. Lymphoedema

Definition:

Lymphoedema is a long term condition requiring post diagnosis treatment and lifelong reviews. It is a swelling of the body tissue caused by failure of the lymphatic system and can result in discomfort, pain, functional limitation, increased risk of infections and psychological distress.

Lymphoedema can be present at the time of diagnosis of advanced disease or develop at any point during the illness when it may be a sign of loco-regional disease progression. It is important that any potential underlying causes such as thrombosis and extensive nodal disease are investigated and treated (NICE, 2009).

Investigation must include diagnosing the correct form of oedema prior to management as some will be non-lymphoedema or lympho-vascular in origin, and will require alternative management planning (British Lymphology Society (BLS, 2016 a and b).

Prevalence/incidence information:

Oedema in palliative care is a significant problem, and lymphoedema is a sub set of this. In non-cancer patients an oedema prevalence of 85% is reported near the end of life. The oedema may occur many months prior to death and may be amenable to management during this time, (Real et al, 2016 and Woo et al 2011).

The presence of *palliative* oedema is thought to be 5-10% of all lymphoedema referrals, but this is considered an underestimate (International Lymphoedema Framework (ILF), 2010).

A regional audit [2016], demonstrated that lymphoedema teams in Northern Ireland held a 4.42-6.5% palliative caseload from the total new referrals received. This reflects the ILF figure with regard to “total lymphoedema referrals”. This audit also demonstrated that 19.96-26.93% of specialist palliative care physiotherapists’ caseload was for management of lymphoedema.

Overview of interventions:

All interventions for lymphoedema are based on a holistic assessment with emphasis on person centred goal setting. The assessment will involve identifying any reversible medical conditions.

All professionals are responsible for providing education and support to the person and where appropriate their carer. Educating people about lymphoedema helps the development of self- management strategies and enhanced control over their illness.

"*Oedema in advanced cancer signifies deterioration and as such, can be both distressing for the patient, family, and a management challenge for health professionals*" (ILF, 2010).

A key ILF principle is that palliative care health professionals can assess and treat oedema, and that family and caregivers should be involved in simple adapted treatments, where necessary and desirable (2010).

Lymphoedema may be only one of many complex problems presenting with advanced disease, and requires management alongside the other conditions. It is often associated with obesity, dependency and reduced mobility. Supportive treatment, intervention and rehabilitation can help reduce the distressing, and often debilitating symptoms that affect the person's functional ability and quality of life, regardless of the disease status (CREST, 2008). Timely intervention is required to reduce the impact on quality of life of both the person and their carers (BLS, 2016 a and b).

Intervention	**Evidence Base**
LYMPHOEDEMA THERAPISTS (All professions)	
• Assess the person with lymphoedema for treatable medical underlying factors before starting any lymphoedema management programme • Consider Complex Decongestive Therapy as the first stage of management • Consider using multi-layer lymphoedema bandaging for volume reduction as a first treatment option before compression hosiery • When appropriate, supply each person with at least 2 suitable compression garments or other devices • Provide people (with lymphoedema) with clear, written information and the contact details of support groups • People who present with advanced disease may not always want or tolerate the full recommended therapy and, as a consequence, the assessment, intervention and overall management will be modified according to each person's preference and needs • As overall status can deteriorate quickly at any given time, people must be reviewed regularly by a specialist lymphoedema therapist (CREST, 2008); burden of treatment should not exceed benefit gained • Enhance the ability of carers to support the healthcare professional management; domiciliary care may be required.	NICE, 2009 International Lymphoedema Framework, 2010 British Lymphology Society, 2016 a and b CREST, 2008

AHPs - general	
• People require an interdisciplinary approach • Consider psychological support.	British Lymphology Society, 2016 a and b
PHYSIOTHERAPY & OCCUPATIONAL THERAPY	
• Mobility/functional assessment (if there is associated restricted mobility and loss of independence) • Potentially assessment of the home environment to promote independence e.g. assistive equipment and adaptations • Impact of fatigue and pain should be addressed (refer to fatigue section) • Psychological support for self-esteem and body image issues.	Tiberini & Richardson, 2015
DIETETICS	
• A high Body Mass Index (BMI) may require dietetic referral.	Shaw, 2007

Examples of good practice/existing models for lymphoedema:

The Lymphoedema Network Northern Ireland (LNNI) is established as the lead for lymphoedema regionally. It is staffed to manage out-patients with rare acute and domiciliary input. Currently between 4.42 and 6.5% of total referrals are palliative lymphoedema.

The BHSCT and SEHSCT specialist palliative care physiotherapists hold a successful lymphoedema caseload which is, on average, 22.3% of their total domiciliary capacity. This is for people with complex multiple symptoms who are unable to attend out-patient appointments; they work in partnership with the trust lymphoedema teams.

The NHSCT specialist palliative care team is based in an acute palliative care unit; 20% of total caseload is dedicated to palliative lymphoedema management for the unit residents.

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APPENDIX A

Specialist Palliative Care Allied Health Professionals Forum Members through the development of the document.

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Appendix B: Glossary

Holistic assessment

Holistic assessment serves to identify the person's unmet needs and highlights where other practitioners need to be involved in order to address this. A person's preferences and wishes regarding both the type and location of care can also be elicited - helping them remain in control and supporting dignity and choice.

The Holistic Assessment should be undertaken by staff at the key stages of the patient pathway as indicated above. The documented assessment should be transferred to the relevant health care professionals involved in the patient's care. (National Cancer Action Team (2010), National End of Life Care Programme (NHS) Improving End of Life Care Holistic common assessment of supportive and palliative care needs for adults requiring end of life care; www.goldstandardsframework.nhs.uk)

Person centred care and realistic goal setting

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

Person-centred goal setting is not about creating an environment of false hope. While goals should be realistic, research suggests the process of setting goals and working towards them is more important than achieving them and that this can be constructive in helping patients understand, and come to terms with, what is manageable and what is not. (Tiberini & Richardson, 2015)

Supportive care

Supportive care helps patients and their families cope with [their condition] and its treatment (*National Institute for Clinical Excellence*).

Palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual *(World Health Organisation).*

End of life care

End of life care is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support *(Department of Health*).

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