



# **Nutrition Framework for People Affected by Cancer**

**November 2022**

## Contents

Introduction .....	3
Background .....	3
Policy Context .....	6
Guiding Principles of Nutritional Care and Support.....	7
Guiding Principles .....	7
Key Messages .....	8
Nutrition Screening and Care Process .....	8
Nutritional Screening .....	9
Nutrition Assessment.....	13
Nutrition Diagnosis.....	13
Nutrition Intervention.....	14
Nutrition Monitoring and Evaluation .....	15
Education and Training .....	16
Conclusions .....	16
References.....	17
Appendix 1: Nutrition Referral Pathway.....	21
Appendix 2: Nutrition in Palliative and End of Life Care.....	22
Appendix 3: Education and Training Grid.....	24
Appendix 4: Resources .....	29
Screening .....	29
Assessment.....	29
Management .....	29
Additional Resources for People Affect by Cancer.....	29
Appendix 5: Case Studies .....	30
1. Karina.....	30
2. James.....	31
3. Stuart.....	33
4. Jo.....	34
Appendix 6: Prehabilitation Nutrition Framework Working Group Membership .....	36

## Introduction

Nutrition is a vital component in delivering successful cancer outcomes. Despite this, malnutrition remains both under-identified and under-treated, leading to adverse effects.

The Nutrition Framework for People Affected by Cancer defines the nutritional care that should be available to all adults affected by cancer in Scotland (aged 16 years and above) and provides a structure for delivery of care. It is equally relevant to all professions and services providing care and support to people affected by cancer, independent of their sector or setting i.e., health, social care and the third sector; acute and community care. It brings existing services together in a collaborative manner and illustrates a good practice model that will drive equitable and efficient access to the appropriate nutrition services for those affected by cancer. It encompasses all stages of the cancer pathway and seeks to assist those working with people affected by cancer to discuss, signpost and refer to appropriate services that best meet a person's needs. This should facilitate service planning and development, and thereby ensure that services are designed to truly meet the holistic needs of people affected by cancer.

The Framework has been developed by a multi-disciplinary, collaborative group comprised of representatives from the Scottish Government, NHS Boards, Health and Social Care Partnerships, and third sector organisations.

## Background

Dietitians are skilled to undertake a detailed nutrition assessment, provide individualised dietary counselling and guide decision making on nutrition support. However, nutritional issues are common and affect a high number of individuals with cancer. So, to improve the overall experience of people affected by cancer and optimise outcomes, others, such as, but not limited to, nurses, doctors, health care support workers, speech and language therapists, pharmacists, link workers and carers, must (and do) play a crucial role in both identifying and alleviating nutritional issues, and in monitoring nutritional status. Collectively this helps to ensure that the right care is available to an individual at the right time and in the right place, every time.

Although there is no single accepted definition for malnutrition, the condition can be described as an unbalanced nutritional state, resulting from inadequate nutrient intake and/or altered nutrient requirements related to disease and treatment, that alters body mass, body composition and function (Gillis and Wischmeyer, 2019; Laur et al., 2017). In short, malnutrition can refer to over or under-nutrition and is not determined by body size.

Under-nutrition can be defined as a deficiency of energy, protein and other nutrients that causes adverse effects on the body and clinical outcomes (Holdoway et al., 2017; NICE, 2017). Estimates of rates of under-nutrition in the oncology population vary from 30-70% in some studies, to 10-85% in others (Arends et al., 2017; Bozzetti, 2012; Gillis et al., 2021; Ryan et al., 2019). Either way, it is accepted that the prevalence of under-nutrition is extremely high in this patient group. Older age, disease stage and tumour type can influence risk of under-nutrition, with risk

increasing in oesophageal and/or gastric and pancreatic cancers; and weight loss increasing in upper gastrointestinal tumours and advanced disease (Bozzetti, 2012; Hebuterne et al., 2014). Cancer cachexia<sup>1</sup> is also thought to affect 38-70%, and sarcopenia<sup>2</sup> 20-70% of cancer patients (Prado, Purcell & Laviano, 2020; Ryan et al., 2019). In the UK and Ireland estimates derived via systematic review show that annually, 34% of patients may experience clinically significant unintentional weight loss of over 5% body weight; with an additional 18.5% of patients experiencing unintentional weight loss of over 10% (highly clinically significant); whilst a further 35% of patients are likely to be experiencing sarcopenia (Sullivan et al., 2020).

Undernutrition remains both under-identified and undertreated, leading to adverse effects (Stratton et al., 2018). The consequences of under-nutrition include a physical and functional decline that can negatively affect performance status and clinical outcomes, impair immunity thereby increasing the risk of infection, increase length of hospital stay, and increase risk of mortality (Van Cutsem and Arends, 2005; Stratton et al., 2018). Unintentional weight loss is associated with negative oncological outcomes including reduced survival (Marshall et al., 2019; Sullivan et al., 2020; Prado et al., 2020) and can decrease the response to chemotherapy and increase the frequency and severity of chemotherapy-induced toxicity (Van Cutsem and Arends, 2005). Risk of under-nutrition and unintentional weight loss is also linked to reduced quality of life (Rasheed and Woods, 2014; Sullivan et al., 2020) with fear, depression and anxiety affecting appetite and oral intake, further increasing risk (Van Cutsem and Arends, 2005).

People diagnosed with cancer are at high risk of under-nutrition due to the disease itself, as well as cancer treatment(s) and side effects. Reduced food intake, altered metabolism, changes to resting energy expenditure and a decrease in physical activity levels all influence risk of under-nutrition and loss of muscle mass (Arends et al., 2017b). The effects of treatment on nutritional intake can vary according to tumour site, treatment type, treatment strength and duration (Ryan et al., 2016). Common treatment side effects that can affect nutritional intake include swallowing difficulties, early satiety, nausea, taste changes, mucositis, sore/dry mouth, increased oral secretions, fatigue, malabsorption and altered bowel habits (Zhang et al., 2019; Grant and Kravits, 2000; Arends et al., 2017). Treatment may also impact indirectly on nutritional intake, due to time spent travelling to hospital appointments, receiving treatment, and fasting ahead of investigations, all of which can impact on fatigue, appetite and the time available to prepare and consume food. Individuals with cancer might also purposely alter their diet, as a method of exerting control at a time when other aspects of their life/treatment may feel pre-determined or in the hands of others. A diagnosis can also be a major source of motivation resulting in lifestyle changes (Paterson et al., 2003). Whilst some of these changes may result in an improvement in diet quality, some could leave an individual at increased risk of malnutrition, particularly when whole food groups or common ingredients are avoided and substitution is sub-optimal, for example animal protein, dairy, sugar etc.

---

<sup>1</sup>Involuntary weight loss characterised by anorexia, loss of adipose tissue and skeletal muscle mass (Muscaritoli et al., 2010)

<sup>2</sup>Sarcopenia in cancer can be primary (aging related), secondary (disease related) or both. Primary sarcopenia is defined as depleted muscle mass and strength. Secondary sarcopenia is defined as a measure of depleted muscle mass and this definition is often used in oncology-related publications on the topic (Gillis et al., 2021)

Excess body weight (as assessed by Body Mass Index (BMI)) is present in 65% of adults in Scotland. It is a risk factor for at least 13 cancer sites (IARC, 2018), and is frequently observed in people diagnosed with cancer. Body fatness and sub-optimal fat free mass are also associated with poorer outcomes. Weight management has therefore become the focus of cancer prevention and secondary risk reduction strategies. However, once diagnosed with cancer, the time to treatment is often short and the emotional and physical burden of cancer on the individual is substantial. In addition, clinically significant intentional weight loss within the pre-treatment timeframe is often difficult to achieve without negatively impacting nutritional status and or mental health. As such, the focus of nutritional interventions in the pre-treatment phase should be on nutritional quality and building or maintaining fat free mass (muscle).

Reversing under-nutrition in the pre-treatment time period is also challenging, with some observational evidence suggesting that a longer period is required to improve parameters of physical functioning in malnourished patients (Canadian Nutrition Society, 2020). Thus, nutritional screening and appropriate intervention should be embedded within cancer pathways at the earliest possible opportunity and extend into neo-adjuvant and perioperative treatment, during treatment, post treatment and/or advanced care periods. However, nutritional prehabilitation is not just about replacing nutritional deficits. Nutritional intervention for approximately 7-14 days before surgery has been found to improve post-operative outcomes, reduce length of stay and limit serious complications (Burden et al., 2012; Kabata et al., 2015; Weismann et al., 2017; Gillis et al., 2018). Maintaining skeletal muscle mass also has the potential to support an individual to withstand chemotherapy, reduce chemotherapy induced toxicity and support overall response to treatment (Jarvinen et al., 2018; Palmela et al., 2017). Thus, a shift to pre-emptive rather than reactive nutrition assessment and intervention must be emphasised (West et al., 2017).

During treatment, excess body fatness and low fat free mass are likely to impact treatment response. Weight gain and changes in body composition (increased fat mass and decreased fat free mass) are also common during chemotherapy and hormone therapy, and can be distressing for individuals. Nutritional information and support at this time can ameliorate this effect, and when combined with information and support that is focused on physical activity and mental wellbeing, can improve clinical and experiential outcomes. It may also engage people at a time when they are motivated to change and are actively seeking information. Evidence suggests that many patients alter their diet in an attempt to cure their cancer or alleviate symptoms, however with one-third of cancer-related social media articles containing misinformation and nearly 80% of those containing harmful information, pro-active information and support could also prevent negative unintended consequences (Ford et al., 2022).

Once treatment has finished, it is postulated that excess body fat continues to influence the quality of cancer survivorship and impacts disease-free survival after primary curative treatment (Anderson et al., 2020) Thus, cancer survivors are encouraged as far as possible, to follow the same recommendations that are set out for cancer prevention (WCRF, 2018). The evidence for these recommendations in the context of survivorship is weak but emerging, and relevant in the prevention and progression of other non-communicable diseases notably diabetes. They are also largely supported by ESPEN guidance (Muscaritoli et al., 2021). The eight WCRF

recommendations focus on achieving balance through physical activity and food and dietary intake:

1. Keep your weight within the healthy range and avoid weight gain in adult life.
2. Be physically active as part of everyday life – walk more and sit less.
3. Eat wholegrains, vegetables, fruit and beans
4. Limit ‘fast foods’
5. Limit red and processed meat
6. Limit sugar sweetened drinks
7. Limit alcohol consumption
8. Do not use supplements for cancer prevention

It must be acknowledged that the challenge of achieving and maintaining dietary recommendations (in people with excess weight or under nutrition) will not be equal across population groups and support is required both by health professionals and the wider community. The reasons why we eat and drink what we do, are multiple and complex (Foresight, 2007; Foresight, 2012) and these challenges should not be ignored. Support for weight management (through holistic care that includes physical activity, appropriate caloric intake, a nutrient dense diet) should be offered in an appropriate, timely manner bearing in mind concerns about stigma and other sensitivities (see Appendix 3: Challenging weight stigma hub).

### Policy Context

The Scottish Government’s 2020 cancer strategy, ‘[Recovery and Redesign: An Action Plan for Cancer Services](#)’, sets out three key overarching aims:

1. Adopt a ‘Once for Scotland’ approach where appropriate, to cancer services
2. Create smoother and more efficient patient pathways, from initial referral and diagnosis to the personalised care and support received after treatment, with the aim of improving both outcomes and experience throughout an individual’s journey.
3. Integrate innovative solutions to cancer services as we continue to learn from the impact of COVID-19 on the NHS.

A scoping exercise carried out in Scotland specifically looking at cancer prehabilitation informed the development of that strategy. The scoping exercise found that access to nutrition information and support is generally lacking in the pre-treatment phase of cancer pathways in Scotland (Provan et al., 2021). As such, Scotland’s Cancer Recovery Plan has called for the development of a framework for nutritional care that would support the effective delivery of cancer prehabilitation across Scotland’.

A wider review of policy brings ‘Food Fluid and Nutritional Care Standards’ (HIS, 2014), and the ‘Complex Nutritional Care Standards’ (HIS, 2015) into focus. The former applies to the care of all patients, paediatric and adult, in both community healthcare and hospital care in Scotland, whether directly provided by an NHS Board or secured on behalf of an NHS Board. The latter acknowledges that the nutritional requirements of some people cannot be met by the usual oral route, and outline what should be in place to support feeding by a tube into the gut or through a line placed into a vein i.e., ‘complex nutritional care’.

Amongst other things, these standards call for:

- Effective and person-centred nutritional care, irrespective of specialty and location (hospital or community)
- Screening for the risk of malnutrition on admission to hospital and on an on-going basis
- The creation, implementation and evaluation of person-centred care plans
- Informed and shared decision making at all stages of care
- Knowledgeable and skilled staff able to meet patients' food, fluid and nutritional care needs
- Systems which ensure patients who require complex nutritional care are safely and effectively managed

[A healthier future: Scotland's diet and healthy weight delivery plan](#) (2018) sets out wide ranging action to support diet and healthy weight. This includes actions to ensure the food environment supports healthier choices and people have access to effective weight management services.

In August 2020, the Scottish Government published the '[Framework for Supporting People through Recovery and Rehabilitation during and after the COVID-19 Pandemic](#)'. It sets out overarching principles and priorities for planning and delivering high quality, person-centred rehabilitation and recovery services. In June 2022, this was complemented by '[Rehabilitation and Recovery: A Once for Scotland Person-Centred Approach to Rehabilitation in a Post-COVID Era](#)' outlining 'Six Principles of Good Rehabilitation':

1. Easy to access for every individual
2. Provided at the right time
3. Realistic and meaningful to the individual
4. Integrated
5. Innovative and ambitious
6. Delivered by a flexible and skilled workforce

The approach set out in this 'Nutrition Framework for People Affected by Cancer' complies with each of the six principles outlined above, and it is aligned with the overarching general rehabilitation framework.

## **Guiding Principles of Nutritional Care and Support**

The following guiding principles and key messages underpin the Nutrition Framework for People Affected by Cancer. Appendix 1 provides an overview of the pathway which supports the Framework thereby ensuring execution of these principles.

### Guiding Principles

- it is expected that a person's nutritional needs will be impacted by their cancer and cancer treatment
- early identification of a person's nutritional needs (whether in under nutrition or excess body weight) and early intervention could avoid escalation of issues and facilitate access to treatment where poor nutritional status may otherwise preclude it
- nutritional risk should be detected through screening and managed appropriately

- further assessment will determine intervention(s) required and should be outcomes focused
- preserving muscle, not just weight, is key to improving cancer outcomes, including response to treatment and quality of life
- nutritional care should be proactive and holistic with the social, psychological, environmental and physical challenges associated with eating and a cancer diagnosis and treatment, considered from the beginning of the care pathway, and maintained throughout
- a food-first approach should be advocated wherever possible
- where nutritional intake is restricted, every effort should be made to help an individual to resume 'normal' eating or as close to normal as possible, as soon as possible
- shared decision making should be enabled with personalised care and support planning central to all care
- in the case of palliative and end of life care, advanced care planning decisions should incorporate decisions about nutritional intake/withdrawal of nutritional support
- the impact of nutritional issues can be far reaching and a source of distress for those supporting individuals diagnosed with cancer. Proactive management, good communication and compassionate care can minimise distress and positively impact experience and quality of life

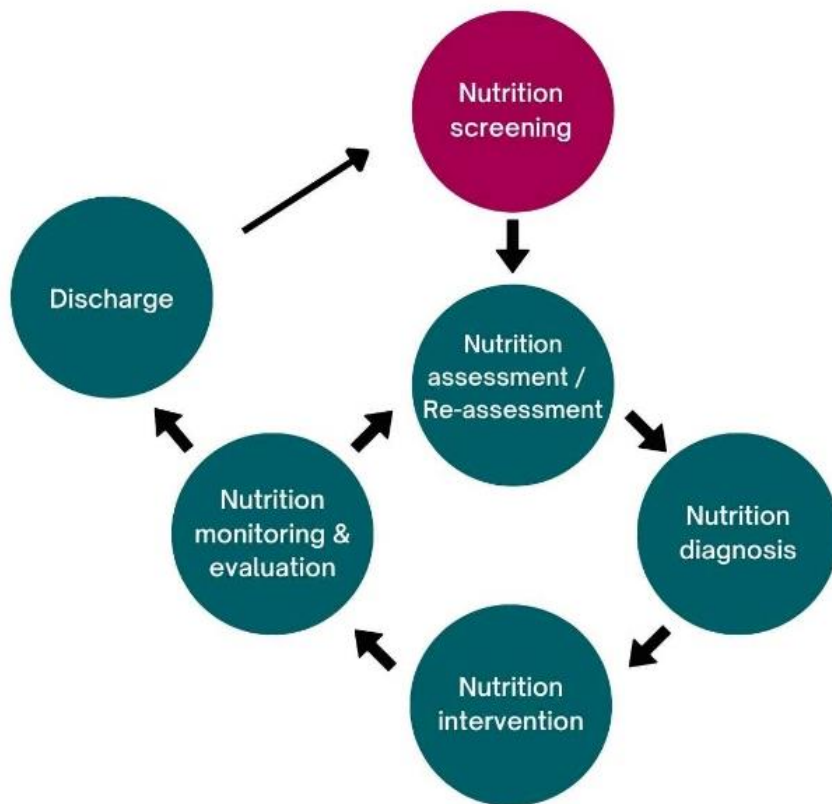
#### Key Messages

1. People diagnosed with cancer are at high risk of under-nutrition
2. Nutrient intake is a vital component in delivering successful cancer outcomes
3. People should have easy access to appropriate nutritional care and support as part of the overall care package
4. People should be screened for nutrition risk in advance of each treatment, when their condition changes, and as per the screening management plan (whichever is sooner)
5. Nutrition is a responsibility of the whole multi-disciplinary team (MDT)
6. Individuals should be supported to be as involved in their care as they want to be, with shared decision making and person-centred care and support planning at the centre of all interactions

## **Nutrition Screening and Care Process**

The Nutrition Care Process Model is preceded by nutrition screening, the outcome of which may result in step-by-step process of assessment, diagnosis, intervention, monitoring and evaluation, and either re-assessment or discharge (Gillis et al, 2021). Alternatively, an individual may stay at the screening stage if nutritional need and risk is continually identified as low.





**Figure 1: Nutrition Screening and Care Process**

(Adapted from British Dietetic Association (BDA), 2021; Gillis et al, 2021)

Implementation of the full Nutrition Care Process Model is expected to improve clinical management and therefore positively impact outcomes, including patient reported outcomes and experiential measures, and service outcomes such as efficacy, efficiency, quality and safety.

### Nutritional Screening

Nutritional screening should be carried out with all individuals diagnosed with cancer (Weismann et al., 2017). Early screening using a validated tool offers the opportunity to intervene as required (universal, targeted and/or specialised intervention – Figure 2) and improve patient outcomes (Trujillo et al., 2018). However, those receiving end of life care may not benefit from screening and clinical judgement should be applied. That said, the role of diet and nutrition in palliative and end of life care should not be underestimated and changes in weight, appetite, and ability to eat should be discussed compassionately and proactively (See Appendix 2 for more guidance on nutrition in palliative and end of life care).

Patients who screen ‘low’ or ‘0’ for nutrition risk at the time of urgent suspicion of cancer referral and/or first hospital appointment, should be re-screened in advance of each treatment and when their condition changes. This will ensure the level of nutritional support provided remains appropriate. They should also be provided with verbal and written information to help them understand the role of nutrition in both preparing for and withstanding cancer treatment. This ‘universal’ information (See Fig. 2, pg. 14-15) can be delivered through individual or group means (face-to-face or digital) but should be person-centred and tailored.

Any persons involved in the delivery of care and support should be mindful of the wider factors which can impact nutritional status for example, anxiety, pain, nausea, financial insecurity, fear, immobility, low mood etc. Consideration should also be given as to how individuals access food i.e. shopping locally, 'meals on wheels' service, pre-prepared frozen/chilled delivery services, supermarket delivery, food banks etc. Cross-sector collaborative working has a role in addressing these needs, and holistic needs assessment (HNA) with a tool such as the (Cancer) Concerns checklist and person-centred care planning as part of a prehabilitation/rehabilitation approach to care is advised.

A core component of prehabilitation and rehabilitation, physical activity and exercise can both complement and be complemented by a good nutritional intake (Prado, Purcell & Laviano, 2020). Those who are unable to meet their nutritional requirements are unlikely to be able to maintain or increase their activity levels and reach their full potential. The result of which, is delayed or suboptimal recovery, and a decreased ability to withstand treatment. On the contrary physical activity can protect against sarcopenia, drive appetite and reduce problems commonly associated with anti-cancer treatments such as constipation, so long as the individual is also suitably hydrated. Thus, physical activity and nutrition should be considered collectively and screening tools or measurements used to determine functional status and body composition can support the identification of sarcopenia even when body weight is maintained. Sarcopenia is associated with immediate post-operative complications, prolonged length of hospital stays, and reduced toleration of chemo-radiotherapy due to increased prevalence of side effects and treatment interruption (Anjanappa et al., 2020). The latter explained by the variation in pharmacokinetics of drugs when using body surface area for dose calculation when there is an abnormal distribution of fat and fat-free mass.

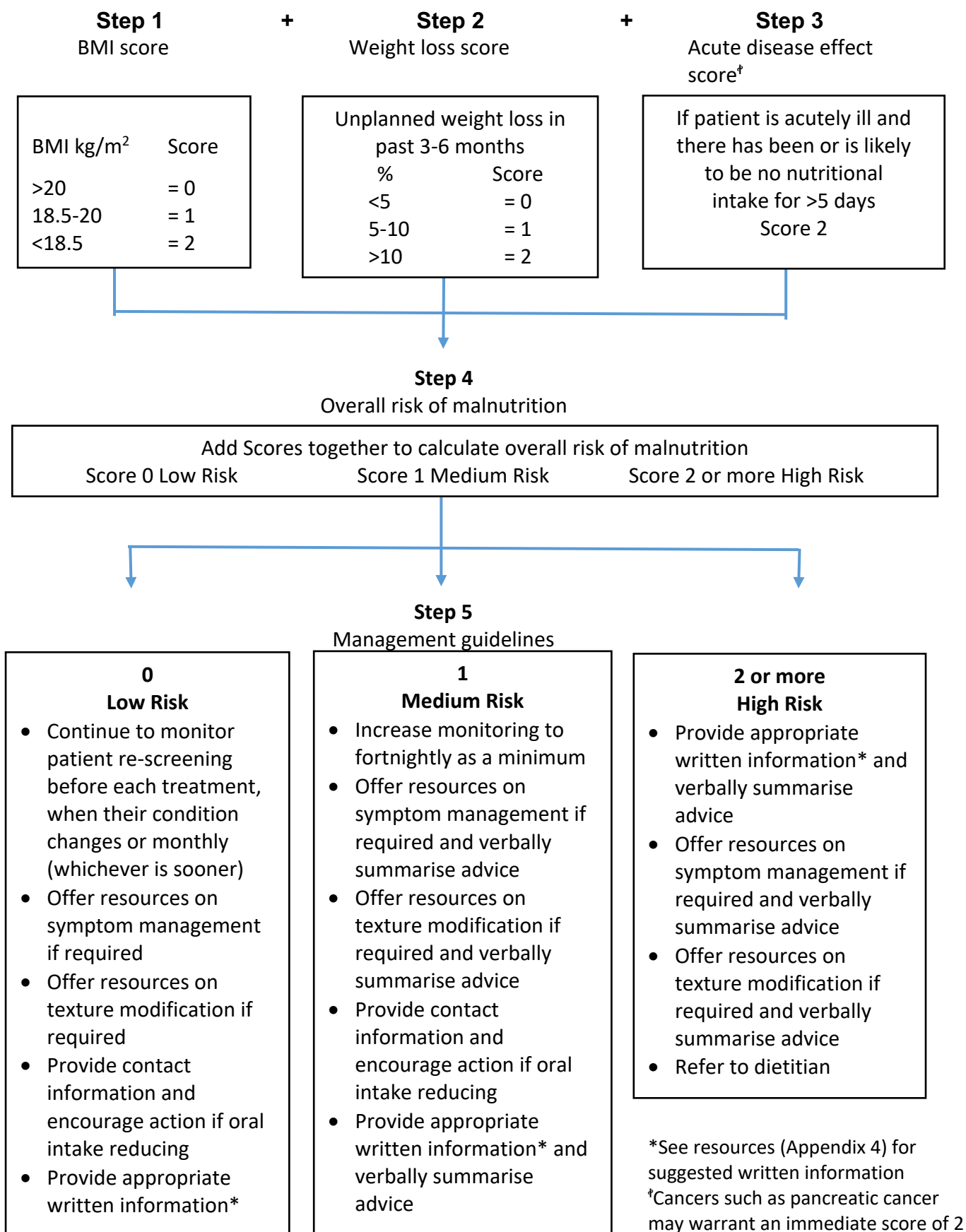
Patients identified as being at risk for sarcopenia and/or malnutrition must be managed as per the screening tool's associated management guideline and where appropriate, referred to a dietitian for a full nutrition assessment (Gillis et al., 2021). Local management plans resulting from screening may already be in place however, where these are missing, further guidance is provided below (see MUST screening and Assessment, pg. 12). Those identified as at risk for sarcopenia should be managed by the multi-disciplinary team but would benefit from early first-line interventions associated with both physical activity and diet. A [food first approach](#) should always be promoted i.e. choosing nutrient dense foods and fluids to maximise nutritional intake and enriching foods/drinks with other foodstuffs/fluids to further increase macronutrient content with limited increase in food volume.

Note: No screening tool is perfect in identifying malnutrition risk across all patient groups/populations. The Malnutrition Universal Screening Tool (MUST) includes the phenotypes of unintentional weight loss and low BMI; and reduced food intake and disease burden as aetiology. MUST has been validated in various cancer types and against multiple interventions associated with cancer treatment, with varying degrees of sensitivity (67.8-96%) and specificity (75-94.5%). This suggests that up to 32.2% of those with malnutrition could be missed, and up to 25% of patients without malnutrition could be falsely labelled as being at risk of malnutrition. This limitation could have significant impact at an individual and population level. As such, rapid weight loss (i.e.,  $\geq 1-2\%$  in 1 week,  $\geq 5\%$  in 1 month) should be considered, and clinical judgement applied (Atkinson and Atkinson, 2021). Frequent screening (as

per the management plan which follows any screening process) and implementation of advised actions should also mitigate against these risks.

The [HNA/concerns checklist and care plan](#) is not a validated screening tool for detecting nutritional issues and should not be used to identify risk of malnutrition. It may communicate weight gain as self-identified issue, and can also identify nutrition impact symptoms (amongst other things). It is often used by clinical and Macmillan services across Scotland (such as Improving the Cancer Journey) to understand and address a person's holistic needs. As demonstrated in the Case Studies (Appendix 5) it may be a useful practical tool which indicates MUST should be completed and it can also be used alongside a nutrition assessment to understand a person's wider concerns and priorities.

## MUST Screening and Management Guideline



## Nutrition Assessment

Those identified as being at medium risk for malnutrition or those at high risk but who are unlikely to have their nutritional intake adversely affected by imminent/future treatment, may benefit from assessment and 'targeted' intervention by a member(s) of the care team with additional training in cancer care and/or nutrition. To establish level of need, assessment with the Subjective Global Assessment (SGA) or Patient Generated Subjective Global Assessment (PG-SGA) is recommended (Appendix 4).

Those identified as being at high risk of malnutrition and/or those who are unable to manage their nutritional needs without specialist support should undergo an objective and quantitative assessment which considers nutritional intake, nutrition impact symptoms, muscle mass, physical performance, and the degree of systemic inflammation (Gillis et al., 2021; Muscaritoli et al., 2021). This should be an interactive process carried out by an appropriately trained individual (See Appendix 1 and Appendix 3). The process may be supported by the SGA or PG-SGA, food records or dietary food recall, biochemical assessment, anthropometry and/or measures of strength and function such as handgrip strength, 6-min walk, timed up and go etc., and will demonstrate critical reasoning that informs decision making (BDA, 2021). The ultimate purpose is to collect, classify and synthesise important and relevant data that allow a diagnosis of malnutrition or other nutrition-related problems to be made. Each tool selected and used as part of that process will be used to describe dietary patterns, assess dietary intake, examine an association, or to evaluate the effect of an intervention (Gillis et al., 2021). The individual at the centre of the assessment's ideas, priorities, concerns, and expectations will also be integral to all decisions and the chosen management approach (BDA, 2021).

## Nutrition Diagnosis

Data collected as part of the nutritional assessment are compared against accepted standards, expert recommendations, and/or patient-defined goals to establish nutritional status. In Scotland, the most appropriate general surgery and oncology-specific standards are likely to be those produced by the European Society for Clinical Nutrition and Metabolism (Weimann et al., 2021), the Enhanced Recovery After Surgery Society (ERAS) (various) and the European Society of Surgical Oncology (Sandrucci et al., 2018), with the [Perioperative Quality Initiative](#) providing consensus statements on nutrition and emerging topics of interest such as protein and immune-nutrition. However, disease-specific standards may also exist. The aforementioned data, together with the patient's medical and social history, are then used to diagnose nutrition-related problems that can be addressed with the support of the dietitian and/or nutrition team (Gillis et al., 2021).

The individual's diagnosis is expressed using standardised language, labelling the identified **P**roblem, citing the **A**etiology of the problem, and noting **S**igns and **S**ymptoms that provide evidence of the problem (PASS statement) (BDA, 2021). For example, Chronic disease-related malnutrition (SNOMED CT: 441971000124107) (problem) related to nutrition-impact symptoms, including constipation (14760008), early satiety (79890006) and fatigue (716749005) (aetiology), as evidenced by

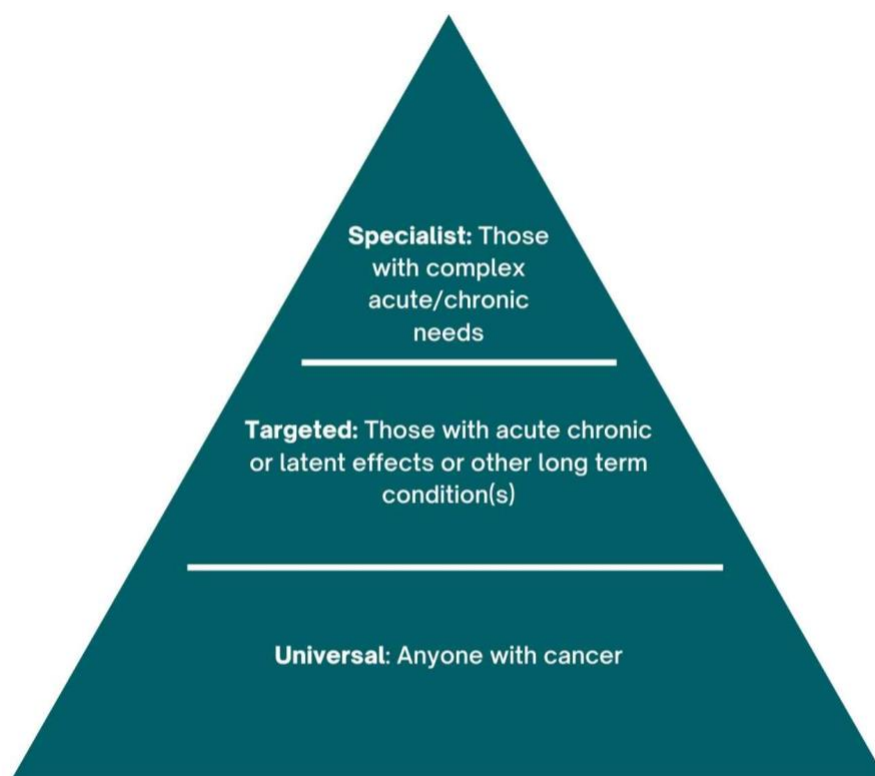
meeting 65% of estimated protein requirements (190606006), 10% weight loss in past 6 months (448765001), and low handgrip strength (198281000000108) (signs and symptoms) (BDA, 2021; Gillis et al., 2021).

### Nutrition Intervention

A nutrition intervention is a purposefully planned action(s) designed with the intent of changing nutrition-related behaviours, risk factors, environmental conditions, or an aspect of physical or psychological health (BDA, 2021; Swan et al, 2017 cited by Gillis et al, 2021). The nutrition intervention is designed to improve or resolve the nutrition diagnosis/problem. If it is not possible to resolve the diagnosis or its aetiology, the nutrition plan is aimed at relieving signs and symptoms (Gillis et al, 2021).

All interventions are personalised to reflect the needs and preferences of the individual concerned. The length, frequency and duration of the intervention will also be defined with roles and responsibilities agreed and communicated appropriately with all those concerned (BDA, 2021). Resources that aid understanding and support change will also be used as required i.e. diet sheets, digital applications, written care plans etc. Once again, the beliefs and preferences of the individual at the centre of care must be fully considered and discussed, particularly when the individual has questions about or is following what could be considered an alternative and/or complementary diet that single out particular food groups, nutrients and/or ingredients. Any individuals supporting the person with the diagnosis of cancer to obtain and prepare food may also benefit from inclusion in the intervention stage, subject to consent.

[‘Prehabilitation for people with cancer: Principles and guidance for prehabilitation within the management and support of people with cancer’](#) was released in 2019 by Macmillan Cancer Support, the Royal College of Anaesthetists and the National Institute of Health Research Cancer and Nutrition Collaboration. This guideline proposed a risk-stratified approach to prehabilitation with the level of care delivered based on the outcome of individual assessment (Figure 2) and corresponds with wider guidance that advocates for a right care, right place, right time approach. The risk stratified model was then adapted by Gillis et al. (2021) to reflect nutritional screening and assessment processes. This latter nutrition specific model acts as a useful guide for local referral processes and pathways as per Appendix 1. It also explains the role of the wider cross-sector multi-disciplinary team in assessing nutritional need and delivering care.



**Figure 2: Levels of Intervention**  
(Adapted from Macmillan Cancer Support, 2019)

### Nutrition Monitoring and Evaluation

Relevant outcome measures should be utilised at appropriate time points to determine whether the applied intervention is appropriate, and if progress towards the specified goal(s) has been made (BDA, 2021; Gillis et al., 2021). This step provides an opportunity to identify any barriers and/or facilitators that are impacting progress and to review or agree any new goals with the individual concerned.

The selection of appropriate outcomes measures will be based on the nutrition diagnosis. For example, 'inadequate oral intake' may be assessed by food record charts and regular weight monitoring, with biochemical markers used to complement data. Patient-reported outcomes such as changes in quality of life and knowledge/attitudes related to food and nutrition may also be used. The method of review will be dependent on level of individual need and place of care. For example, at the targeted level, telephone calls to troubleshoot barriers and self-monitoring of weight can be appropriate. Whereas, at the specialist level, the individual may require close monitoring and re-assessment so that the nutrition prescription can be quickly modified if it is not adequately meeting individual needs or achieving expected outcomes. Finally, the timeframe for review will also be based on individual circumstance, for example, in the case of prehabilitation it is likely the individual will be reviewed weekly or bi-weekly given the short window of opportunity before first treatment.

If the desired outcome has been achieved, it should be appropriate to discharge the individual from the nutrition service. However, should the risk of malnutrition remain due to further planned treatment(s), diagnosis of a progressive illness etc., then

regular screening (self-screening may be suitable) should continue, with information given on risk management and rapid re-entry to targeted/specialist services as appropriate. If the desired outcome is not met, re-assessment may be warranted and the process should continue (BDA, 2021; Gillis et al., 2021).

## Education and Training

Detecting nutritional issues at an early stage can help minimise or prevent deterioration in nutritional status and prevent or minimise muscle mass loss that may otherwise be resistant to intervention and become irreversible later on (Donald and Holdoway, n.d.). Members of the healthcare team should be trained to screen for nutrition risk, and regularly observe and evaluate nutritional intake, recording changes in weight and body mass index (BMI) and acting on the findings. This should start as early as possible i.e., at the point of an urgent suspicion of cancer referral or as close to a cancer diagnosis as possible, and should be repeated as per management guidelines thereafter (see local guidance and/or MUST Screening and Management Guideline on pg. 12).

The Education and Training Grid (Appendix 3) details the knowledge and competencies required at each level of intervention, the likely interventions utilised by each staff group and recommended core training at each level. The core training tools included have been mapped against the core competencies outlined within the [Macmillan AHP competency framework](#) launched in 2017 and endorsed by 11 AHP Professional Bodies; the Association of Chartered Physiotherapists in Oncology and Palliative Care; and the Oncology Nurse Society UK.

The case studies listed in Appendix 5 are designed to help readers understand what the different levels of intervention (universal, targeted, specialist) may look like in practice, and what level of knowledge and skill the provider of that intervention should possess.

All NHS and non-NHS organisations can access training resources available through [Turas](#). Training programmes delivered by NHS Education Scotland (either online or face to face) can also be accessed by both NHS staff and partnership organisations.

## Conclusions

Cancer detection and treatment continues to evolve and change as our knowledge and understanding of the disease grows. As we utilise ever more complex and targeted treatment regimens, it is essential that we continue to grow and develop the nutritional care and support that people affected by cancer receive. Through provision of the right support, in the right place at the right time, people affected by cancer can be better equipped emotionally and physically and outcomes improved. Access to high-quality risk-stratified nutritional care and support should therefore be equitable to all regardless of tumour type, demography, geographical or socio-economic status.

To achieve this, it is more important than ever that all care sectors work collaboratively, ensuring care and support feels seamless, connected and easily accessible. This co-designed Framework supports a shared understanding and



outlines agreed pathways of care which promote optimal models of high-quality service provision. However, the presence of a Framework alone is unlikely to lead to widespread change. For the over-arching aim to be achieved, the Framework must be adopted by all partners in Scotland, including health, social care and the third sector and the need for any further work explored. It is therefore recommended that several activities are considered in the short, medium, and longer term. For example:

- adoption should be pan-Scotland to promote trust in interagency working through a common standard and closer working relationships, whilst also furthering the potential for accessible and timely care and support
- existing structures, e.g., Managed Clinical Networks, Patient Support Groups, Third Sector forums etc. be utilised to promote the Framework and raise awareness of the Guiding Principles and Key Messages
- a working group should review the framework and its impact (as a whole and by section), acting on barriers to implementation and updating content as required. A 1-year review date may be appropriate for the first review, with a less frequent review date agreed thereafter. To fully understand barriers (and opportunities), it may be necessary to utilise existing data or to collect additional data, this may be focused on demand and capacity, outcomes, education, and training etc.

By adopting this Framework approach for NHS, social care and third sector organisations to work collaboratively, we can support and optimise existing service provision. Through continued close working, improved access to training and resources, and continued development of trust and respect for the quality of services provided at all levels in all sectors, we can ensure that people affected by cancer are truly at the centre of care planning and delivery.

## References

Anderson, A.S., Martin, R.M., Renehan, A.G., Cade, J., Copson, E.R., Cross, A.J., Grimmett, C., Keaver, L., King, A., Riboli, E., Shaw, C., & Saxton, J.M. On behalf of the UK NIHR Cancer and Nutrition Collaboration (Population Health Stream) (2020) Cancer survivorship, excess body fatness and weight-loss intervention —where are we in 2020? *Br J Cancer* 124: 1057–1065 <https://www.nature.com/articles/s41416-020-01155-2>

Anjanappa, M., Corden, M., Green, A., Roberts, D., Hoskin, P., McWilliam, A., and Choudhury, A. (2020). Sarcopenia in cancer: Risking more than muscle loss. *Technical innovations & patient support in radiation oncology*, 16, 50–57. <https://doi.org/10.1016/j.tipsro.2020.10.001>

Arends, J., Bachman, P., Baracos, V., Barthelemy, N., Bert, H., Bozzetti, F., Fearon, K., Hutterer, E., Isenring, E., Kaasa, S., Krznaric, Z., Laird, B., Larsson, M., Laviano, A., Muhlebach, S., Muscaritoli, M., Oldervoll, L., Ravasco, P. and Presier, JC. (2017) ESPEN guidelines on nutrition in cancer patients. *Clin Nutr* 36:11-48. doi:10.1016/j.clnu.2016.07.015

Bozzetti, F., Mariani, L., Lo Vullo, S., SCRINIO Working Group, Amerio, M. L., Biffi, R., Caccialanza, G., Capuano, G., Correja, I., Cozzaglio, L., Di Leo, A., Di Cosmo, L., Finocchiaro, C., Gavazzi, C., Giannoni, A., Magnanini, P., Mantovani, G., Pellegrini, M., Rovera, L., Sandri, G. and Vigevani, E. (2012). The nutritional risk in

oncology: a study of 1,453 cancer outpatients. Supportive care in cancer 20(8), 1919–1928. doi:10.1007/s00520-012-1387-x

British Dietetic Association (BDA) (2021) Model and Process for Nutrition and Dietetic Practice. Available at: <https://www.bda.uk.com/practice-and-education/nutrition-and-dietetic-practice/professional-guidance/model-and-process-for-dietetic-practice.html>

Burden, S., Todd, C., Hill, J., Lal, S., (2012) Pre-operative nutrition support in patients undergoing gastrointestinal surgery. Cochrane database of systematic reviews 2012, Issue 11. Art. No.: CD008879. DOI: 10.1002/14651858.CD008879.pub2

Canadian Nutrition Society (2020) Scientific abstracts. Applied Physiology, Nutrition and Metabolism 45(4 (Suppl. 1)):S1-56. doi: 10.1139/apnm-2020-0129

Ford, K.L, Orsso, C.E., Kiss, N., Johnson, S.B., Purcell, S.A., Gagnon, A., Laviano, A., Prado, C.M. (2022) Dietary choices after a cancer diagnosis: A narrative review. Nutrition 103–104 doi.org/10.1016/j.nut.2022.111838.

Foresight (2007) Tackling Obesities: Future Choices - Project Report. 2<sup>nd</sup> Edition. Available at: <https://www.gov.uk/government/collections/tackling-obesities-future-choices>

Foresight (2012) Tackling Obesities: Future Choices. Mid-Term Review November 2008 – September 2010. Available at: <https://www.gov.uk/government/collections/tackling-obesities-future-choices>

Gillis, C., Davies, S.J., Carli, F., Wischmeyer, P.E., Wootton, S.A., Jackson, A.A., Riedel, B., Marino, L.V., Levett, D.Z. and West, M.A., 2021. Current landscape of nutrition within prehabilitation oncology research: a scoping review. Frontiers in nutrition, p.63.

Gillis, C., Hasil, L., Kasvis, P., Bibby, N., Davies, S. J., Prado, C. M., West M. A., Shaw C.(2021) Nutrition Care Process Model Approach to Surgical Prehabilitation in Oncology. Front. Nutr. 8:644706. doi: 10.3389/fnut.2021.644706

Gillis, C., Buhler, K., Bresee, L., Carli, F., Gramlich, L., Culos-Reed, N., Sajobi, T.T. and Fenton, T.R., 2018. Effects of nutritional prehabilitation, with and without exercise, on outcomes of patients who undergo colorectal surgery: a systematic review and meta-analysis. Gastroenterology, 155(2): 391-410.

Gillis, C. and Wischmeyer, P.E., 2019. Pre-operative nutrition and the elective surgical patient: why, how and what?. Anaesthesia, 74: 7-35.

International Agency for Research on Cancer (2018) Absence of Excess Body Fatness. <http://publications.iarc.fr/Book-And-Report-Series/Iarc-Handbooks-Of-Cancer-Prevention/Absence-Of-Excess-Body-Fatness-2018>

The International Dysphagia Diet Standardisation Initiative (IDDSI) (2016) The IDDSI Framework. Available at: <https://iddsi.org/framework>

Jarvinen, T., Ilonen, I., Kauppi, J., Salo, J. and Rasanen, J. (2018) Loss of skeletal muscle mass during neoadjuvant treatments correlates with worse prognosis in esophageal cancer: a retrospective cohort study. *World J SurgOncol.* 16(1):27.

Kabata, P., Jastrzębski, T., Kąkol, M., Król, K., Bobowicz, M., Kosowska, A. and Jaśkiewicz, J., 2015. Preoperative nutritional support in cancer patients with no clinical signs of malnutrition—prospective randomized controlled trial. *Supportive Care in Cancer*, 23(2):365-370.

Laur, C.V., McNicholl, T., Valaitis, R. and Keller, H.H., 2017. Malnutrition or frailty? Overlap and evidence gaps in the diagnosis and treatment of frailty and malnutrition. *Applied Physiology, Nutrition, and Metabolism*, 42(5):449-458.

Macmillan Cancer Support (2019) Principles and Guidance for Prehabilitation. Available at: <https://www.macmillan.org.uk/about-us/healthprofessionals/resources/practical-tools-for-professionals/prehabilitation.html>

Muscaritoli, M., Anker, S.D., Argiles, J., Aversa, Z., Bauer, J.M., Biolo, G., Boirie, Y., Bosaeus, I., Cederholm, T., Costelli, P., Fearon, K.C., Laviano, A., Maggio, M., Rossi Fanelli, F., Schneider, S.M., Schols, A. and Sieberet, C.C. (2010) Consensus definition of sarcopenia, cachexia and pre-cachexia: joint document elaborated by Special Interest Groups (SIG) "cachexia-anorexia in chronic wasting diseases" and "nutrition in geriatrics". *ClinNutr.* 29(2):154-9 doi: 10.1016/j.clnu.2009.12.004

Muscaritoli, M., Arends, A., Bachmann, P., Baracos, V., Barthelemy, N., Bertz, H., Bozzetti, F., Hütterer, E., Isenring, E., Kaasa, S., Krznaric, Z., Laird, B., Larsson, M., Laviano, A., Mühlebach, S., Oldervoll, L., Ravasco, P., Solheim, T. S., Strasser, F., de van der Schueren, M., Preiser, J.C. and Bischoff, S. C. (2021) ESPEN practical guideline: Clinical Nutrition in cancer. *Clinical Nutrition*, 40(5): 2898 – 2913 doi: 10.1016/j.clnu.2021.02.005

Palmela, C., Velho, S., Agostinho, L., Branco, F., Santos, M., Santos, M.P., Oliveira, M.H., Strecht, J., Maio, R., Cravo, M. and Baracos, V.E. (2017). Body Composition as a Prognostic Factor of Neoadjuvant Chemotherapy Toxicity and Outcome in Patients with Locally Advanced Gastric Cancer. *Journal of Gastric Cancer*, 17: 74 – 87 doi: 10.5230/jgc.2017.17.e8

Prado, C.M., Purcell, S.A. and Laviano, A. (2020) Nutrition interventions to treat low muscle mass in cancer. *J Cachexia Sarcopenia Muscle* 11:366-80. doi: 10.1002/jcsm.12525

Provan, D., McLean, G., Moug, S.J., Phillips, I. and Anderson, A.S. (2021) Prehabilitation services for people diagnosed with cancer in Scotland e Current practice, barriers and challenges to implementation. *The Surgeon* doi.org/10.1016/j.surge.2021.08.005

Royal College of Physicians (2021) Supporting people who have eating and drinking difficulties. A guide to practical care and clinical assistance, particularly towards the end of life. Report of a working party. London: RCP

Ryan, A.M., Prado, C.M., Sullivan, E.S., Power, D.G. and Daly, L.E. (2019) Effects of weight loss and sarcopenia on response to chemotherapy, quality of life and survival. *Nutrition* 67-68:110539. doi: 10.1016/j.nut.2019.06.202.

Sandrucci, S., Beets, G., Braga, M., Dejong, K. and Demartines, N., 2018. Perioperative nutrition and enhanced recovery after surgery in gastrointestinal cancer patients. A position paper by the ESSO task force in collaboration with the ERAS society (ERAS coalition). *European Journal of Surgical Oncology*, 44(4), pp.509-514.

Shaw, C. (2011) Nutrition and palliative care. *Nutrition and cancer*, pp.173-187.

Shaw, C. (2021) Nutrition Care Process Model Approach to Surgical Prehabilitation in Oncology. *Front Nutr* 8:644-706 doi: 10.3389/fnut.2021.644706

Sullivan, E.S., Rice, N., Kingston, E., Kelly, A., Reynolds, J., Power, D. and Ryan, A., (2021) A national survey of oncology survivors examining nutrition attitudes, problems and behaviours, and access to dietetic care throughout the cancer journey. *Clinical Nutrition ESPEN* 41, 331-339. doi: 10.1016/j.clnesp.2020.10.023

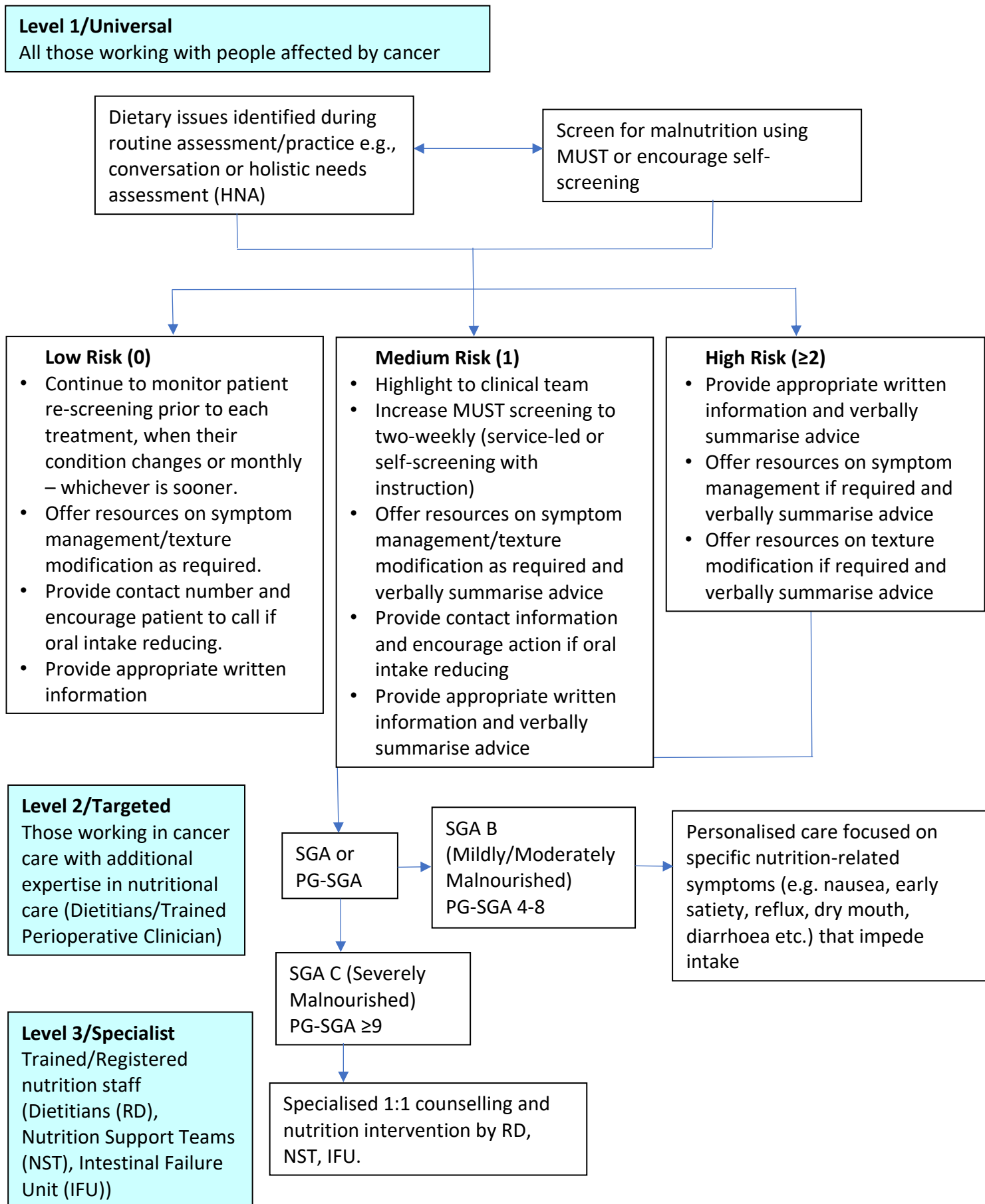
World Cancer Research Fund (2018) Cancer survivors: evidence on survivors of breast and other cancers. <https://www.wcrf.org/dietandcancer/cancer-survivors>

World Cancer Research Fund/American Institute for Cancer Research (2018) Diet, nutrition, physical activity and cancer: a global perspective. Continuous update project expert report Available at: <https://www.wcrf.org/wp-content/uploads/2021/02/Summary-of-Third-Expert-Report-2018.pdf>

West, A., Wischmeyer, P.E. and Grocott, M.P.W. (2017) Prehabilitation and Nutritional Support to Improve Perioperative Outcomes. *Curr Anesthesiol Rep* 7:340-349 doi: 10.1007/s40130-017-0245-2

Weimann, A., Braga, M., Carli, F., Higashiguchi, T., Hübner, M., Klek, S., Laviano, A., Ljungqvist, O., Lobo, D.N., Martindale, R.G. and Waitzberg, D. (2021) ESPEN practical guideline: Clinical nutrition in surgery. *Clinical Nutrition*, 40(7), pp.4745-4761.

# Appendix 1: Nutrition Referral Pathway



## Appendix 2: Nutrition in Palliative and End of Life Care

Weight loss and loss of appetite are some of the most common symptoms experienced by those with advanced cancer, with studies suggesting at least 60% of patients rank anorexia as one of their five most challenging symptoms (Shaw, 2011). However, decisions about nutrition and hydration and when to start, continue or stop treatment can be some of the most challenging in medical practice (RCP, 2021).

Dysphagia is a well-known symptom in cancer and affects 23% of patients with advanced disease, possibly affecting up to 46% of patients at the end of life (Shaw, 2011). It is often well recognised in patients with head and neck cancer but may also occur in other diagnoses such as lung, breast and gastrointestinal cancer which may make the identification and assessment of such patients less likely. Practical strategies used by speech and language therapists can be used to minimise aspiration risk, facilitate eating and drinking, and improve dietary intake. Advice may include texture modification, swallowing manoeuvres, positioning, and postural strategies, carer support for those who are helping the patient to eat and drink, and may also include behavioural and cognitive techniques (Shaw, 2011). When someone is unable to swallow safely alternative feeding routes would usually be considered, however individual choice and prognosis will influence decisions, and risk may need to be managed. Further guidance on the complex decision-making process that support adults to eat and drink in the presence of risk is available in the Royal College of Speech and Language Therapists' [‘Eating and Drinking with acknowledged risks: Multidisciplinary team guidance for the shared decision-making process \(adults\)’](#) (2021)

Medications intended to relieve symptoms have the potential to either positively or negatively impact on oral intake for example, opioid analgesia reducing pain but causing constipation. As such it is important for nutrition and medicines management to remain a core consideration of the multi-disciplinary team throughout palliative and end of life care, and a pro-active approach should be taken.

Weight loss and nutritional problems can also have a profound psychological effect on people with advanced cancer. Studies exploring the experience of weight loss in this group highlight how weight loss triggers ideas and beliefs about death, physical and emotional weakness, and can be seen to symbolise cancer taking control and inevitability (Hopkinson, Wright & Corner, 2006; Shaw, 2011). Thus, when weight loss is not raised, acknowledged or discussed by family and health and care professionals in particular, it can exacerbate these negative beliefs and feelings whilst creating a ‘weight loss taboo’ with damaging effect (Hopkinson, Wright & Corner, 2006).

ESPEN guidelines (2021) recommend that those with advanced cancer are repeatedly screened for risk of malnutrition, weight loss and low BMI, and that those found to be at risk are appropriately managed. This is important since individuals with advanced cancer may have a life expectancy of several months to several years, and any deficits in nutritional status may impair performance status, quality of life, tolerance to anticancer treatments, and survival. When an individual has a shorter expected survival, alleviating nutrition impact symptoms may relieve/minimise disease burden (ESPEN, 2021) and positively impact relationships with supporters if nutritional intake has become a focus of care. However, prognosis, expected benefit on quality of life, potential survival, and burden associated with nutritional care should be considered with the individual concerned (and their supporter(s) if appropriate) before any nutritional interventions are offered or implemented (ESPEN, 2021). If expected survival is several months or years, nutrition therapy should aim to achieve an adequate intake of energy

and protein, to diminish metabolic disturbances, and to maintain an adequate performance status and quality of life. If expected survival is in the range of a few to several weeks, interventions should be non-invasive and primarily aimed at psychosocial support. In end-of-life care, treatment should be based on comfort (ESPEN, 2021). However, supporters of the individual with cancer may seek medical nutrition or hydration. It is essential therefore that the goal of comfort is explained, the pros and cons of continued nutritional treatment communicated, and expectations of care appropriately managed. Further information about this issue and the legal and ethical framework to guide decisions about giving and withholding treatment can be found in the Royal College of Physicians' [‘Supporting people who have eating and drinking difficulties’](#) (2021).

## Appendix 3: Education and Training Grid

You must be signed in to [Turas](#) to access the links below.

**Please note** Turas is open to NHS and non-NHS staff – if you do not have an account you can request one via the Turas helpdesk.

Training associated with lower levels of interventions are still relevant across higher levels.

Core competencies	Interventions	Expected level of training
<p><b>‘Universal’ - for all those working in cancer care (registered and unregistered staff)</b></p>		
<ul style="list-style-type: none"> <li>• Treat those diagnosed with cancer and their carers with kindness, dignity and respect</li> <li>• Ability to communicate honestly and compassionately</li> <li>• Ability to undertake accurate nutrition screening</li> <li>• Ability to offer general support through knowledge and understanding of first line dietary advice (e.g. evidence based healthy eating advice or food first advice for those at risk of malnutrition)</li> <li>• Knowledge of when and how to refer on to senior colleagues or appropriate services/agencies</li> <li>• Knowledge of the range of nutrition/dietetic support services available</li> </ul>	<ul style="list-style-type: none"> <li>• Nutrition screening</li> <li>• Effective information giving to provide evidence based supportive self-care nutrition and hydration guidance</li> <li>• Signposting/referral to local nutrition and dietetic services/agencies</li> </ul>	<p><a href="#">BAPEN ‘Nutritional Screening using MUST’ e-learning modules</a> OR <a href="#">Eat Well Age Well ‘Raising the Issue of Malnutrition’ training</a></p> <p><a href="#">TURAS Learn ‘Health literacy’ e-learning</a></p> <p><a href="#">Prehabilitation, Rehabilitation and Personalised Care (PROsPer)e-learning</a></p> <p><a href="#">Challenging Weight Stigma Hub</a></p> <p><b>Additional training (where specific requirement of role)</b></p> <p><a href="#">NES Health Care Support Worker learning framework and resources to support each pillar of practice</a></p> <p><a href="#">Macmillan ‘for your role’ training resources</a></p> <p><a href="#">Scottish Social Service Council (SSSC) learning zone resources</a></p> <p><a href="#">MAP Health behaviour change (includes foundation level e-learning plus wider training offer)</a></p>



Core competencies	Interventions	Expected level of training
<p><b>‘Targeted’ - for all those working in cancer care with additional expertise in nutritional care (e.g., Dietitians and trained perioperative clinicians)</b></p>		
<ul style="list-style-type: none"> <li>• Knowledge and/or experience in managing nutrition related issues commonly experienced by people with cancer/palliative care needs</li> <li>• Knowledge and competency in the appropriate use and interpretation of assessment tools</li> <li>• Knowledge and understanding of nutrition support options</li> <li>• Ability to use a range of skills and strategies to communicate difficult matters, promote health and well-being; health literacy and empower patients to share decision making</li> <li>• Ability to offer</li> </ul>	<ul style="list-style-type: none"> <li>• Undertake nutritional assessment and risk stratification based on the person’s history and assessment tools</li> <li>• Provide safe, evidence-based and realistic person-centered counselling to support an appropriate nutrition/hydration intake/the management of nutrition impact symptoms</li> <li>• Where appropriate provide advice on co-existing conditions and use of supplementation</li> <li>• Signpost/refer onto other professional services/agencies when deemed appropriate</li> <li>• Deliver suitable and supportive weight management services that are free from stigma and bias</li> </ul>	<p>Appropriate professional qualification and registration</p> <p>CPD in line with professional/ regulatory body post registration frameworks and national competency frameworks (where these exist)</p> <p><b>Additional training (where specific requirement of role)</b></p>

<p>appropriate problem-solving techniques to enhance patients' and carers' capacity to cope and meet their own nutritional needs</p> <ul style="list-style-type: none"> <li>• Knowledge and understanding of professional guidelines/ local and national healthcare policies to ensure the promotion and implementation of safe, effective and quality focused service delivery</li> <li>• Ability to promote high quality nutritional care by proactively collaborating with other members of the multidisciplinary team</li> <li>• Recognition of boundaries of own professional responsibility and competence and to refer on as appropriate</li> </ul>		
<b>Core competencies</b>	<b>Interventions</b>	<b>Expected level of training</b>
<b>'Specialist' - for trained and accredited staff (e.g., Dietitians, Nutrition Support Teams, Intestinal Failure Units)</b>		

<ul style="list-style-type: none"> <li>• Specialist knowledge and experience of assessing and using creative and innovative solutions to address complex nutrition problems</li> <li>• Ability to autonomously undertake a comprehensive nutrition assessment considering all relevant medical, social, familial and cultural factors</li> <li>• Ability to use skills of critical analysis and evaluation to make justifiable and timely clinical judgements utilising appropriate and sometimes limited information from a wide range of sources to assess, diagnose, plan, implement or direct complex care/interventions and evaluate effectiveness</li> <li>• In depth knowledge and critical understanding of the evidence-based rationale for the use of targeted nutrition interventions</li> <li>• Ability to use a range of skills and strategies to communicate difficult matters, promote health and well-being; health literacy and empower patients and carers to share decision making</li> <li>• Ability to promote high quality</li> </ul>	<ul style="list-style-type: none"> <li>• Holistic assessment of complex nutritional problems</li> <li>• Specialist nutrition interventions for managing complex nutritional problems</li> </ul>	<p>Appropriate professional qualification and registration</p> <p>CPD in line with professional/regulatory body post registration frameworks and national competency frameworks (where these exist)</p> <p><b>Additional training (where specific requirement of role)</b></p>
---	---	--

<p>nutritional care by proactively collaborating with other members of the multidisciplinary team and providing consultations for other healthcare professionals</p> <ul style="list-style-type: none"> <li>• Ability to apply knowledge and understanding of professional guidelines/ local and national healthcare policies to ensure the promotion and implementation of safe, effective, and quality focused service delivery</li> <li>• Ability to act as a specialist resource to local cancer and palliative care services by providing expertise in nutrition and supporting education, supervision, and research</li> <li>• Ability to work and liaise at an organisational and strategic level to lead and implement the provision of safe, effective, and high quality nutritional care</li> </ul>		
---	--	--

## Appendix 4: Resources

The following list includes a selection of resources, which may be helpful for both those affected by cancer and those working to support others affected by cancer, to identify and manage nutrition needs. It is not a comprehensive list of all resources available.

### Screening

[BAPEN: The MUST Toolkit](#)

### Assessment

[Scored Patient Generated Subjective Global Assessment PG-SGA](#)

[Subjective Global Assessment \(SGA\)](#)

### Management

[Food First Approach](#)

[Macmillan Healthy Eating and Cancer Resources](#) (Exemplar written information as per MUST Screening and Management – Pg. 10 (Low risk))

[Macmillan Eating Problem resources](#) (Exemplar written information as per MUST Screening and Management – Pg. 10 (Medium to High Risk))

[Macmillan Building-up Diet resources](#) (Exemplar written information as per MUST Screening and Management – Pg. 10 (Medium to High Risk))

### Additional Resources for People Affect by Cancer

[BAPEN: MUST Self-Screening Tool](#)

[Prehabilitation for Scotland – Small changes make a big difference \(nhs.scot\)](#)

[Scotland's Service Directory](#)

[Care Opinion – Tell your story / share your experience of a health and care service in Scotland](#)

## Appendix 5: Case Studies

### 1. Karina

Karina is a 54-year-old mother of three teenage children and her mother and father live close by.

#### Universal level– All those working in cancer care

Karina has been experiencing unexplained back pain for several weeks and has noticed a change in bowel habit more recently. Because of this, Karina has not been eating as much as normal but only noticed how much weight she'd lost when putting on a pair of trousers not worn for a while. She goes to her GP.

Assessment	Intervention
GP consultation and screened for risk of malnutrition using Malnutrition Universal Screening Tool (MUST)	Urgent suspicion on cancer referral. First line written information provided on how to increase energy and protein intake to prevent further weight loss and urgent referral to local community Nutrition and Dietetic Service.

#### Targeted level– All those working in cancer care with additional expertise in nutritional care

Karina is diagnosed with pancreatic cancer. Soon after diagnosis, Karina and the Clinical Nurse Specialist (CNS) discuss the immediate impact of the diagnosis and the impact on family and day-to-day life. Karina remains concerned about the amount of weight already lost and managing treatment whilst looking after family. The CNS talks to Karina about local support including from cancer charities and liaises with Karina's dietitian.

Assessment	Intervention
Patient-generated subjective global assessment (PG-SGA) HNA/Concerns checklist and care plan	Review and reinforcement of first line nutrition advice provided by GP and process agreed to monitor weight weekly. Instigation of pancreatic enzyme replacement therapy (PERT) with written information provided.

### Specialist level – Trained and accredited nutrition staff

Karina had agreed to have surgery followed by chemotherapy. Weight has stabilised somewhat but remains low. Bowel problems continue with intermittent diarrhoea and bloating.

Assessment	Intervention
Full nutrition assessment	Reviewed PERT including when and how much is taken and protein pump inhibitors considered. Initiation of oral nutritional supplements and discussed pre- and post-operative nutrition. Plan for monitoring and review agreed.

### 2. James

James is 67 years old, married and a parent to two grown-up children. James retired a year ago and recently presented to their GP with a persistent cough, shortness of breath and unexplained weight loss. James was subsequently diagnosed with lung cancer. James and their partner look after their grandchild 3-day per week. James also plays golf and enjoys walking, cycling, and going out for meals with friends and family.

### Universal level – All those working in cancer care

James meets with the CNS and together they discuss the immediate impact of the cancer diagnosis on family and day-to-day life. James is concerned about being able to support their partner with the supervision of the grandchildren due to impending treatment. They also worry about the lack of energy and recent weight loss.

Assessment	Intervention
MUST screen and discussion about dietary problems identified i.e., reduced appetite coinciding with breathlessness, coughing and fatigue.	<p>The CNS and James talk about concerns and discuss what to expect going forward and support available.</p> <p>The CNS and James agree to a referral to Improving the Cancer Journey (ICJ) service for assessment and care planning of his holistic needs. James also agrees that they will go with their partner to the Maggie's prehab workshop and is signposted to the national prehab for Scotland website and is assessed by the physiotherapist with the aim of managing breathlessness and building strength.</p> <p>First line written information on eating problems is provided to James and in line with MUST management plan. James agrees to monitor their weight at least two weekly and to contact CNS if problems including weight loss persist.</p>

**Targeted level – All those working in cancer care with additional expertise in nutritional care**

James’s breathlessness and fatigue continues to impact appetite. Treatment further exacerbates the problem and James is finding it difficult to maintain/increase physical activity as per their prehabilitation plan.

Assessment	Intervention
Nutrition assessment with PG-SGA	<p>Current food intake is discussed, and food fortification information re-enforced in response to opportunities identified via diet history. Small, frequent meals and examples of high-protein nutritious snacks discussed in the context of prehabilitation plan to aid understanding and allow self-management. Medical management of symptoms including medication review carried out by CNS and physiotherapy interventions continue.</p> <p>Weekly weight monitoring agreed.</p>

**Specialist level – Trained and accredited nutrition staff**

James starts oxygen treatment, and the increasing tiredness caused them to miss meals. James’ energy levels have become low, and they are not able to spend so much time with family. Their weight continues to decrease.

Assessment	Intervention
Full nutrition assessment	<p>One to one consultation with specialist dietitian. Symptom management discussed and nutrition-related goals and care plan agreed. Partner present as per James’ request. Nutritional supplements prescribed to meet estimated nutritional requirements with current dietary habits and preferences guiding selection and timing of recommended intake.</p> <p>Monitoring and evaluation plan agreed and written care plan with additional written hints and tips provided to support James and their partner.</p>



### 3. Stuart

Stuart is 54 years-old, married and a farmer. He was diagnosed with tongue cancer following a period of facial pain, difficulty swallowing and weight loss. His plan for treatment includes 6 weeks of adjuvant chemoradiotherapy.

#### **Universal level – All those working in cancer care**

Stuart has an appointment with the CNS, dietitian and speech and language therapist soon after his diagnosis.

<b>Assessment</b>	<b>Intervention</b>
HNA/Concerns checklist and care plan	Provision of information on support available via ICJ and third sector including prehabilitation website and workshop.
MUST screen and basic assessment of nutrition intake	Provision of first-line written information on eating problems and cancer and swallowing. Discussion about likely impact of treatment on future intake and starter pack of nutritional supplements arranged.
	Follow-up appointment with dietitian and speech and language therapist arranged for full assessment and care planning.

#### **Targeted level – All those working in cancer care with additional expertise in nutritional care**

Stuart is becoming increasingly concerned about the running of the farm while having treatment. He is finding eating very difficult, especially when away from the house and is missing out meals, often just having hot drinks. His wife is equally concerned and trying to prepare foods that are easy to eat in an attempt to support him.

<b>Assessment</b>	<b>Intervention</b>
Full nutrition assessment	Range of speech and swallowing exercises explained and demonstrated to proactively manage swallow and speech. Advised to modify diet texture as per IDDSI framework (2019) to aid safe swallowing and promote nutritional intake. Thickener prescribed and written information to support use provided.
Speech and swallow assessment	Dietary intake reviewed and concerns of Stuart and his wife discussed. Discussed preferences re. trial of nutritional supplements and appropriate prescription provided. Food fortification advice emphasised with focus on appropriate textures as per IDDSI framework (2019) and suggestions re. snacks that can be eaten whilst working outside put forward.
	Discussed and re-enforced advice regarding mouth wash and mouth care, secretions, and pain

	management, as per the instruction of Stuart's clinical team.
--	---

### Specialist level – Trained and accredited nutrition staff

Weight loss continues and patient not taking adequate fluids. Complaining of choking on foods and poor intake. Wife upset by decreased intake and weight loss despite attempts to prepare and provide high energy texture modified foods at regular intervals.

Assessment	Intervention
Nutrition review using anthropometry, biochemistry and diet history  Review of swallowing  Review of pain and HNA with Concerns checklist	One-to-one review with CNS, specialist dietitian and specialist speech and language therapist.  Agreed to commence nasogastric feeding. Timing of feeding planned to maximise oral intake and to allow Stuart to continue to work as per his goals. Stuart encouraged to continue to eat and drink texture-modified foods and fluids as per IDDSI Framework (2019).  Community dietetic team notified re. commencement of home enteral feeding and arrangements made to support Stuart and his wife at home. Plan for monitoring and review agreed.  Concerns of Stuart's wife discussed, and reassurance given. Sources of support also discussed, and both identify third sector services that they plan to engage with, including complementary therapies and peer support.

#### 4. Jo

Jo lives alone and was diagnosed with breast cancer after presenting to the GP with pain in the left breast. Jo had a mastectomy and is currently undergoing chemotherapy. Prior to treatment Jo had a busy working and social life, with lots of family and friends close by that she would spend time with on evenings and over weekends.

### Universal level – All those working in cancer care

Jo is shocked by her diagnosis and has found it difficult to manage the reaction of work colleagues, family, and friends. However, she feels well supported and flexible working arrangements have been agreed that allow her to continue working which is her preference.

Assessment	Intervention
HNA with Concerns checklist	Supportive discussion with CNS and ICJ staff. Low risk of malnutrition. Written information about breast cancer

MUST screening	and its treatment provided alongside eating well information (Macmillan Healthy Eating and Cancer Booklet). Jo is encouraged to aim to maintain her weight with a focus on eating a balanced diet as per Eat Well Guide (PHE, 2018), limiting/avoiding alcohol and keeping active to maintain/build muscle mass.
----------------	--

**Targeted level – All those working in cancer care with additional expertise in nutritional care**

After being told about links between diet and cancer by a fellow patient, Jo raises a number of questions about particular foods. She is experiencing taste changes, brain fog and is struggling with both her body image and fatigue following treatment. She has gained a small amount of weight but feels she is eating less and is physically weaker.

Assessment	Intervention
Holistic assessment as part of initial assessment for group rehabilitation programme including weight, height, BMI, 6-minute walk, Scot-PAQ, PHQ-4	Facilitated dietitian-led group discussion about common dietary myths and signposting towards reputable sources of information and support. Importance of balanced eating discussed as a group with a focus on protein, energy and fluid requirements during exercise and treatment for cancer.  Weekly group exercise class with individualised programme for remainder of week provided.

**Specialist level – Trained and accredited nutrition staff**

Four years after finishing treatment for breast cancer Jo is diagnosed with secondary breast cancer. She is treated with chemotherapy, targeted therapies, and steroids. She is still coming to terms with her diagnosis. It is very important to her that she can manage her diet and remains physically active.

Assessment	Intervention
HNA with Concerns checklist  Full nutrition assessment	Acute side-effects of treatment mean Jo is struggling to meet her nutritional requirements. The dietitian listens to Jo's concerns about particular foods, and they discuss dietary preferences, nutritional requirements and supplements Jo has read about online. An individualised plan is drawn-up that is co-created with Jo and should meet her estimated nutritional requirements. Monitoring and review is agreed.

## Appendix 6: Prehabilitation Nutrition Framework Working Group Membership

Debbie Provan	Clinical Advisor, Scottish Government (Chairperson)
Joanne Adamson	Partnership Manager - North of Scotland, Macmillan Cancer Support
Alison Alan	Centre Head – Fife, Maggie’s
Sandra Bagnall	Improving the Cancer Journey (Lothian) Macmillan Programme Manager (Improving the Cancer Journey Representative)
Fraser Breed	Macmillan Project Dietitian, NHS Borders
Christine Brown	Acute Clinical Lead Dietetics, NHS Lanarkshire
Seona Carnegie	Policy Manager, Scottish Government
Julia Clark	Registered Dietitian, CLAN Cancer Support (Scottish Cancer Coalition Representative)
Lucy Eldridge	Head of Nutrition & Dietetics, The Royal Marsden NHS Foundation Trust (BDA Oncology Specialist Group Representative)
Carole-Anne Fleming	Dietetic Clinical Team Lead - Oncology, NHS GGC/BWoSCC (Head and Neck Cancer Managed Clinical Network (WoSCAN) Representative)
Fiona Huffer	Chief AHP West Lothian Health and Social Care Partnership
Rachel Reel	Team Leader, Scottish Government
Jayne Ritchie	Colorectal ERAS Nurse Specialist, NHS Fife, (Scottish Cancer Nurses/Cancer Nurse Consultants Group Representative)
Clare Shaw	BRC lead for NIHR Cancer and Nutrition collaboration and Consultant Dietitian and Lead for Therapy Research, Royal Marsden NHS Foundation Trust (BDA Oncology Group Specialist Group Representative)
Fiona Struthers	Acute Dietetics Coordinator, NHS Forth Valley (Scottish Dietetic Leadership Network Representative)
Helen Webster	Oncology Lead for Nutrition and Dietetics, NHS Tayside
Sara Smith	Acting Head of Speech & Hearing Sciences, Queen Margaret University

### Guest Contributors:

Katie Cunningham	Specialist Nutritional Support Dietitian, NHS Fife (Head and Neck Cancer Managed Clinical Network (SCAN) Representative)
Leigh Hamilton	Contribution to Framework made whilst in previous role <i>i.e.</i> , <i>Specialist Dietitian Oncology, NHS GGC/BWoSCC</i> <i>(Upper GI Cancer Managed Clinical Network (WoSCAN) Representative)</i>
Kerrie McGough	Specialist Nutritional Support Dietitian, NHS Fife