



European Cancer  
Patient Coalition

*Living well  
during*

# **CANCER TREATMENT**

**ECPC Nutrition Booklet**

Addressing cancer patients concerns  
Series I out of II



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The Nutrition Consultation Document: addressing cancer patients' concerns is based on the **ESPEN guidelines** on nutrition in cancer patients and the **ESMO Handbook of Nutrition and Cancer. The Document addresses common questions patients might have about diet, nutrition, and physical activity during treatment and provides general information regarding nutrition and cancer.** For comments and /or inquiries please email Head of Health and Research Programmes, MPH, BPharm: [info@ecpc.org](mailto:info@ecpc.org)

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Europa Uomo



Fight Bladder Cancer



Hellenic Cancer Federation- ELL.O.K.



HungerNdThirst



Sláinte an Chláir, Clare Cancer Support



Les Amis de l'Institut Bordet



Federazione Italiana delle Associazioni di Volontariato in Oncologia

Italian Federation of Volunteer-based Cancer Organizations (FAVO)

# Introduction

*Nutrition is a crucial component of cancer treatment and rehabilitation as it helps patients better cope with illness. However, given the focus on the cancer and its cure, nutrition is often neglected, leaving patients and their families with doubts, questions and the need for practical guidance on how to eat better on a daily basis, especially during therapy.*

In 2015, the European Cancer Patient Coalition (ECPC) sent out an extensive survey on nutrition and its importance on the treatment and life of cancer patients. The results were presented during the ECPC Annual Meeting 2015 in Brussels. The preliminary data obtained from the survey suggested that discrepancies still existed between patients' expectations and the answers they may get from physicians about the metabolic and nutritional issues in cancer.

Building up on the pilot survey, in 2016 the ECPC continued its efforts with a second round of the survey in order to have enough data and maximize the impact of the answers received. The new version was adapted in order to directly address individual cancer patients and cancer survivors. It aimed to describe and understand the perception of the importance of metabolic and nutritional problems among patients and cancer survivors. The study was conducted by a survey of cancer patients and survivors. A total 907 patients and survivors, distributed in 10 European countries (Finland, Italy, Spain, Czech Republic, Greece, Denmark, Slovenia, Romania, Poland, Bulgaria) answered the questionnaire. Patients were aware that weight loss related to their condition was negatively impacting on their therapy management, quality of life and social aspects. While not aware about cachexia and its implications, they were willing to receive more information about how to manage this issue.

They were also not aware about artificial nutrition options, nor potential negative impacts of vitamins and antioxidants on their therapy. Furthermore, they reported that their physicians were generally not focused on nutrition. Respondents reported that their physicians were not regularly checking for weight loss, providing information about weight loss management or appetite improvement, or referring patients to a nutritionist.

The study showed a substantial gap in terms of need for information and practical management of cancer-related nutritional problems for people with cancer.



European Cancer  
Patient Coalition



SAPIENZA  
UNIVERSITÀ DI ROMA

# European Survey

*European survey of 907 people with cancer about the importance of nutrition*

M. Muscaritoli<sup>1</sup>, A. Molino<sup>1</sup>, F. Scala<sup>2</sup>, K. Christoforidi<sup>3</sup>, I. Mannek-Vangramberen<sup>3</sup>, F. De Lorenzo<sup>3</sup> | Sapienza University of Rome, Rome, IT<sup>1</sup> | Strategy, Healthcare International, Salerno, IT<sup>2</sup> | European Cancer Patient Coalition, Brussels, BE<sup>3</sup>

## Background

Nutritional and metabolic disorders are highly prevalent among cancer patients. We aimed to analyse the dimension of nutritional alterations **among cancer patients and survivors** in Europe by using a structured questionnaire encompassing the perspectives of patients and their physicians on nutritional issues.

## Methods

A structured questionnaire was designed to analyse the importance of nutrition for people with cancer. The questionnaire was subdivided in specific areas of interest, such as the presence of feeding problems, perception of nutrition importance, role of food supplements, and their view of their physician's approach to nutrition. All cancer patients and survivors were eligible to answer the questionnaire, except for people diagnosed with **brain and breast cancer**.

ECPC ensured the dissemination of questionnaire to its Members in **10 countries** who translated and disseminated the questionnaire including: **Italy, Czech Republic, Greece, Spain, Romania, Poland, Bulgaria, Slovenia, Denmark, and Finland**. ECPC Members **also ensured sufficient participation of target audience**.

SurveyMonkey® online platform was used to circulate the questionnaires from ECPC to its affiliates. On their turn, the affiliates used individual methods to submit the questions to their national audiences. In particular, personal interviews during treatments, Facebook protected pages, paper and online mailing, Whatsapp® and phone calls were variously used, in relation to specific channel affinity of national audiences and local privacy regulations.

In all communications from ECPC to its affiliates, it was specified that all types of cancer patients or survivors were eligible to answer the questionnaire, except for brain and breast cancer.

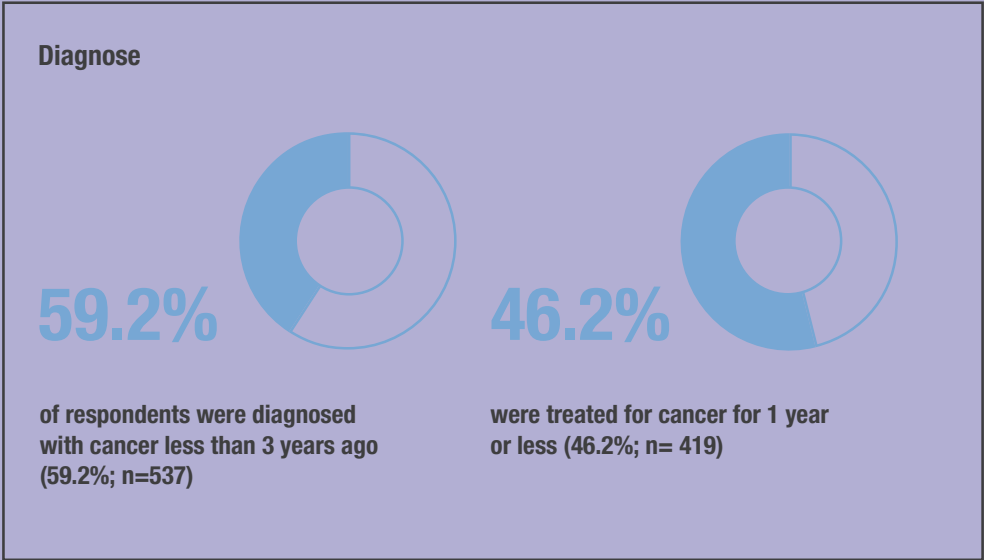
Abstract 3714

European survey of 907 people with cancer about the importance of nutrition

European Society of Medical Oncology (ESMO) 2017 Congress

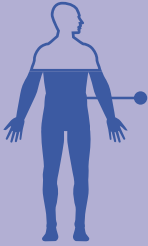
Category: Public health

Authors: M. Muscaritoli<sup>1</sup>, A. Molfino<sup>1</sup>, F. Scala<sup>2</sup>, K. Christoforidi<sup>3</sup>, I. Manneh-Vangramberen<sup>3</sup>, F. De Lorenzo<sup>3</sup>, <sup>1</sup>Sapienza University of Rome, Roma, IT, <sup>2</sup>Strategy, Healthware International, Salerno, IT, European Cancer Patient Coalition (ECPC), Brussels, BE<sup>3</sup>.



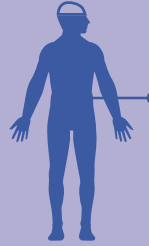


## “cachexia”



**72.9%**

of the respondents didn't know the meaning of the term “cachexia” (72.9%; n=603)



**92.4%**

did not receive any information about cachexia from their health professionals (92.4%; n=764)

## Activity



**82.4%**

of respondents (n=689) believed it was important to maintain physical activity during cancer treatment

**53.8%**

although only 53.8% (n=450) of the respondents reported that their physicians advised them to do so

## Lost weight



**36.7%**

of respondents reported that their weight loss was moderate to severe (36.7%; n=309)



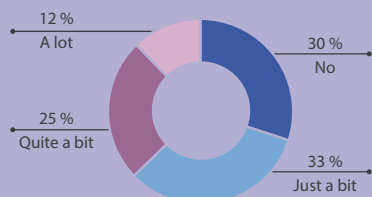
**67.7%**

of respondents reported that they lost weight after the cancer diagnosis (69.7%; n=586)

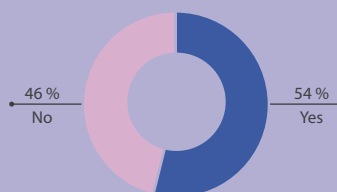
## Results

907 cancer patients and survivors replied. The majority of the sample (59,2%; n=537) was affected by cancer since less than 3 years, and treated from less than 1 year (46,2%; n=419).

Did you lose weight during the illness?



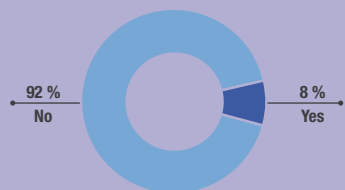
Did you know that losing weight can worsen the adverse effects of therapy?



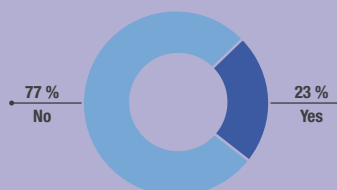
**Weight loss and cachexia:** 69.7% (n=586) of respondents reported that they lost weight after the cancer diagnosis, and for 36.7% (n=309) this loss was moderate to severe. More than half of physicians (54,3%; n=457) did pay attention to weight loss, but 2/3 (62,7%; n=520) did not provide any advice to improve appetite. 72.9% (n=603) of the respondents didn't know the meaning of the term "cachexia", and 92.4% (n=764) did not receive any information about cachexia from their health professionals. Almost 2/3 of the patients (69,4%; n=574) knew that persistent loss of appetite could be caused by the tumour.

**Feeding problems:** More than 70% of the participants experienced feeding problems during the disease and/or therapy and all the responders declared to be aware about feeding importance. More than 80% of the responders believed that their feeding problems were linked to illness or therapy and that avoiding weight loss during therapy was important.

Did your physician / oncologist give you or your relatives any information about cachexia?



Did your physician / oncologist refer you to a nutrition specialist?



Presented at the European Society for Medical Oncology Conference in Madrid, September 2017

Despite this, almost 30% of the sample had no information on nutritional support, including artificial nutrition. The majority of physicians (53,9%; n=467) did not check the nutritional status of their patients, including their body weight, or did not refer patients with feeding problems to a nutrition specialist (76,7%; n=462).

**Supplements:** About a half of the patients (56,9%; n=472) know nothing about the potential negative effects on therapy of taking vitamins or antioxidants, or were informed about the need to make the therapist aware if they do so (43,6%; n=362).

**Physical activity:** 82.4% of respondents (n=689) believed it was important to maintain physical activity during cancer treatment, although only 53.8% (n=450) of the respondents reported their physicians advised them to do so.

## Conclusions

Most people with cancer surveyed reported that they would like to receive more information about how to improve their nutrition during and after treatment. There is a need to empower individual patients and patient associations by producing more information on cancer patients' nutritional needs. Such information material should be produced by patients in close collaboration with medical oncologists and other healthcare professionals.

This survey demonstrates that medical oncologists are not giving the appropriate importance to nutrition and physical activity when interacting with cancer patients.

## Acknowledgements

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# Living well

*Nutrition is the process of food intake in relation to the body's dietary needs: growth, replacement of tissue, and maintenance of body well-being. It is, thus, an essential part of cancer treatment.*

Eating the right kinds of food can help you feel better and maintain your strength, whereas poor nutrition can lead to reduced immunity, increased susceptibility to disease, impaired physical and mental development, and reduced productivity.<sup>23</sup>

Living healthy during cancer treatments is a combination of good nutrition, which consists of an adequate and well balanced diet, regular physical activity and limiting time spent sitting as much as possible.<sup>24 25</sup> However, the nutrient needs of each individual may vary. Consulting with your cancer care team can help you identify your nutrition goals.

To this day, there are still many uncertainties in relation to nutrition in the world of cancer, from when to best provide nutritional support to how to best monitor patients who are receiving it.

Patients are advised to try and maintain a healthy life style as it is an important step in reducing risk of cancer recurrence, second primary cancers, limiting alcohol and tobacco intake, and improving physical<sup>24</sup> and emotional health.

Regular exercise is a cornerstone of healthy living and overall weight management: reducing anxiety, fatigue, stress, as well as decreasing the risk of heart disease, diabetes, and high blood pressure.

The ESMO-ECPC Survivorship Guide also highlights the importance of coping with stress and its correlation to improving patients' quality of life.

## Healthy Lifestyles - Stress management

### Ways to reduce stress

  
Seek support from friends and family

  
Engage in relaxation

  
Exercise

  
Do yoga

  
Eat right

  
Mediate

  
Have a hobby you enjoy

  
Take time off from the usual

  
Keep wake/sleep times consistent

European Society for Medical Oncology (ESMO), European Cancer Patient Coalition (ECPC).  
Patient Guide on Survivorship, 2017

# Screening

*Nutritional screening can predict the probability of better or worse health outcomes. However, these outcomes may vary according to circumstances, e.g. age or type of illness. Screening should be mandatory and regularly performed as part of medical care. Try to take part in regular screening programmes.<sup>24</sup>*

## Nutritional Screening Tools

Screening tool	Method
Subjective Global Assessment (SGA)	<ul style="list-style-type: none"> <li>• Patient's history (weight loss, change in dietary intake, gastrointestinal [GI] symptoms, functional capacity)</li> <li>• Physical examination (muscles, subcutaneous fat, edema, ascites)</li> <li>• Clinicians overall subjective judgment               <ul style="list-style-type: none"> <li>• good nutritional status – A</li> <li>• moderate malnutrition – B</li> <li>• severe malnutrition – C</li> </ul> </li> </ul>
Malnutrition Universal Screening Tool (MUST)	<ul style="list-style-type: none"> <li>• BMI score</li> <li>• Unplanned weight loss during last 3-6 months</li> <li>• Acute disease effect score</li> </ul>
Nutritional Risk Screening (NRS)	<ul style="list-style-type: none"> <li>• BMI &lt; 20,5</li> <li>• Body weight loss during last 3 month</li> <li>• Low dietary intake during last week</li> <li>• Disease severity</li> </ul>

European Society of Medical Oncology (ESMO). ESMO Handbook of Nutrition and Cancer. ESMO Press. 2011

# Body mass index

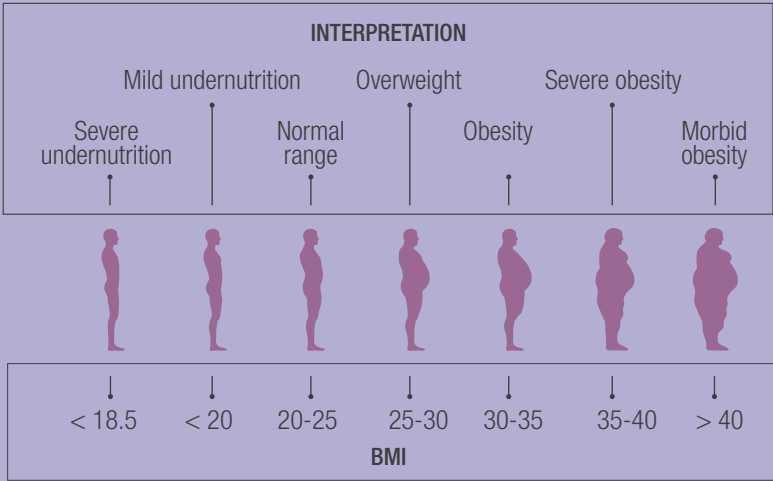
*The Body Mass Index (BMI) was developed by Adolphe Quetelet in the 19th century as a risk indicator of disease by gaging the body's overall nutritional status.<sup>3</sup>*

BMI is measured by dividing a person's weight in kilograms by the square of the person's height in meters.<sup>26</sup> Like any other measurements the BMI is not perfect because it is only dependent on height and weight, and does not take into consideration age, sex, physical activity levels or a person's health status.

Keep a BMI log to reference any weight variation over time.

## BMI and its Interpretation

$$\text{BMI} = \text{body weight (kg)} / \text{body height (m)}^2$$



European Society of Medical Oncology (ESMO). ESMO Handbook of Nutrition and Cancer. ESMO Press. 2011



BODY MASS INDEX LOG

Date			
Weight		Height	
BMI			

Date			
Weight		Height	
BMI			

Date			
Weight		Height	
BMI			

Date			
Weight		Height	
BMI			

Date			
Weight		Height	
BMI			

Date			
Weight		Height	
BMI			

Date			
Weight		Height	
BMI			

Date			
Weight		Height	
BMI			



## HSPH Nutrition Guide

*Your food plan is personalized, based on your age, sex, height, weight, health and physical activity level.<sup>27</sup>*

The Harvard School of Public Health (HSPH) Pyramid and the Healthy Eating Plate addresses flaws in both the United States Department of Agriculture (USDA) Food Guide Pyramid and USDA's My Plate.

Currently, the Healthy Eating Pyramid and the Healthy Eating Plate summarize the best dietary information available and can be used as a starting point to make the best eating choices, including:



### **vegetables and fruits**

(aim for colour and variety)



### **whole grains**

(e.g. whole wheat, barley, quinoa, oats, brown rice)



### **proteins**

(e.g. chicken, fish, beans, nuts)



### **healthy plant oils in moderation**

(e.g. olive, sunflower, corn, canola)



### **water, coffee, tea**

(limit sugary drinks)

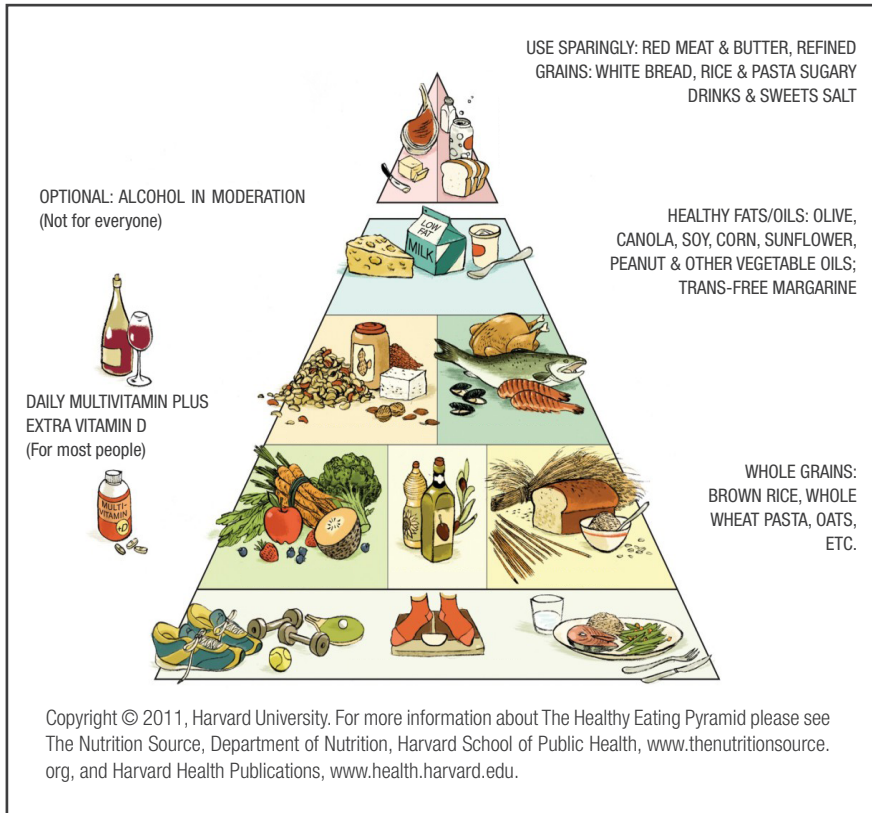


### **exercise**

(stay active)



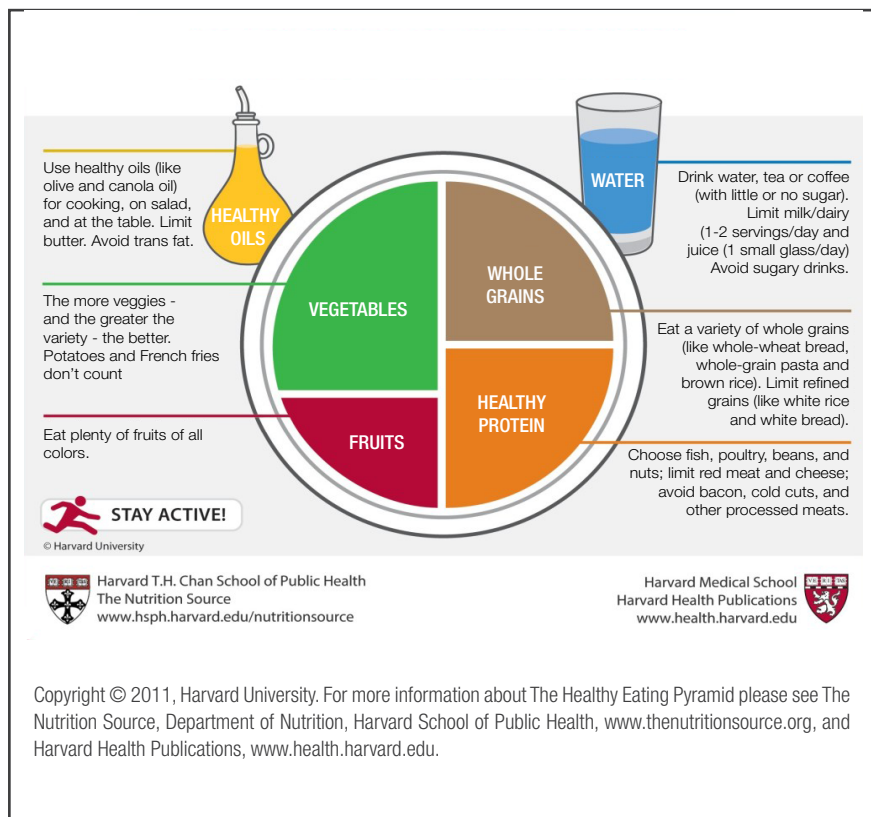
# HSPH Healthy Eating Pyramid



'The nutrient needs of each individual may vary, your cancer care team can help you identify your nutrition goals.'



## HSPH Healthy Eating Plate



'The HSPH Healthy Eating Pyramid and the HSPH Healthy Eating Plate can be used as a starting point of daily nutritional choices.'

## WCRF/AICR Recommendation

*Recommendations for cancer prevention based on the evidence for food, nutrition, and physical activity according to the World Cancer Research Fund (WCRF) and the American Institute for Cancer Research (AICR) <sup>29</sup>*

Body Fatness	Be as lean as possible without becoming underweight
Physical activity	Be physically active for at least 30 minutes every day
Plant foods	Eat more of a variety of vegetables, fruits, whole grain and pulses such as beans
Animal foods	Limit the consumption of red meats (such as beef, pork and lamb) and avoid processed meats
Alcoholic drinks	If consumed at all, limit alcoholic drinks to 2 for men and 1 for women per day
Preservation, processing, preparation	Limit the consumption of salty foods and food processed with salt (sodium)
Dietary supplements	Don't use supplements to protect against cancer
Breastfeeding	It is best for mothers to breastfeed exclusively for up to six months and then add other liquids and foods
Cancer survivors	After treatment, cancer survivors should follow the recommendations for cancer prevention

European Society of Medical Oncology (ESMO). ESMO Handbook of Nutrition and Cancer. ESMO Press. 2011



# 8 Questions to ask your Oncologist:

Questions that people  
with cancer may choose  
to ask their doctor  
after diagnosis

### *What is my current weight?*

It is important to know your current weight and compare it to your weight during and after treatment. Screening can predict the probability of better or worse health outcomes.<sup>23</sup>

### *Is it important for me to maintain my weight during treatment?*

Cancer and cancer treatment can affect the way your body tolerates certain foods and nutrients, changing your appetite and/or your eating habits.<sup>25</sup>

### *How can I improve my appetite and nutrition during treatment?*

Treatment-related side effects like nausea, pain and constipation can result in a loss of appetite. Talking about these issues with your cancer care team and discussing various solutions that would better suit your specific health status, will help you eat better and ensure your overall well-being. A decrease of food consumption should be communicated to your health professional in order for it to be properly addressed.<sup>26</sup>

### *What do you recommend I eat during treatment?*

As a cancer patient you should eat well, which means eating a variety of foods to get the nutrients your body needs to fight cancer. The nutrient needs of each individual may vary, consulting with your cancer care team can help you identify your nutrition goals.<sup>25</sup>

### *Are there any foods I should avoid?*

Your cancer type, stage and treatment needs should be taken into consideration when deciding which foods you should avoid. Try having a healthy and balanced diet, maintain a healthy weight, stay physically active, limit your alcohol intake, stop smoking and protect your skin from sun damage.<sup>24</sup>

### *What are my options if my normal daily nutritional intake is insufficient?*

In case your nutritional intake is insufficient, your doctor could prescribe you vitamins, while in more complex and severe cases enteral/parenteral nutrition intervention might be crucial.<sup>30</sup>

### *Should I be taking vitamins or antioxidants during treatment?*

Consuming large doses of vitamins or antioxidant supplements is not recommended.<sup>26</sup> Some vitamins and/or herbal supplements can interfere with your therapy. That is why you should always consult with your medical team.

### *How can I maintain my physical activity during my treatment?*

Reasonable exercise has the ability to improve anxiety, fatigue and self-esteem. It also benefits the heart, blood vessels, fitness and muscle strength.<sup>26</sup>





# Key Messages



**CANCER AND CANCER TREATMENT COULD AFFECT YOUR TASTE, SMELL, APPETITE AND / OR YOUR BODY'S ABILITY TO ABSORB NUTRIENTS**

Aim to eat several meals throughout the day: try cold foods and keep high-calorie and protein snack handy. Drink most of your liquids between meals, and talk to your cancer care team about physical activity.

**'It is essential to individualise dietary counseling and the adaptation of nutritional plans.'**



**MALNUTRITION HAS A NEGATIVE IMPACT ON ONCOLOGICAL OUTCOMES**

If an adequate oral intake from food and/or nutritional supplements can not be attained, artificial nutrition may be considered: enteral tube feeding (via a nasogastric tube), or parenteral feeding (through veins).<sup>26</sup>

**'Patient-reported weight loss is critical in assessing cancer related malnutrition.'**<sup>23</sup>



**SOME VITAMINS AND/OR HERBAL SUPPLEMENTS CAN INTERFERE WITH YOUR THERAPY**

Interactions with chemotherapy are difficult to assess, a 2004 study by McCune<sup>28</sup> et al reported a frequency of 78% for the use of herbal supplement and vitamins in patients receiving chemotherapy with a 27% risk of detrimental chemotherapy-herbal and/or chemotherapy-vitamin interaction in study participants.

**'Ask your cancer care team for advice before taking any vitamins and/or herbal supplements!'**



**WHEN DIETARY MEASURES FAIL TO MEET PROTEIN-CALORIE REQUIREMENTS, ORAL NUTRITIONAL SUPPLEMENTS ARE CONSIDERED**

Ask your cancer team for reliable information on dietary supplements and check product labels for both quantity and concentration of active ingredients in each product.<sup>25</sup>

**'Oral nutrition is consistently the first method of choice for treatment.'**<sup>23</sup>



**DIFFERENT DRUGS CAN CAUSE DIFFERENT SIDE EFFECTS IN A VARIETY OF PATIENTS**

Certain types of chemotherapy have common side effects: anorexia, mouth sores, dry mouth, trouble swallowing, nausea, vomiting, diarrhea, constipation, pain, depression and anxiety.<sup>23</sup> However, individual experiences vary.

**'If you have concerns about side effects, contact your cancer care team.'**



**REQUEST REGULAR NUTRITIONAL SCREENING, DIETARY COUNSELING, AND PSYCHO-ONCOLOGICAL SUPPORT AS PART OF YOUR MEDICAL CARE**

Cancer therapy can change your senses of taste and smell. Patients often describe a metallic taste.<sup>23</sup> Try using sugar-free lemon drops, gum or mints. Serve foods cold or at room temperature.

**'Nutritional counseling and psycho-oncological is correlated with increased patient compliance.'**



# Anorexia and other changes in your eating habits are symptoms of cancer cachexia

## CANCER ANOREXIA-CACHEXIA

is a multifactorial syndrome in which altered metabolism and reduced food intake contribute to loss of muscle mass and reduction in body weight, resulting in impaired physical function, tolerance to treatments and reduced survival rates.

Fearon K, et al. Lancet Oncol 2011;12(5):489–95





{ 'Consulting your cancer care team  
early is key to sustaining treatment  
& minimizing side effects.' }

## *Call for Contribution to the Cancer Charter for appropriate and prompt Nutritional Support*

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**The Cancer Patients' Charter of Rights for appropriate and prompt Nutritional Support is a proposed bill of rights for cancer patients with regards to nutrition.**

Nutrition is a crucial component of cancer treatment and rehabilitation as it helps people to better cope with the illness. However, given the focus on the cancer and its cure, nutrition is often neglected, leaving people with cancer and their family with doubts, questions and the need for practical guidance on how to eat better daily, especially during therapy.

In response to the worrying collective results of recent European surveys, a team of experts in collaboration with ECPC are adapting the Cancer Patients' Charter of Rights for appropriate and prompt Nutritional Support.

The Charter is aligned with existing elements such as the ESMO nutrition guidelines and was drafted by the Italian Federation for Associations of the Cancer Volunteers (FAVO)<sup>31</sup>, the Italian Society for Medical Oncology, and the Society for Parenteral Nutrition.

The document firstly aims to empower cancer patients by affirming they are aware of their rights in regards to nutritional care, then at sensitizing the public opinion and the Institutions on the problem of malnutrition in oncology.

It has been formally adapted by the Italian Ministry of Health and submitted to the European Cancer Patient Coalition for subsequent revision and application at the EU level.

# Cancer Patient's Charter of Rights for Appropriate and Prompt Nutritional Support

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**The Charter aims to empower cancer patients and raise awareness to their nutritional rights while sensitising the public opinion and the European Institutions on the challenges of malnutrition in oncology.**

**Right to correct information and nutritional counseling:** every cancer patient has the right to comprehensive evidence-based clinical information on their nutritional status, possible associated consequences and available nutritional therapeutic options. People with cancer also have the right to nutritional counseling to adapt their diet to suit ensuing medical, surgical or radio-therapeutic treatment.

**Right to nutritional screening and assessment:** every cancer patient has the right to nutritional screening to reduce the risk of malnutrition, using validated tools, both at diagnosis and at regular intervals, while ensuring that the cancer type, stage and treatment are taken into account. Every cancer patient at nutritional risk has the right to prompt referral for comprehensive nutritional assessment and support from health professionals with documented skills in clinical nutrition. Nutritional assessment must be an integral part of any diagnostic-therapeutic regimes developed by oncology units.

**Right to dietary prescriptions:** every cancer patient at nutritional risk or malnutrition has the right to receive personalised dietary prescriptions by health professional with documented skills in clinical nutrition.

**Right to oral nutritional supplements:** every cancer patient at nutritional risk has the right, according to clinical conditions and specific nutrient deficiencies, to receive oral nutritional supplements, including vitamins and minerals.

**Right to appropriate and prompt artificial nutrition:** artificial nutrition is a complex therapeutic procedure that requires specific medical skills, as it may be associated with severe complications if not carried out according to evidence-based standard operating protocols. Every cancer patient at nutritional risk, who is unable maintain an adequate nutritional status

despite nutritional counseling and oral nutritional support, has the right to receive appropriate and swift artificial nutrition in every healthcare setting, as part of continuous care.

**Right to appropriate and safe home artificial nutrition:** every cancer patient, who needs to continue artificial nutrition after hospital discharge, has the right to receive appropriate and safe home artificial nutrition, prescribed by health professionals with documented skills in clinical nutrition.

**Right to nutritional support monitoring:** every cancer patient requiring nutritional support has the right to periodic reassessment of treatment adequacy and efficacy using established integrated health care regimes which ensure the collaboration of the multidisciplinary team.

**Right to treatment for overweight-related health problems during or after cancer treatment:** every cancer patient has the right to be referred to a health professional with documented skills in clinical nutrition, during or after oncologic rehabilitation programs, so that ideal body weight can be recovered or maintained, to avoid the negative impact of increased weight on prognosis and the clinical course of many cancer types.

**Right to psychological support:** malnutrition considerably affect body image and can cause social and emotional challenges. Any patient likely to experience such problems has the right to receive appropriate and swift psychological support.

**Right to be considered for participation in relevant clinical nutrition trials:** every cancer patient has the right to be considered for enrollment in relevant clinical studies on nutritional support.



European Cancer  
Patient Coalition

# Nutrition Glossary

**Antioxidants:** Molecules capable of immobilising free radicals before they attack cell bodies. Antioxidants can be obtained as a part of a diet or as dietary supplements.<sup>1</sup>

**Artificial nutrition:** A medical intervention when oral intake of food and liquids is not possible or does not adequately provide nutrients necessary for the body's daily activities. It could be oral nutritional supplements (ONS), enteral nutrition (EN) or parenteral nutrition (PN).<sup>16</sup>

**Asymptomatic:** Lack of symptoms or subjective manifestations of a disease.<sup>2</sup>

**BMI:** Body mass index (BMI) is a measure for indicating nutritional status in adults (normal weight, overweight, and obesity). It is a person's weight in kilograms divided by the square root of the person's height in meters (kg/m<sup>2</sup>).<sup>3</sup>

**Basal metabolic rate (BMR):** BMR is the required energy to maintain essential body functions. It is measured in mega joules, kilojoules, or kilocalories per minute, hour, or day.<sup>4</sup>

**Cachexia:** A complex metabolic syndrome characterized by loss of muscle (with or without loss of fat mass) in adults, and growth suppression in children, frequently associated with inflammation, anorexia and insulin resistance.<sup>5</sup>

**Carcinogen:** A substance that increases the incidence of cancer in living tissue, this could be chemical, physical, or biological.<sup>6</sup>

**Carcinoma:** A type of cancer derived from epithelial cells, malignant tumour able to spread into the surrounding tissue (invasion) and create secondary tumours (metastases).<sup>4</sup>

**Central venous catheter:** Also, called a central line. It is a thin, flexible tube used to give medicines, fluids, nutrients, or blood products over a long period of time. It is often inserted in the arm or chest through the skin into a large vein.<sup>19</sup>

**Chemoradiation:** The combination of chemotherapy with radiation therapy.<sup>7</sup>

**Chronic:** A term used to describe a disease or a condition that persists or progresses over a long period of time.<sup>2</sup>

**Clinical examination:** Searching for signs of disease by physically examining the body.<sup>2</sup>

**Clinical trial:** A research study that tests how well new medical approaches work in people, for example, new methods of screening, prevention, diagnosis or treatment.<sup>2</sup>

**Deep vein thrombosis (DVT):** DVT is a blood clot formation in a deep vein of the leg that may include pain, feeling of warmth in the leg, swelling, and redness.<sup>2</sup>

**Dietary factors:** Substances and characteristics of the diet; e.g., the amount of total fat, dietary fiber and the method of cooking.<sup>4</sup>

**Electrocardiogram (ECG):** An ECG show changes in the electrical activity of the heart over time. It can identify abnormal conditions, such as blocked arteries and changes in electrolytes.<sup>7</sup>

**Endoscopy:** A medical procedure where a tube-like instrument is inserted into the body for professional medical observation.<sup>7</sup>

**Enteral nutrition:** Nutritional support is provided by

constructing an artificial line to the gastrointestinal system. It could be a tube in the nose (nasogastric) a tube through the skin into the stomach (gastrostomy) or a tube into the small intestine (jejunotomy).<sup>8</sup>

**Energy balance:** Energy balance occurs when the absorbed energy from foods and drinks equal the total energy spent. In the case of intake exceeding expenditure, it is a positive energy balance. When the expenditure exceeds intake, it is a negative energy balance.<sup>4</sup>

**Enzyme:** A protein that accelerates chemical reactions in the body.<sup>9</sup>

**Fermentation:** A metabolic breakdown of molecules, such as glucose, which converts energy to lactate, acetate, ethanol, or other simple products.<sup>4</sup>

**Follow-up:** Observing a person's health over time, during/after receiving treatment.<sup>2</sup>

**Gastroesophageal reflux:** The back flow of stomach acid contents into the esophagus. Also, called gastric reflux, esophageal reflux or acid reflux.<sup>7</sup>

**Glucose:** Body fuel, present as a simple form of sugar, carried by the blood to cells for energy. It is produced when foods are metabolized in the digestive system.<sup>9</sup>

**Helicobacter pylori:** Also known as *H. pylori*. A bacterium that causes inflammation and ulcers in the stomach or small intestine. People with that infection are more likely to develop cancer in the stomach, including MALT (mucosa-associated lymphoid tissue) lymphoma.<sup>7</sup>

**High-protein diet:** A type of weight loss plan based on the overall consumption of high-protein-containing foods.<sup>20</sup>

**Proteins:** Complex molecules made up of hundreds or thousands of smaller units called amino acids, which are attached to one another in long chains. Proteins play many critical roles in the body, they

do most of the work in cells and are required for the structure, function, and regulation of the body's tissues and organs.<sup>21</sup>

**Hormones:** Chemical messengers produced by the body's endocrine glands and distributed in the bloodstream. Hormones control the activities of certain cells or organs.<sup>10</sup>

**Hyperplasia:** An increase in the number of cells in a tissue or organ leading to enlargement.<sup>4</sup>

**Immune system:** A biological system of structures and processes that defends the body from diseases by identifying and killing foreign bodies such as viruses, bacteria and tumour cells.<sup>2</sup>

**Invasive cancer:** Tumours that grow into surrounding healthy tissue.<sup>4</sup>

**Lifestyle factors:** Identifiable and quantifiable habits and ways of living (e.g. diet, smoking, drinking, hobbies) that are useful in differentiating population clusters for epidemiological studies.<sup>11</sup>

**Lymphocyte:** A form of white blood cell, found in the blood and lymph glands and part of the body's immune system.<sup>4</sup>

**Melanoma:** The most dangerous form of skin cancer. A malignant tumour derived from the pigment-producing cells (melanocytes).<sup>4</sup>

**Metabolism:** The chemical changes that occur in living organisms to maintain life, so it can be used to store or use the energy needed by the body.<sup>9</sup>

**Metastasis:** The development of secondary malignant cancer cells to distant locations around the body.<sup>4</sup>

**Muscle wasting:** A weakening, shrinking, and loss of muscle mass due to a disease or immobility resulting in an overall decrease in strength and movement.<sup>18</sup>

**Mutagen:** A chemical or physical agent that interacts

with DNA causing permanent, transmissible change in the genetic material of a cell. <sup>4</sup>

**Nasogastric probe:** A specific device used for enteral nutrition in particular clinical cases where the patient is unable to self-nourish. <sup>22</sup>

**Nausea:** An unpleasant sensation, painless with subjective feeling that one will urgently vomit. <sup>12</sup>

**Neoplasm:** Abnormal growing of tissue in a part of the body. Neoplasms could be benign or malignant tumours. <sup>4</sup>

**Obesity:** Surplus of body fat leading to increased risk of various diseases. Obesity is defined as a BMI of 30 kg/m<sup>2</sup> or more. <sup>4</sup>

**Parenteral nutrition:** Nutritional support is given via the blood stream 'intravenously', formulae contain nutrients such as glucose, salts, amino acids, lipids and added vitamins and dietary minerals. <sup>13</sup>

**Processed meat:** Meat that is transformed through smoking or other procedures-examples include hot dogs, ham, sausages, corned beef and canned meat. <sup>10</sup>

**Prognosis:** The likely cause of a disease and the chance of recovery or recurrence. <sup>2</sup>

**Red meat:** Refers to meat originating from beef, veal, pork, lamb, mutton, horse, and goat. <sup>2</sup>

**Relapse:** Return of a disease after a period of recovery. <sup>2</sup>

**Remission:** Withdrawal of or decrease in signs and symptoms of cancer. <sup>2</sup>

**Risk factor:** A causative element which could increase the possibility of developing a disease. Cancer risk factors may include: age, family history, exposure to certain chemicals or radiation, tobacco use and specific genetic changes. <sup>2</sup>

**Dietary supplement:** A product intended for

consumption that contains a "dietary ingredient" which has not been consumed in sufficient quantities. A "dietary ingredient" may be one, or any combination of, vitamins, minerals, amino acids, herbs or other botanicals. <sup>14</sup>

**Supportive care:** Provision of care to patients who have a serious or life-threatening disease to improve the quality of their life. The goal is to prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment of a disease, and the social and psychological problems related to a disease or its treatment. <sup>2</sup>

**Systemic therapy:** A medicinal remedy that travels through the bloodstream, reaching and affecting cells all over the body. Examples of systemic therapy are chemotherapy and immunotherapy. <sup>7</sup>

**Targeted therapy:** A treatment that uses drugs or other substances to identify and attack specific cancer cells. It may have fewer side effects when compared to other types of cancer treatments. <sup>7</sup>

**Trace elements:** Minerals needed by the body in very small quantities for the appropriate growth, development, and physiology of the organism. <sup>4</sup>

**Veins:** Blood vessels which carry deoxygenated blood from the tissues back to the heart, with two sole exceptions: the pulmonary and umbilical veins which carry oxygenated blood to the heart. Veins are often closer to the skin and mostly have valves to prevent backflow. <sup>17</sup>

**Vitamins:** Vitamins are organic compounds and vital nutrients that the body needs in small amounts to sustain life. Sources of vitamins include plant-based or animal-based food products and supplements. <sup>15</sup>



# References

1. Rahman K. Studies on free radicals, antioxidants, and co-factors. *Clinical Interventions in Aging*. 2007; 2(2): 219-236. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2684512/>
2. Anticancer Fund & ESMO (European Society for Medical Oncology). *Acute Myeloblastic Leukaemia: A Guide for Patients*. Brussels: ESMO; 2013. Available from: <http://www.esmo.org/content/download/6583/114891/file/EN-AML-Guide-for-Patients.pdf>
3. World Health Organisation (WHO). *Body Mass Index – BMI*. Copenhagen: WHO Regional Office for Europe; 2017. Available from: <http://www.euro.who.int/en/health-topics/disease-prevention/nutrition/a-healthy-lifestyle/body-mass-index-bmi>
4. World Cancer Research Fund (WCRF), American Institute for Cancer Research (AICR). *Food, Nutrition, Physical Activity, and the Prevention of Cancer: A Global Perspective, Volume 1*. Chicago: American Institute for Cancer Research; 2007 p. 532-526. Available from: [http://www.aicr.org/assets/docs/pdf/reports/Second\\_Expert\\_Report.pdf](http://www.aicr.org/assets/docs/pdf/reports/Second_Expert_Report.pdf)
5. William J. E. Cachexia: A new definition. *Clinical Nutrition*. 2008; 27(6):793-799. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/18718696>
6. National Research Council (US) Committee on Diet, Nutrition, and Cancer. *Diet, Nutrition, and Cancer: Directions for Research*. Washington (DC): National Academies Press (US); 1982. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK216712/>
7. Anticancer Fund & ESMO (European Society for Medical Oncology). *Oesophageal Cancer: A Guide for Patient*. Brussels: ESMO; 2012. Available from: <http://www.esmo.org/content/download/6609/115065/file/EN-Oesophageal-Cancer-Guide-for-Patients.pdf>
8. Food and Drug Administration (FDA). *Glossary for Nutrition Facts Label*. Silver Spring: Food and Drug Administration (FDA); 2016. Available from: <https://www.fda.gov/downloads/Food/IngredientsPackagingLabeling/UCM275396.pdf>
9. Wilder LB, Cheskin LJ, Margolis C. *Nutrition And Weight Control for Longevity*. Johns Hopkins Health. 2007
10. World Health Organisation (WHO). *Q&A on the carcinogenicity of the consumption of red meat and processed meat*. Copenhagen: WHO Regional Office for Europe; 2015. Available from: <http://www.who.int/features/qa/cancer-red-meat/en/>
11. Susan T. Mayne, Mary C. Playdon & Cheryl L. Rock. Diet, nutrition, and cancer: past, present and future. *Nature Reviews Clinical Oncology*. 2016; 13: 504-515. Available from: <https://www.nature.com/articles/nrclinonc.2016.24>
12. William L. H. & William D. C. (American Gastroenterological Association). *Nausea and vomiting*. 2003; 125(6):1860-1867. Available from: [http://www.gastrojournal.org/article/S0016-5085\(03\)01575-0/fulltext](http://www.gastrojournal.org/article/S0016-5085(03)01575-0/fulltext)
13. Chowdary K.V.R., Reddy P.N. Parenteral nutrition: Revisited. 2010; 54(2): 95-103. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2900762/>
14. Food and Drug Administration (FDA). *FDA Basics*. Silver Spring: Food and Drug Administration (FDA); 2016. Available from: <https://www.fda.gov/AboutFDA/Transparency/Basics/default.htm>
15. PubMed Health - National Library of Medicine - NCBI - NIH. *Public Health Glossary*. Bethesda: National Cancer Institute; 2017. Available from: <https://www.ncbi.nlm.nih.gov/pubmedhealth/PMHT0023352/>
16. Druml C. *ESPEN guideline on ethical aspects of artificial nutrition and hydration*. Luxembourg: Elsevier Ltd and European Society for Clinical Nutrition and Metabolism; 2016. Available from: [http://www.espen.org/files/ESPENGuidelines/3\\_\\_ESPEN\\_guideline\\_on\\_ethical\\_aspects\\_of\\_artificial\\_nutrition\\_and\\_hydration.pdf](http://www.espen.org/files/ESPENGuidelines/3__ESPEN_guideline_on_ethical_aspects_of_artificial_nutrition_and_hydration.pdf)
17. Dorland D. *Dorland's Illustrated Medical Dictionary*, 32nd ed. Philadelphia: Elsevier; 2011.
18. National Cancer Institute. *NCI Dictionary of Cancer Terms*. Bethesda: National Cancer Institute; 2017. Available from: <https://www.cancer.gov/publications/dictionaries/cancer-terms>
19. Parsons R. F, Dumon R. K. *Gowned and Gloved Surgery: Introduction to Common Procedures*. Philadelphia: Elsevier - Health Sciences Division; 2009.



20. Todd K. High-Protein Diets and Weight Loss. *Today's Dietitian*. 2017; (vol.26): 12-32. Available from: <http://www.todaysdietitian.com/newarchives/1217p32.shtml>
21. Genetics Home Reference. What are proteins and what do they do? Bethesda: U.S. National Library of Medicine; 2017. Available from: <https://ghr.nlm.nih.gov/primer/howgeneswork/protein>
22. Cole E. Improving the documentation of nasogastric tube insertion and adherence to local enteral nutrition guidelines. *BMJ Quality Improvement Reports*. 2015; 4(1): u203207.w1513. Available from: <http://doi.org/10.1136/bmjquality.u203207.w1513>
23. European Society of Medical Oncology (ESMO). *ESMO Handbook of Nutrition and Cancer*. ESMO Press. 2011
24. World Health Organisation(WHO) & International Agency for Research on Cancer (IARC), *European Code Against Cancer*, 2016, Available from: <http://www.euro.who.int/en/health-topics/noncommunicable-diseases/cancer/news/news/2016/02/preventing-cancer-the-european-code-against-cancer#>
25. Arends J, et al., ESPEN expert group recommendations for action against cancer-related malnutrition, *Clinical Nutrition* (2017), Available from: <http://www.espen.org/files/ESPEN-Guidelines/PIIS0261561417302285.pdf>
26. Arends J, et al., ESPEN guidelines on nutrition in cancer patients, *Clinical Nutrition* (2016) Available from: <http://dx.doi.org/10.1016/j.clnu.2016.07.015>
27. Harvard University. For more information about The Healthy Eating Plate, please see The Nutrition Source, Department of Nutrition, Harvard School of Public Health, [www.thenutritionsource.org](http://www.thenutritionsource.org), and Harvard Health Publications, [www.health.harvard.edu](http://www.health.harvard.edu).
28. McCune JS, Hatfield AJ, Blackburn AA, Leith PO, Livingston RB, Ellis GK. Potential of chemotherapy–herb interactions in adult cancer patients. *Supportive care in cancer*. 2004
29. World Cancer Research Fund (WCRF), American Institute for Cancer Research (AICR). *Food, Nutrition, Physical Activity, and the Prevention of Cancer: A Global Perspective, Volume 1*. Chicago: American Institute for Cancer Research; 2007 p. 532-526. Available from: [http://www.aicr.org/assets/docs/pdf/reports/Second\\_Expert\\_Report.pdf](http://www.aicr.org/assets/docs/pdf/reports/Second_Expert_Report.pdf)
30. European Patients Forum (EPF), Patient Platform Voeding, Patients Network for Medical Research and Health (EGAN), Report and recommendations of the EU Patient Group Conference on Nutrition, 2017. Available from: <https://european-nutrition.org/wp-content/uploads/2017/05/Report-nutrition-conference-June-29-2017.pdf>
31. De Lorenzo F, et al., Cancer Patients' Bill of Rights for appropriate and prompt Nutritional Support, Fondazione IRCCS Policlinico San Matteo



*Living well  
during*

**CANCER  
TREATMENT**

ECPC Nutrition Booklet addressing cancer patients'  
needs and concerns



# European Cancer Patient Coalition

This Document addresses common questions patients might have about diet, nutrition, and physical activity during treatment and provides general information regarding nutrition and cancer.

It is not intended to offer medical advice or replace advice given by your healthcare team. It is important to address all medical questions and concerns about your care with your healthcare team.

