Organisation of European Cancer Institutes



## INTERACTIVE NUTRITIONAL RECOMMENDATIONS FOR CANCER PATIENTS



# DEVELOPING THE FUTURE IN COMPREHENSIVE CANCER CARE



Organisation of European Cancer Institutes

# Interactive nutritional recommendations for cancer patients



#### Interactive nutritional recommendations

for cancer patients

An OECI - Eurocancercoms study

#### Editors:

Wim van Harten<sup>6,7</sup> (Amsterdam) and Claudio Lombardo<sup>4,7</sup> (Genoa)

#### Authors:

Patrizia Gnagnarella<sup>1</sup>, Demosthenes Akoumianakis<sup>2</sup>, Sergio Bottero<sup>4,7</sup>, Laura Del Campo<sup>3</sup>, Francesco De Lorenzo<sup>3</sup>, Claudio Lombardo<sup>4,7</sup>, Margherita Marincola<sup>4,7</sup>, John Gordon McVie<sup>1</sup>, Giannis Milolidakis<sup>2</sup>, Alessandro Maria Misotti<sup>1</sup>, Luigi Santoro<sup>1</sup>, Richard Sullivan<sup>5</sup> and Wim Van Harten<sup>6,7</sup>

#### Editorial Office:

Giorgia Pesce<sup>4,7</sup> and Georgette van Velzen<sup>6,7</sup>

1. Istituto Europeo di Oncologia, Milan - Italy

- 2. Center for Technological Research of Crete,
- Technological Education Institution of Crete Greece 3. Federazione Italiana delle Associazioni di Volontariato in Oncologia, Rome - Italy
- 4. IRCCS Azienda Ospedaliera Universitaria San Martino
- IST- Istituto Nazionale per la Ricerca sul Cancro, Genoa Italy
- 5. Kings College London UK
- 6. The Netherlands Cancer Institute- Amsterdam The Netherlands
- 7. Organisation of European Cancer Institute, Brussels Belgium

Publisher: OECI-EEIG Reg. Brussels REEIG n. 277 D/2011/12.243/3 - ISBN: 9789080625686

Organisation of European Cancer Institutes European Economic Interest Grouping c/o Fondation Universitaire, Rue d'Egmont 11 B-1000 Brussels, Belgium www.oeci.eu - oeci@oeci.eu

Graphic Designer: Studio Sichel, Piacenza

Illustrations: Cristina Vanazzi, Lodi

Printed in Piacenza Italy, 2011

This study has been partially supported by Alleanza Contro il Cancro as part of the Programme 4 of the Ministerial Decree 21<sup>st</sup> July 2006 of the Italian Ministry of Health "National Support Network and International Cooperation".



This publication presents the results coming from the study undertaken by the OECI as part of the Eurocancercoms FP7 Coordinating Action Grant agreement No. 230548 and is financed by the same Coordinating Action.



eurocancercoms

# Interactive nutritional recommendations for cancer patient

#### **Table of contents**

Foreword Umberto Veronesi	5
<b>Preface</b> Wim van Harten	7
Eurocancercoms: a new approach to cancer communication John Gordon McVie and Richard Sullivan	9
The OECI participation to the Eurocancercoms Support Action Claudio Lombardo, Sergio Bottero and Margherita Marincola	17
<b>Improve nutrition knowledge, quality of life and the psychological distress in cancer patients</b> Patrizia Gnagnarella, Demosthenes Akoumianakis, Laura Del Campo, Francesco De Lorenzo, Claudio Lombardo, John Gordon McVie, Giannis Milolidakis, Alessandro Maria Misotti, Luigi Santoro and Richard Sullivan	19
Nutrition and cancer: hints for patients Patrizia Gnagnarella, Alessandro Maria Misotti, Laura Del Campo and Francesco De Lorenzo	49

### Foreword

Cancer survivorship has grown tremendously over the past decades, mainly due to the enhancements in early detection and treatment. During cancer treatment, survivors often experience adverse effects that persist for months or years thereafter. Nutritional difficulties arising during cancer therapies are a common problem that may affect patients' quality of life, their psychological status, and treatments' outcomes.

Better communication could provide motivation and skills needed to reduce the risks associated with vulnerability of the disease, and Internet would jointly contribute to the general health promotion creating a new "place" to interact.

This study is part of Eurocancercoms partnership, an ambitious FP7-funded European Commission project aimed at using web technology to provide novel ways to turn cancer information into knowledge for patients, policy-makers, researchers, and healthcare professionals. This study represents an exemplary communication improvement model between cancer patients and researchers, scientists, and physicians involved at different level in cancer care.

The prototype Internet website <u>www.supportonutrizionale.it</u>, dedicated to cancer patients dealing with nutritional problems, provides a dimension where they can freely interact, request, and comment on weekly published contents.

This book synthesizes the intervention, though the major section is the last chapter that contains useful and practical hints for patients, covering the most common nutrition-related side effects. This textbook is a good, user-friendly guidebook for oncological patients, also aimed at whoever manages and cares for patients with neoplasms. For this reason, this book could be considered as other guidelines and practice manuals.

Chalinto Versuis Umberto Veronesi

### Preface

Gradually more knowledge is becoming available on the relation between nutrition and cancer. Although mainly based on epidemiological studies and to a lesser degree on fundamental biological research or chemo prevention studies, patients increasingly choose for a healthy diet in an effort to influence the chance of developing cancer or diminishing the relapse chance. Moreover it is worthwhile to optimalise the physical condition during and alter treatment as it is obvious that this will add to the quality of life. It is therefore very useful that Eurocancercoms project dedicated a major part of its efforts in assembling knowledge on this topic, but also on how knowledge is accessed and communicated with- and towards patients. Although the way of publishing (in print) is rather "proven technology", the project objective in aiming to develop innovative communication routes for various aspects of knowledge and communication in oncology is laudable.

Nutrition is a relevant issue for all tumour fields and an important element in the multidisciplinary approach of cancer. It is important to note that the OECI, the European Organisation of Cancer Institutes, representing more than 70 cancer centres all over Europe, has played a significant role in establishing this report. Cancer treatment is increasingly becoming a multidisciplinary exercise in which the active role of the institution and organisational issues is gaining weight.

As chairman of the OECI and co-editor of this book, I hope that its publication will contribute to the diffusion of knowledge on nutrition and oncology, consequently improving the quality of life of many cancer patients.

Prof. Wim H. van Harten MD, Ph.D.

PREFACE

# Eurocancercoms: a new approach to cancer communication

John Gordon McVie and Richard Sullivan

#### Introduction

The lack of efficient, integrated communication among cancer scientists, health professionals, patients and policy makers remains a significant barrier to collaboration in the European Union (EU). The recent EUROCAN+PLUS Feasibility Study for Coordination of National Cancer Research Activities surveyed all constituents in Europe involved in some way or another with the cancer research "business" and concluded unanimously that information overload and an overwhelmingly fractionated, exhaustive array of resources, networks and knowledge providers are seriously hindering the translation, application and implementation of research across Europe. With the constant explosion of data we can expect to face increasingly challenging times for co-ordinated, reliable and effective scientific dissemination and communication. Furthermore other forms of information such as policy-reports, etc. remain out-of-reach to key opinion leaders as they form part of the unsearchable 'dark material' of the web.

With no workable model the European Commission funded a consortium of some of the key European partners (OECI, ECCO, EORTC, EACR, ecancer.eu, EUSOMA etc.) called Eurocancercoms to make a list of all existing information tools currently in use, from gene databases to clinical trials and guidelines, their faults and flaws and recommendations for future requirements. Elsewhere in the Eurocancercoms project, a review of new technologies available to assist in the dissemination of the information was a deliverable. E-surveys and other online research tools were used to provide rapid and easily collated information and a specific focus was developed on nutrition. This developed from observations from the charitable sector that the commonest request for support from cancer patients was about diet. It is known that supplying information and advice in the form of leaflets has little influence on change of behaviour. With the increased popularity of social media it was thought appropriate to test this format as a way of supplementing information with direct interaction and conversation via a social media network. A randomised trial was therefore designed to offer volunteer cancer patients the chance of receiving a standard information package via the internet, plus or minus access to a discussion group. As part of this project a wide range of policy research was instigated (all results will be openly available following publication at www.eurocancercoms.eu), for example,

- Perceptions of risk: how do patients understand risk?
- The media reporting of cancer
- The state of R&D communication in paediatric oncology
- The state of R&D communication in academic cancer surgery
- A pan-European survey of patient organisations and their e-information needs
- Survey of e-information usage by European patients
- A major study of cancer clinical guidelines: patient involvement, organisational development and use of e-tools for developing guidelines
- Review on the use of NCI caBIG science tools across Europe
- Review and collation of novel tools and databases for European cancer scientists
- The use of social media tools, e.g. twitter in cancer communication
- Decision making aids for cancer patients: a review.

#### **Barriers to Effective Cancer Communication**

The cancer community is extremely heterogeneous, something that Eurocancercoms was critically aware of on preparing its review of communication barriers (and solutions). Basic science needs to be original and to publish research ahead of anyone else. Scientists' careers progress or not, according to the number and originality of papers they publish, so they are therefore unwilling to share initial findings and remain secretive about ongoing data. Negative results are infrequently published in scientific journals [1]. Furthermore participants in cancer networks will share information, though not often raw data, however they rarely link with other cancer networks on a functional basis. Pharmaceutical companies also carry out a large proportion of medical research in Europe (around 50%) in the cancer area), but an estimated 80% of their science findings are never published. Scientists, researchers and even companies do not like to publish negative results. Negative results at the end of a study may be disappointing but they can add to the scientific world's knowledge of a particular subject. If such results remain unpublished, then future academics and researchers may waste time and money exploring the same areas. If journals do not publish research that has, for example, disproved commonly-held hypotheses, then people will continue to believe those assumptions, and even continue to base research on them. Whilst these issues were beyond the reach of eurocancercoms highlighting them serves to remind us that there remain major socio-political issues around a truly open, integrated cancer community.

Clinical research is also impaired by many of the same problems that beset the basic science community, but in addition has the added restriction of maintaining patient confidentiality. The issues of data protection and privacy are of prime importance in communicating the results of studies involving patients whether to other cancer professionals or to other patients, their families and indeed the general public. However, unthinkingly applied regulation has and continues to damage efforts for communication between the research community and between the research community and public. There is ample evidence that highlights the heterogeneity of outcomes of cancer care throughout Europe. What is clear is the detrimental impact of lower social class, deprivation, ethnicity, low educational achievement, and lack of access to relevant information amongst cancer patients. Furthermore patients are increasingly using the Internet in a hunt for reliable cancer information. One website on cancer opens each day of the year, and the word "cancer" is searched on Google more than any other except "pornography"!

The EU clearly needed to establish an integrated model for a European-wide comprehensive cancer information and policy exchange portal which could also subsequently be applied to other areas of healthcare, such as cardiology, neurobiology etc. However, there was no 'off the shelf' solution, and those potential approaches failed to embrace and utilise novel approaches such as social media. Furthermore communication across the EU by the cancer community is fragmented, unstructured and dis-aligned. For example, dissemination of scientific results is performed by a large number of cancer journals often focussed on different sections of the cancer community. As pointed out in the Commission Communication document Scientific information in the digital age: access. dissemination and preservation there are some 2000 scientific journal publishers globally, producing about 1.4 million articles a year. Some 780 of these publishers are located in the EU, producing 49% of the total journal output. They employ some 36 000 persons directly in the EU and have a strong position in the world market [2]. There are over 120 European cancer journals published in the EU read by cancer professionals in the EU and across the globe.

The dissemination of research from the professional cancer community to the general public often happens via the main stream media where the key messages are frequently confused and distorted. After translation into their own tongue

patients in non-English speaking countries are receiving third or fourth hand information. The decision on what the mainstream media covers is not always in the best interests of cancer patients and professionals. Often cancers that affect a smaller, less vocal part of the population, the so called 'Cinderella cancers' have a low media profile in the EU.

The issue of inaccurate information on the internet has been addressed by researchers at the University of Texas [3]; "In an extended analysis of Web pages dedicated to disseminating breast cancer information, researchers at two University of Texas institutions in Houston have determined that while most breast cancer data found online was accurate, one in 20 breast cancer Web pages featured inaccuracies and also that sites displaying complementary and alternative medicine were 15 times more likely to contain false or misleading health information".

A study published in the *Journal of Public Health* [4] presented data on access to the internet by French breast cancer patients confirmed these findings but added the major concern of difficulty of understanding English language information. The study highlights the need for accurate and trusted sources of information. There are no official endorsements for health websites with accurate information, making it difficult for people to know what information is reliable and trustworthy. However, a NGO called the *Health on the Net Foundation* [5] gives a seal of accreditation to attest to the quality of medical web sites aimed at a lay public. Sites must meet the HON Code (a system attempting to accredit trustworthy websites) criteria regarding authority, financial disclosure etc. This model could perhaps be considered and developed for cancer-specific content across Europe allowing people to search a reliable source of information.

Cancer patients and their families are severely handicapped in Europe by lack of access to research projects, e.g. appropriate clinical trials in which they might participate, by technical language (both medico-technical and geographic), and by disinterest from publishers who see no profit therein, or media which will select positive messages and neglect negatives. Many patients consult <u>www.clinicaltrials.gov</u> to find the larger European cancer trials advertised there (in the USA) in desperation at the absence of access to such listings in Europe. The EMEA (European Medicines Evaluation Agency) has recently opened access to its clinical trials database, EUDRACT https://eudract.ema.europa.eu/ and this will match the American www.nci.gov.

Overall Eurocancercoms found a lack of quality control for content (including

tools, Apps etc.) or information that was 'hidden', little good intelligence on the various cancer communities (and their needs) and a failure of cancer to grasp novel internet technologies (e.g. social media, decision support tools etc).

#### A Cutting Edge Solution: ecancerHub

The internet has created huge opportunities for the sharing of research, policy, tools and apps. Academic search engines such as Google scholar - which only scan academic texts - are gaining in popularity for those looking for scientific papers. However, all these approaches suffer from a lack of integration and the use of novel multimedia platforms. As cancer technology advances so does the need for innovative ways of sharing information. Traditional paper journals cannot support the new multi-media research that needs to be published. 3-dimensional videos of new robotic surgical operations, dynamic imaging, and 3-dimensional molecular structures cannot be shown to their advantage by static 2-dimensional images on paper. Innovative solutions are needed to ensure that the publication of, and access to understandable results of research can keep up with the speed of innovation, discovery and development. But more than this, there needs to be an integration of different types, sources and media for truly cross-disciplinary, open communication.

As a result the consortium has established ecancerHub (<u>www.ecancerhub.eu</u>), a state of the art communications system based on social media platform to connect and involve all those implicated in translation of basic cancer research

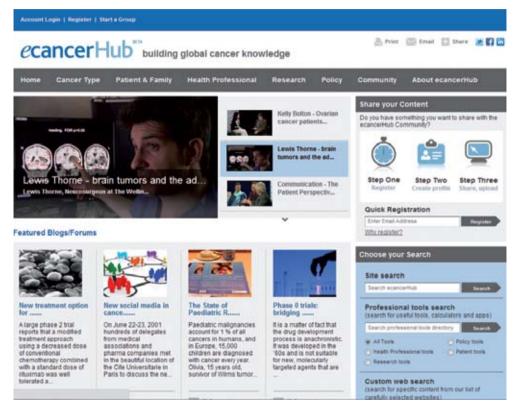




The online cancer community for patients, scientists and healthcare professionals.

> Watch, join, share - get involved! www.ecancerhub.eu

into clinically testable hypotheses, cancer management guidelines, public health prevention strategies, patient information provision and support activities including social networking. This integrating platform has been built with the best social media technology based on in-depth analysis of community needs and collation of high quality, open information.



The challenge must now be presented to the European Commission to maintain and continue to build this extraordinary one-stop-shop for those interested in or affected by cancer. If ecancerhub were made widely available to all Europeans preferably in their own language, we predict a slight fall in cancer incidence, but a sharp increase in patients presenting to their doctor with early curable disease. It is likely that speed of taking new medicines, technologies and devices from the lab to the clinic will increase paralleled with a growth of volunteering for clinical trials. The ecancerhub paradigm is now available for the EC to apply to other common killers such as cardiovascular and cerebrovascular diseases.

#### REFERENCES

- <sup>[1]</sup> Kirsch I, Deacon BJ, Huedo-Medina TB, Scoboria A, Moore TJ, et al. (2008) 'Initial Severity and Antidepressant Benefits: A Meta-Analysis of Data Submitted to the Food and Drug Administration'. PLoS Med 5(2): e45 doi:10.1371/journal.pmed.0050045
- <sup>[2]</sup> EU Commission (2007) 'Communication from the Commission to the European Parliament, the Council and the European Economic and Social Committee on scientific information in the digital age: Access, dissemination and preservation'. Retrieved February 2008 www.ec.europa.eu/ research/science-society/document\_library/pdf\_06/communication-022007\_en.pdf
- <sup>[3]</sup> Bernstam, E. et al (2006) 'Accuracy and self correction of information received from an internet breast cancer list: analysis of posting content', BMJ 2006; 332:939-942 (22April), doi:10.1136/ bmj.38753.524201.7C
- [4] Mancini, J. (2006) 'Patients' characteristics and rate of Internet use to obtain cancer information' Journal of Public Health 2006 28(3):235-237; doi:10.1093/pubmed/fdl019
- <sup>[5]</sup> WHO: Hinari project www.who.int/hinari

#### **KEY PUBLISHED RESULTS FROM THE EUROCANCERCOMS PROJECT**

Warden R., The internet and science communication: blurring the boundaries, *ecancermedicalscience*, 4, 2010, DOI: 10.3332/ecancer.2010.203

Warden R., Impact of caBIG on the European cancer community, *ecancermedicalscience*, 5, 2011, DOI: 10.3332/ecancer.2011.225

Kenney R., Warden R., An Open Access Future? Report from the eurocancercoms project, ecancermedicalscience, 5, 2011 DOI: 10.3332/ecancer.2011.223

Maddox C., Camporesi S., Lewis I., Ahmed K., Sullivan R. Online information as a decision making aid for cancer patients: recommendations from the Eurocancercoms project. *Eur J Cancer 2011* (in press)

Purushotham A., Lewison G., Sullivan R. The state of research and development in global cancer surgery. *Annals of Surgery* 2011 (in press)

Pritchard-Jones K., et al, Sullivan R. The state of research into children with cancer across Europe. New policies for a new decade. *ecancermedicalscience*, 2011, 5:210 DOI: 10.3332/ ecancer.2010.210

Maddock C., Information Needs of Cancer Patients and their Organisations, *ecancermedicalscience*, 2011 (in press)

Gnagnarella P., Misotti A. M., Santoro L., Akoumianakis D., Milolidakis G., De Lorenzo F., Lombardo C., Sullivan R., Mcvie J. G. A dedicated website for cancer subjects, the nutritional support study: preliminary results. *Ecancermedicalscience* 2011 (in press)

Gnagnarella P., Akoumianakis D., Del Campo L., De Lorenzo F., Lombardo C., Mcvie J.G., Milolidakis G., Misotti A.M., Santoro L., Sullivan R. and Van Harten W. Interactive nutritional recommendations for cancer patients: an OECI – EuroCancerComs study. 2011. *Publisher: OECI-EEIG Reg. Brussels REEIG n. 277 D/2011/12.243/3 - ISBN: 9789080625686* 

### The OECI participation to the Eurocancercoms Support Action

Claudio Lombardo, Sergio Bottero and Margherita Marincola

The production and validation of knowledge within the OECI network of Comprehensive Cancer Centres must be associated with an organised process of communication and dissemination that allows professionals and patients to quickly access to information that should improve the diagnostic and therapeutic process and the quality of life during treatment and after recovery.

In order to support this process, the OECI has placed great emphasis on the promotion of interventions that could facilitate the aggregation of the entities that in Europe should pool their efforts to accelerate the process that from discovery leads to exploitation by full involvement of end users, professionals or patients, realising what is commonly identified as "living-lab".

With this in mind the "Eurocancercoms" coordinating action of the European Commission was born in 2009.

The Organisation of European Cancer Institutes represents 71 cancer related organisations across Europe. Most of the members are Comprehensive Cancer Centres which ultimate objective is the development of oncology in Europe for reducing mortality and morbidity due to cancer and increasing survival and quality of life of the patients.

For innovation to occur, research requires to be done in the same place as health care of high quality is being delivered, with the resultant potential for the latest knowledge to be implemented swiftly into routine care. So far, Comprehensive Cancer Centres are the only institutions that have really taken this idea on board, integrating care and prevention with research and education since the model of oncology is based on a global vision of the cancer problem. The OECI main mandate is therefore related to the detection of new and better treatments for cancer patients, providing comprehensive health care, and improving patients' quality of life through an evidence-based medicine also thanks to a holistic approach.

The Eurocancercoms aims at establishing a communication platform that can profit to all the professionals involved in the cancer field producing, in a certain way, "knowledge" to be shared potentially among the cancer community and the citizens. This communication platform is a cancer hub implemented thanks to the direct participation of the users that can give a contribution to the content itself.

As part of Eurocancercoms, the OECI was charged of different tasks such as the measurement of the degree of change in the publication of cancer science. In fact, few fields have been more transformed by the Internet than scientific publishing, but corresponding increase in application and exploitation was not observed. Furthermore, the OECI together with the other partners evaluated which dissemination methods are most effective in changing practice among health professionals. The OECI was also charged to assess the current information needs, sources of information, checks on reliability of messages, degree of reliance on different media and barriers such as language among patients, patient advocacy groups and consumer groups.

This book reports the results coming from a pilot study run among the above tasks leaded by the OECI as part of the Eurocancercoms coordinating action.

The increasing number of patients with cancer, related also to the ageing of the population and of the increased survivorship, urges the need to guarantee optimal nutritional status. This is an important goal for the management of individuals diagnosed with cancer. Although nutrition therapy recommendations may vary throughout the continuum of care, the benefit of optimal caloric and nutrient intake is fundamental whether patients are undergoing active therapy, recovering from cancer therapy, or in remission.

We hope that this book will help to improve nutritional knowledge, quality of life and the distress in cancer subjects thanks to an improved interactive approach giving an easy access to health information making new grounds for turning experience.

## Improve nutrition knowledge, quality of life and the psychological distress in cancer patients

Patrizia Gnagnarella<sup>1</sup>, Demosthenes Akoumianakis<sup>2</sup>, Laura Del Campo<sup>3</sup>, Francesco De Lorenzo<sup>3</sup>, Claudio Lombardo<sup>4</sup>, John Gordon McVie<sup>5</sup>, Giannis Milolidakis<sup>2</sup>, Alessandro Maria Misotti<sup>1</sup>, Luigi Santoro<sup>1</sup>, Richard Sullivan<sup>6</sup>

- <sup>1</sup> Divisione di Epidemiologia e Biostatistica, Istituto Europeo di Oncologia, Milan, Italy
- <sup>2</sup> Centre for Technological Research of Crete, Technological Education Institution of Crete, Greece
- <sup>3</sup> Federazione Italiana delle Associazioni di Volontariato in Oncologia, Rome, Italy
- <sup>4</sup> IRCCS Azienda Ospedaliera Universitaria San Martino IST Istituto Nazionale per la Ricerca sul Cancro, Genoa, Italy, Organisation of the European Cancer Institutes, Brussels
- <sup>5</sup> Direzione Scientifica, Istituto Europeo di Oncologia, Milan, Italy
- <sup>6</sup> Kings College London, and Project Manager of EuroCancerComs- FP7

#### INTRODUCTION

Nutritional status is an important factor in prediction of the risks associated with cancer disease and treatment affecting clinical outcomes, including survival and the ability to tolerate treatments [1, 2]. Nutrition management has been proposed as auspicious to cancer patients [3] because the nutritional status and the nutritional intake are relevant factors affecting also the quality of life and the psychological status of cancer patients [4, 5]. Nutritional screening has been identified for early intervention in clinical practices [1], however there is not always a proactive strategy that can be used when the patient is discharged to home.

The number of cancer survivors continues to increase due to many factors, including a growing ageing population, early detection, improved diagnostic methods, more effective treatments, and improved clinical follow-up after treatment [6]. It is important for physicians, patients and public health professionals to be knowledgeable of issues survivors may face, especially effects of treatment on their physical and psychosocial well-being. This understanding is critical in promoting good health and coordinating comprehensive care for cancer survivors. Furthermore, a significant proportion of the worldwide burden of cancer could

be prevented through the application of existing cancer control knowledge, implementing programmes and public health campaigns promoting, for instance, physical activity and healthier dietary patterns [7].

The world wide web has changed the mass and health communication in the last decades [8, 9, 10, 11]. The Internet and the associated technologies can contribute to disease prevention and health promotion in a number of contexts, enabling a swift, inexpensive and easy distribution of content information; this may turn experience into learning [12, 13]. The Internet offers potential for interaction and is a medium for influencing learning and behaviour change [14, 15]. Evidences from randomised studies suggest support through the Internet to cancer survivors in order to reach a positive outcome regarding social functioning, ability in searching for information [16], depression [17] and state of health perceived [18] though cancer patients quality of life seems not to have improved [16, 17, 18].

As part of the EuroCancerComs project (<u>www.eurocancercoms.eu</u>) [19], this study has been realised by the *Organisation of European Cancer Institutes* (OECI), thanks to the commitment of the following partners: the European Institute of Oncology (IEO), the *Italian Association for cancer patients, their families and friends* (AIMaC - Associazione Italiana dei Malati di Cancro) and the *Italian Federation of Volunteer-Based Cancer Organisations* (FAVO - Federazione italiana delle Associazioni di Volontariato di Oncologia) and with the generous contribution of the Italian cancer network *Alleanza Contro il Cancro* (ACC).

The change in quality of life, psychological status and nutritional knowledge, measured by study questionnaires, has been used to evaluate the effectiveness of the approach based on the 6-month visits of a website dedicated to the study. We hypothesised that providing an Internet "space" where patients can find information about nutritional care and interact (forum and blog), would positively improve knowledge, quality of life and psychological status of the oncological subjects. This chapter presents the intervention study background and design and provides a discussion of preliminary results

#### **STUDY DESIGN**

Starting in March 2011, the study accrued cancer patients searching for nutritional advice on Internet websites of the study partners. Information about the intervention study has been periodically published on: the AIMaC website, with a section dedicated to the nutritional problems of cancer patients [20, 21], the FAVO website; pages of AIMaC, European Institute of Oncology of Milan (IEO, Istituto Europeo di Oncologia) and Umberto Veronesi Foundation (Fondazione Umberto Veronesi) on social networking sites such as Facebook and Twitter. In addition printed leaflets have been distributed at the IEO.

The study has been designed as a 6-month randomized intervention study [22, 23, 24, 25]. Subjects have been invited to take part to it. Online screening preceded randomization to ensure that the study population meets the inclusion criteria (Table n. 1).

Inclusion criteria
– Italian residency;
- cancer subjects: any subject who has been diagnosed with a cancer (all sites);
- age: 18 years and older;
<ul> <li>availability to be contacted by the study team over 6 months;</li> </ul>
<ul> <li>regular access to the internet;</li> </ul>
<ul> <li>e-mail address to receive communication from the study team;</li> </ul>
<ul> <li>not receiving "enteral nutrition" or "tube feeding";</li> </ul>
<ul> <li>not receiving "parenteral nutrition";</li> </ul>
<ul> <li>not presenting a loss of appetite and a reduced nutritional intake associated with a significant weight loss (10% reduction of normal weight in the last 6 months);</li> </ul>

- not receiving palliative care.

Table n. 1. Inclusion criteria of the study.

Using a computer–generated scheme located at TENALEA website (<u>http://tenalea.net</u>), a two-arm randomization list has been generated by stratifying subjects according to their participation to previous clinical trials creating two study groups after receiving the signed informed consent form: Intervention (IG) and Control group (CG) (Fig. 1).

The study protocol has been approved by the Independent Ethical Committee of Eurocancercoms.

IMPROVE NUTRITION KNOWLEDGE, QUALITY OF LIFE AND THE PSYCHOLOGICAL DISTRESS IN CANCER PATIENTS

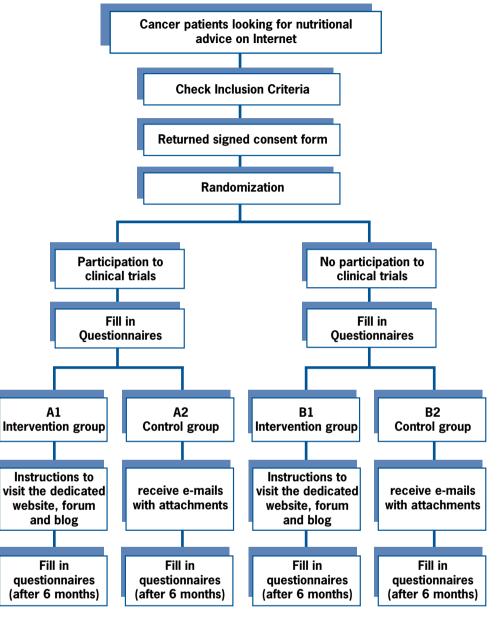


Fig. 1. Flow chart of the study design.

#### Intervention and website

In collaboration with the Technological Educational Institution of Crete, a dedicated website (www.supportonutrizionale.it) has been set up for the Intervention Group (IG) (A1 and B1 in Fig. 1). The website relied on generic tools developed specifically for EuroCancerComs and deployed for various purposes in the course of the project [26]. A variety of sections and functions have been made accessible for

the IG on the website using a personal password and a username. Here, they can find information on nutritional symptoms, information about the study, working groups and study partners (Fig. 2 and Fig. 3).



Fig. 2. Supporto Nutrizionale Homepage (www.supportonutrizionale.it)

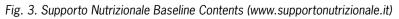
All information about the nutritional problems arising during cancer disease or cancer treatments is published in the contents section and in the blog. It has been drawn up referring to guidelines, documents and recommendations from literature [20, 27, 28, 29, 30, 31]. It is divided into three blocks: "baseline contents", "weekly contents" and "in-depth blog examinations".

- 1. The *baseline contents* (Fig. 3) have been published on the website at the beginning of the study and they refer to general information about ways to reach healthy eating habits, diet and lifestyle recommendations to prevent malignancy, cancer and its therapies and nutritional problems occurring during the disease (see p. 49);
- 2. Weekly contents have been delivered weekly on the website and they are published in the contents area. They are about managing every single eating problem during cancer therapies (from nausea to constipation, changes intaste etc), controlling the weight and avoiding weight loss (see p. 70);

3. In-depth *blog examinations* refer to specific questions posted on the blog by participants or they consist of insights regarding a variety of topics ranging from nutritional labelling to management of diabetes, from celiac disease to recipes recommended for side effects of treatment.

E-mail reminders were sent to subjects when a new content was posted on the website. Moreover, the website hosts a discussion forum where subjects could interact and share ideas, opinions and advice on nutritional problems or other topics that could come out from discussions. Participants from IG may also take part to some activities on the website like polls and they may interact with a group of experts expressly defined for the study. These specialists cover different areas: medical oncology, legal aspects, medicinal drugs, nutrition, psychology and palliative care.

	S S	upportonutrizionale.it	
farsenti .			
Questionen			
Conternati	Company of	Lase Contenut Settimonal	
Paryan	cost a.c	AACKG E LE SHE POLITINEJ TITAAME	
Blog Partners	is staff	NUTRICIONALI LINGUTI AL TUMORE E ALLE SUE TEXADE	mar; 58 hts 2015 13:58
Contattaci	16.027		mar, 88 his 2011 12:03
	in sec.		Way, 20 Yes 2012 12:12
	LA PERSON	De ALDHIN DALE	mar; 58 too 2012 00:04
	LE 18 MAC	COMMICATION: HIR LA PREVENTIONE DEL FUNDIE	the set has read to be
Conte		🕫 Visione d'Amienne 💽 Contenuiss 😨 Buchiche	
Control Fortune Maria		Visione d'Uniens     Contenues     El Notifiche  Certificatione et ausse auchie ausset  Certificatione et ausset  Certificatione et ausset  Certificatione  Certification	
Parum Mesi Perine		Critic Economit in National Schwart Baltingertin Vicent & Economit Economic non public exerce consideratio una singola malatita, me	Vote Carls I cannot a la sua possibil scraper
Forum Mina		Crist Ensure to Known SiX www Enterprise VCerk & Ensure Research one pub essere considerate una singula malerta, ma represente una sole al più di 300 (più diversi di malerta cusuate de di fabrisi didetti. Male mergior partire di piot, en-	
Parum Mesi Perine		Crist I connect in texture in Schwarz Intereste V Crist I facess? I cancol non pub essere considerate ana singula malitita, ma regenerate una sede al pub di 320 dipi diversi di malitita, ma regenerate una sede interestato ambidari parta atta redificacione delle informaziori generate andificari parta redificacione delle informaziori generate andificari parta atta redificacione delle informaziori generate al antificacione dei la sudi	Serapir' Van sin 5 4353 大学校大学
Parum Mesi Perine		Constitutioner de la cons	Straper" Vite cardi < 35.0 黄油素素
Parum Mesi Perine		Const inserver to it use result is beinger Vice & 8 damme Transmission of the server consideration area imposed multitrative response to use a damin of 200 light cherent of and that, me response to the server is the server to the card, was which cool to the measure term of the server is the server to its measure term of the server is the server is the server is a certre of the server is the server is the server is a certre of the server is the server is the server is a certre of the server is the server is the server is a certre of the server is the server is the server is a certre of the server is the server is the server is a certre of the server is the server is the server is a certre of the server is used to server is the server is a certre of the server is used to server is the server is a certre of the server is used to be a server is the server is a certre of the server is used to be a server is the server is a certre of the server is used to be a server is the server is a certre of the server is a server is the server is the server is a certre of the server is a server is the server is the server is a certre of the server is a server is the server is a server	Seraper' Vela venil: 436.0 <b>Artistat</b> ion Cameronita 'Cor's il cancro e le sue paresiteti teregin'
Parum Mesi Perine		Const Inserve Link and even bit for even Vice & I format Vice & I format I control on public enserve consideration are integrite maintening. In proprietation and the integrity parts did runk, which makes and there is also and the angebra parts did runk, which indexed as the massa formation and and the parts did and the parts did the the integrity parts did runk, which indexed as an massa formation and the parts did provide did the did (results, in regist) and based and the parts provide did to based on the single and the parts did provide did to based on the parts of the parts of the parts of the parts of the massa of the theorem of the parts of the parts of the parts of the massa of the parts of the parts of the parts of the parts of the parts of the parts of the parts of	senaper Vete viewe « 25,0 <del>30 pl al al</del> pr Comments Vor's il cantro e le sue pansibili tempio <sup>4</sup> esementa 50
Parum Mesi Perine		Constitutions of the second seco	senaper Vete viewe « 25,0 <del>30 pl al al</del> pr Comments Vor's il cantro e le sue pansibili tempio <sup>4</sup> esementa 50
Parum Mesi Perine		Control Interest in the series I table and I tabl	Margeri Versiehen 4.36.6 Sectorsberger Commente Contri il cantro è la sur panshitt Margeri Anna della Sectorsberger Margeri Ma
Parum Mesi Perine		Control in concrete the borner         Restruction           Vice it it issues         Vice it it issues           Vice it it issues         Vice it it issues           Response on public except conductivity are single maintime, replay the intervention of th	Marger Versen 1201 Web with the second secon
Parum Mesi Perine		Construction of a construction of the construction         Descent on the construction of the	Margeri Vergener 1201 Bedreffeler Cannoners Vari 8 (anne 6 in ser persite strenger sereners anners 2018 (anne 6 in ser persite)
Parum Mesi Perine		Construction of a construction of c	Margeri Vergener Ennovers Vari 8 (anne 6 in ser persite targeri Anne 1997) anne 1997 Anne 1997 A
Parum Mesi Perine		Construction of a construction of constructin of construction of construction of construction of	Margeri Vergener Converses Vari 8 (anne 6 in ser persite) Sargeri Sarg
Parum Mesi Perine		Construction of the second of the second sec	Margeri Vergener - 1315 Sectores for Comments - 1001 il contro è la ser possibili terrapii services



Running in parallel, the *Control Group* (CG) has access to the webspace dedicated to the study only to fill in the questionnaires at the baseline and at the end of the study. The CG receives by e-mail (in Adobe format, pdf) (Fig. 4), documents containing the same information published on the Internet website over the intervention period. Thus, CG subjects do not have access to any web activity, like discussion forums, blogs, polls, but they have no limitations in navigating on the Internet.

Participants (both IG and CG) have at their disposal a dedicated telephone line and e-mail to ask questions, to clarify study aspects and to ask for a technical support.



Fig. 4. Baseline and weekly contents in Adobe format (Acrobat Reader).

#### Questionnaires

A system approach to the evaluation of the effectiveness of the intervention has been established using five instruments. Three questionnaires have been administered at the baseline (pre-test) and will be re-administered at the end of the intervention study (post-test) to all subjects (IG and CG), to assess the changes over time (after 6 months) from the participants (Fig. 5). Once finalized, questionnaires can be inscribed into the website and activated by the administrator for a specified time interval. During this period, web contents are locked (by preventing access) until a subject completes the designated questionnaire.

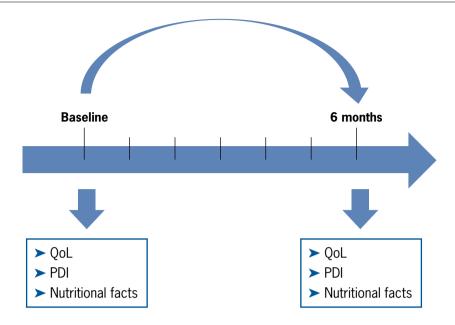


Fig. 5. Questionnaires' timeline administration: at the beginning of the study (baseline) and at the end (6 months later).

**Quality of Life questionnaire** (QoL): an integrated system developed by the European Organization for Research and Treatment of Cancer (EORTC, QLQ-C30, version 3) for assessing the health-related quality of life of cancer patients in clinical trials and others types of research in which patient-reported outcomes are collected. It is designed to be used with a wide range of cancer patients' populations [4]. It includes thirty questions enquiring about physical, cognitive, emotional and social functions, and the presence of symptoms like fatigue, pain, nausea and vomiting (see p. 43).

**Psychological Distress Inventory** (PDI): a validated 13-item self-administered questionnaire, developed by Morasso [5] to measure psychological distress in cancer patients. More specifically it measures: a) reactive anxiety to cancer and its therapies, such as inner tension and worry; b) reactive depression such as sorrow, decreased energy, loss of self-confidence and loss of interests and c) emotional reactions to changes in the body image and disturbances in the interpersonal and sexual behaviours (see p. 44).

**Questionnaire on nutrition facts**: a 20-item questionnaire developed by the working group, inquiring about users' knowledge on healthy eating habits and management of eating problems in addition to questions about food consumption

(vegetables, fruit, meat and alcoholic beverages). It has been tested for readability and comprehension on a group of cancer patients at IEO (pilot study) (see p. 45).

**Socio-demographics questionnaire**: administered at recruitment, this questionnaire collects information on the subject (age, sex, marital status, level of education) and tumour characteristics (site, year of diagnosis, treatment characteristics).

**Satisfaction questionnaire**: administered at the end of the intervention, it consists of 14 and 12-item questionnaire respectively for IG and CG enquiring about the participants' judgment, perceptions and usefulness of the intervention. The total number of questions is different for IG and CG because their function is to evaluate the easiness of use, readability of the website and its contents for IG and to evaluate whether the e-mails were adequate in readability and number for CG.

#### **Statistical analysis**

The study was planned to measure a potential change on nutritional knowledge, quality of life and psychological status in participants (using the study questionnaires), that could result in providing information and giving them opportunities to interact on the study Internet website. The study in its original form requires a final number of 252 subjects to detect a 6-month difference on patients' knowledge of 4 points between IG and CG (10% improvement than the expected value at baseline), with a type I error rate of  $\alpha$ =5%, 80% power and a 20% dropout rate. The sample size calculation was planned to test the primary endpoint with non–parametric (Mann-Whitney-Wilcoxon) test. The present work, however, shows preliminary results on the first 30% of randomized patients and no analysis has been performed on the original primary endpoint. Moreover at this recruiting level, the two randomized groups might be not balanced yet. For this reason the group characteristics at baseline have been compared by a chi-square test for categorical variables and by a t-test for the continuous ones.

The subject's participation is measured for each participant by the number of accesses per day, week and month, number of comments/questions posted on the website, and the active participation to any live activities (i.e.: discussion, pools, votes). The study's website was designed so as to retain these data and to facilitate the relevant statistical analysis. The QoL questionnaire has been analysed following the EORTC procedure [32]. It incorporates nine multi-item scales: five functional scales (physical, role, cognitive, emotional, and social); three symptom scales (fatigue, pain, nausea and vomiting); a global health and quality-of-life scale. Several single-item symptom measures are also included [33]. Using reference values published in the manual [32], our results have been compared against scores for comparable groups of patients.

Regarding PDI questionnaires, it consists of 13 multiple-choice questions ('not at all', 'a little', 'quite a bit', 'much', 'very much'), rated from one to five. Overall scores, ranging from 13 to 65, were derived by summing scores and also dividing them in four classes (None = from 13 to 25; Mild from 26 to 30; Moderate from 30 to 35; Severe >35). The last class, with a score more than 35, includes subjects with a high psychological distress.

The nutrition facts questionnaire consists of 20 multiple-choice questions and each answer is marked in a range from 0 to 3. The total score is divided into 4 score profiles ('poor' 0-29, 'fair' 30-39, 'good' 40-49, 'excellent' 50-60) and, in addition to this classification, three scales are considered: 'lifestyle and healthy eating knowledge', 'nutritional and cancer knowledge' and 'food consumptions'. These scales were constructed summing up the scores from questions belonging to every scale topic. The scores are then rescaled with a proportion from 0 to 100, so that the higher the score is (near to 100), the better the knowledge is. There are no existing reference data, since the questionnaire was developed by the study team expressly for this project.

The satisfaction questionnaire measures over a 4-level scale (excellent, good, fair and poor) the participants' judgment and perceptions of intervention. Findings from this questionnaire are not presented at this time.

#### RESULTS

After the first 7-month recruitment period, 229 subjects filled in the Inclusion Criteria form on the website and 75 of them (33%) were randomized in the two study groups as shown in the participation flow (Fig. 6).

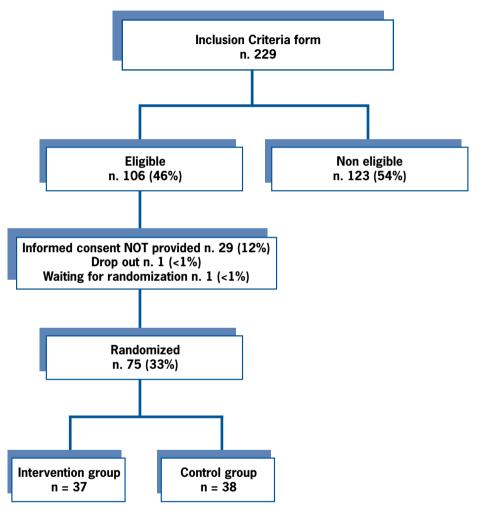


Fig. 6. Participation flow after 7 months recruitment.

Considering the eligible subjects, 29 of them (12%) did not send the signed informed consent form, while not eligible subjects were 123 (54%). The main reasons for exclusion are reported in Table n. 2. Most recorded exclusion criteria were significant weight loss and receiving palliative care, representing the 50% of the total causes of exclusion.

Exclusion criteria	%
Significant weight loss	32%
Receiving palliative care	18%
No email address	14%
No availability for 6 months	8%
Receiving Parenteral Nutrition	8%
Receiving Enteral Nutrition	7%
No cancer diagnosis	7%
Other reasons	6%

Table n. 2. Reasons for exclusion from the study after 7 months recruitment.

Baseline assessments were obtained from 66 individuals, out of 75 randomized subjects. The distribution of the demographic characteristics is not significantly different in the two conditions (IG and CG) at baseline (Table n. 3). Participants are mainly females (79% for IG, 85% for CG), married (64% for IG, 70% for CG) and they achieved a high school education level (42% for IG, 55% for CG). Regarding their occupation status, 70% of the study sample (IG and CG together, data not show in the table) are employed; the remaining 30% are retired, housewives or students. The mean age is 53,4 years (SD $\pm$  10.1, range 32-70) for IG and 49,6 years (SD $\pm$  8.8, range 31-66) for CG.

The average Body Mass Index [BMI: it is calculated as weight (kg) / height (m)<sup>2</sup>] is 23,6 for IG and 24,3 for CG, while 21% and 18% respectively experienced a weight loss of any size.

The majority indicated breast as tumour site (45% for IG, 70% for CG) followed by gastrointestinal tract (24% for IG, 21% for CG). The time of diagnosis was mostly between 2010 and 2011 (64% for IG, 67% for CG). Concerning clinical information, IG and CG subjects received primarily chemotherapy (IG 39% and CG 42%) and other treatments as monoclonal antibodies, hormonal therapy and chemoembolization (IG 27% and CG 30%) and most of them underwent surgery (IG 79% and CG 73%). Dry mouth and mouth soreness (52% for IG and 24% for CG), changes in taste (42% and 27%) and feeling full quickly (15% for IG and 30% for CG) were the most common side effects subjects experienced during treatments. Hypertension was the most frequent concomitant pathology (27% for IG and 9% for CG).

Characteristic	IG n. 33	%	CG n. 33	%	p-value~
Gender					
Female	26	79%	28	85%	0.52
Mean age (SD)	53,4 (10,1)		49,6 (8,8)		0.11[#]
Level of education					
<high school<="" td=""><td>7</td><td>21%</td><td>5</td><td>15%</td><td></td></high>	7	21%	5	15%	
High school	14	42%	18	55%	0.60
>High school	12	36%	10	30%	
Occupation					
Teacher	4	12%	6	18%	
Housewife	7	21%	4	12%	
Retired	4	12%	4	12%	0.04
Employee	2	6%	11	33%	
others	16	48%	8	24%	
Marital status					
Single	2	6%	3	9%	
Living with partner	1	3%	3	9%	
Married	21	64%	23	70%	0.46
Separated/Divorced	8	24%	4	12%	
Widow/Widowed	1	3%	0	0%	
Medium BMI	23,6		24,4		0.26[#]
Weight loss	7	21%	6	18%	0.76
Tumour site					
Breast	15	45%	23	70%	
Gastro-intestinal	8	24%	7	21%	
Gynaecologic	5	15%	0	0%	0.06
others	5	15%	3	9%	

 Table n. 3. Socio-demographic characteristics of Intervention Group (IG) and Control group (CG) at baseline (total n. 66 subjects).

Characteristic	IG n. 33	%	CG n. 33	%	p-value~	
Diagnosis year						
before 2005	3	9%	5	15%		
2005-2009	9	27%	6	18%	0.57	
2010-2011	21	64%	22	67%		
<b>Clinical information</b>						
Treated with chemotherapy	13	39%	14	42%	0.80	
Treated with radiotherapy	1	3%	5	15%	0.09	
Treated with other*	9	27%	10	30%	0.79	
Surgery	26	79%	24	73%	0.56	
Nutritional problems						
Nausea	7	21%	9	27%	0.57	
Vomiting	2	6%	3	9%	0.64	
Trouble swallowing	9	27%	4	12%	0.12	
Changes in taste	14	42%	9	27%	0.20	
Feeling full quickly	5	15%	10	30%	0.14	
Dry mouth or mouth soreness	s 17	52%	8	24%	0.02	
others	6	18%	4	12%	0.49	
Concomitant pathologies						
Hypertension	9	27%	3	9%	0.06	
Diabetes	1	3%	0	0%	0.31	
Respiratory failure	1	3%	0	0%	0.31	
Heart failure	1	3%	0	0%	0.31	
Renal failure	0	0%	1	3%	0.31	
Dyslipidemia	0	0%	1	3%	0.31	
others	5	15%	7	21%	0.52	

^BMI: Body Mass Index calculated as weight (kg)/ height (m<sup>2</sup>)

\* Monoclonal antibodies, hormonal therapy, chemoembolization, etc

~Chi-square test except # (t-test)

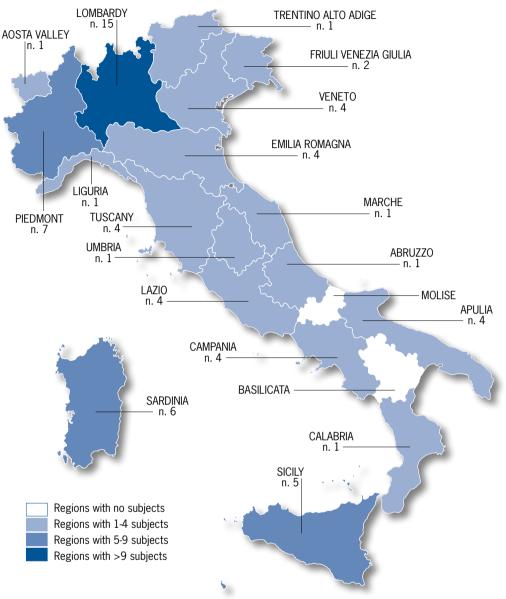


Fig. 7. Number of participants distributed according to Italian regions (total n. 66).

The geographic distribution of subjects according to their territory of residence is shown in Fig. 7. North of Italy is the most represented with 35 subjects (53% of all participants), compared to the Centre, South and the islands respectively with 10, 10, and 11 subjects, and Lombardy is the most representative region (n. 15, 26% of all subjects). Data collected from QoL questionnaire filled at baseline are reported in Table n. 4 and compared with reference values (data for patients with similar characteristics). IG presents a low "Role functioning" score and CG a low "Emotional functioning" and "Social functioning" scores; the worsened symptoms compared to the reference values were "Fatigue", "Nausea and vomiting" and "Constipation" for IG. The Global health status for IG and CG are 58,1 and 60,5 respectively.

Quality of Life	Reference Values*		IG	CG	
Scale§	Mean	SD	Mean SD	Mean SD	
Global Health Status	61,3	24,2	<b>58,1</b> 23,2	<b>60,6</b> 18,2	
Functional scales	Mean	SD	Mean SD	Mean SD	
Physical functioning	76,7	23,2	<b>75,8</b> 19,7	<b>79,6</b> 15,7	
Role functioning	70,5	32,8	<b>57,6</b> 26,1	<b>71,7</b> 20,2	
Emotional functioning	71,4	24,2	<b>63,4</b> 19,8	<b>54,3</b> 23,0	
Cognitive functioning	82,6	21,9	<b>79,3</b> 17,7	<b>78,3</b> 22,2	
Social functioning	75	29,1	<b>68,7</b> 22,0	<b>64,1</b> 19,1	
Symptom scales/items ^	Mean	SD	Mean SD	Mean SD	
Fatigue	34,6	27,8	<b>52,5</b> 23,9	<b>46,1</b> 18,0	
Nausea and vomiting	9,1	19	<b>23,2</b> 24,3	<b>16,7</b> 24,7	
Pain	27	29,9	<b>31,3</b> 23,8	<b>27,3</b> 23,5	
Dyspnoea	21	28,4	<b>25,3</b> 30,1	<b>27,3</b> 19,5	
Insomnia	28,9	31,9	<b>39,4</b> 29,4	<b>38,4</b> 32,4	
Appetite loss	21,1	31,3	<b>18,2</b> 26,5	<b>18,2</b> 25,1	
Constipation	17,5	28,4	<b>32,3</b> 29,4	<b>27,3</b> 30,6	
Diarrhoea	9	20,3	<b>13,1</b> 24,9	<b>18,2</b> 23,7	
Financial difficulties	16,3	28,1	<b>16,2</b> 20,6	<b>21,2</b> 24,7	

All QoL scores range from 0 to 100:

§ for Global Health Status and Functional scales: higher score represents better status/functioning;

^ for Symptom scales: higher score represents more symptoms.

\* All cancer patients: all stages.

 Table n. 4. QoL results for Intervention Group (IG) and Control Group (CG) compared with references values at baseline (total n. 66 subjects).

Participants' distribution of the PDI score, according to the 4 profiles, is presented in Table n. 5 referring to data collected at baseline. Subjects experienced a high psychological distress both in IG (27%) and in CG (39%) and the median score was 29,9 for IG and 32,7 for CG.

Psychological Distress Inventory		IG	C	G
PDI Score profile	n.	%	n.	%
None (13-25)	10	30	7	21
Mild (26-30)	8	24	6	18
Moderate (30-35)	6	18	7	21
Severe (>35)	9	27	13	39
Totals	33	100	33	100
PDI Score	Mean	SD	Mean	SD
Medium score	29,9	6,1	32,7	8,1

 Table n. 5 Psychological Distress Inventory (PDI) distribution of the score and medium score of Intervention Group (IG) and Control group (CG) at baseline (total n. 66 subjects)

Results from the questionnaire on nutrition facts are shown in Table n. 6. As a result, the majority of participants showed a good/excellent score profile (66% for IG, 51% for CG) and the medium score is 42,1 for IG and 40,6 for CG. Regarding the scales, IG and CG report the worst results for the "nutritional and cancer knowledge", although the "Lifestyle & healthy eating knowledge" and "Food consumptions" scales are high.

Nutrition facts questionnaire	IG		CG	
Score profile (range)	n.	%	n.	%
Poor (0-29)	3	9%	3	9%
Fair (30-39)	8	24%	13	39%
Good (40-49)	16	48%	11	33%
Excellent (50-60)	6	18%	6	18%
Totals	33	100%	33	100%
Scales \$	Mean	SD	Mean	SD
Lifestyle & healthy eating knowledge	86,7	15,6	83,3	17,8
Nutritional & cancer knowledge	65,4	20,3	62,6	16,9
Food consumptions	74,2	13,3	73,3	15,8
Score (range)	Mean	SD	Mean	SD
Medium (0-60)	42,1	9,0	40,6	7,7

\$ Scales range from 0 to 100: higher score represents better knowledge/consumption.

 Table n. 6. Nutrition facts questionnaire distribution of score profiles, scales and medium score for Intervention Group (IG) and Control Group (CG) at baseline (total n. 66 subjects).

Analysing IG activities on the website, 74 total actions have been recorded during the first 5 months. They consist mainly of votes to the contents, blog posts and discussions and they represent the 77% (n. 57 actions) of all actions (Table n. 7).

Votes to	n.	%
Contents	25	34
Blog posts	23	31
Forum discussions	9	12
Messages/comments	n.	%
Forum	10	14
Contents	7	9
		100

Table n. 7. Votes, messages or comments posted on the website from IG (n. 33)after 5 months of intervention.

Baseline (B) and weekly (W) contents published on the website during the first 5 months of intervention are showed in Figure 8 and they are sorted by total views. Baseline contents together with "constipation" and "nausea" are the most viewed.

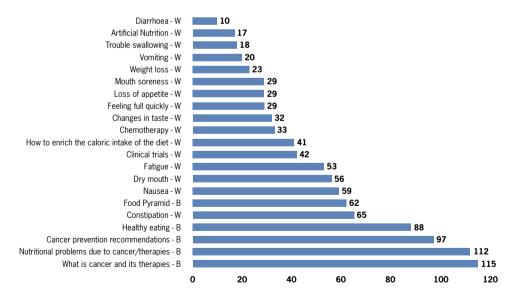


Fig. 8. Baseline (B) and weekly (W) contents published on the web site during the first 5 months of intervention and number of views.

#### **DISCUSSION AND CONCLUSION**

The Supporto Nutrizionale study aims to help cancer patients improving nutrition knowledge, quality of life and psychological status. Cancer patients are stressed and vulnerable from the time of diagnosis through treatment and follow-up [34] and an effective health communication could provide motivation and skills needed to reduce vulnerability and it could help patients to cope better with the disease [35, 36]. In Italy, cancer information is quite lacking in many settings regarding diagnosis, treatments and how to deal with symptoms after hospital discharge [37, 38]. This intervention study offers the chance to evaluate the impact of the Internet to help, to inform and to support cancer patients.

The results are in keeping with those from other studies, regarding the study population. The typical cancer survivors information seeking is a female, well-educated, married, with breast cancer as reported by others study [39, 40, 41, 42, 43]. In addition, our study samples have a good background in nutrition, as showed by the result at baseline of the medium nutritional score profile (42,1 for IG and 40,6 for CG). Education has been widely perceived as one of the most important socioeconomic determinants of health and mortality. It has been suggested that education affects health and mortality through a number of pathways, such as lifestyle, health behaviour, problem-solving abilities, social relations, self-esteem and stress-management, as well as through income or occupation [44, 45, 46, 47].

Patients search for support that could contribute to general well-being and that buffers the impact of stressful experiences [48]. Cancer and its therapies create severe stress situations from depression, anxiety, loneliness, uncertainty and loss of control to fears about cancer recurrence [49, 50, 51]. This status if not controlled can affect social functioning and performance, and a support can have a positive role in reducing the psychological distress in cancer patients [5, 52]. In our study population the psychological distress is high (27% in the IG and 33% in the CG) compared with published study [53], as well as the QoL score results (Global health status 58.1 for IG and 60.5 for CG) at baseline probably due to the short time from the diagnosis and that they were receiving treatments. Taken together the results of the study highlight the well known effect of cancer on the physical and psychological status. We expect a positive effect of this intervention study, but the stage of the disease is the major issue influencing the results.

Advances in technology and the use of the Internet offer the opportunity to provide/deliver information, support or psychotherapeutic interventions to those who are searching for, or are not willing to receive, help in the more traditional face-to-face methods. Synchronous and asynchronous modalities facilitate the interactions and the timely delivery of message. Some interventions can be effective in increasing patients' knowledge or in helping patients to make decisions about their care, but the effect on patients' outcomes is less clear [16, 54, 55, 56, 57, 58]. Outcomes varied widely between studies due mainly to the stage of the disease and to some methodological issue (lack of randomization and/or standardisation) [43, 59].

Considering the strengths of the study, these include the use of a randomized design, the recruitment of participants throughout the country, that allowed to cover 18 out of 20 Italian regions, the use of validated and reliable instruments to measure psychological distress and quality of life of participants as well as the dedicated tools for content management, social interaction and online questionnaire administration. Diversity of cancer diagnosis, treatments and stages can generalise the study findings and give a realistic reflection of the Italian cancer survivors normally using the Internet.

Certain study limitations should be noted. First, the sample size is small, even though the recruitment is still open. The web-based approaches, based on self-reported data and the missing of any direct contact (face-to-face) could be considered as a limitation but at the same time they represent a strength. The web-based approach can play a key role in learning, because digital traces of users' actions and comments can be potentially of interest to others, creating a sort of users' recurrent engagement [10, 11, 60].

This study represents an example of advanced model for communication between cancer patients and researchers, scientists, and physicians involved at different levels in cancer care. To the best of our knowledge, no previous study has examined the effect of such intervention on how to manage the nutrition problems rising during cancer symptoms. The results of this randomized intervention may help in the evaluation of the efficacy of these interventions in cancer setting and considering both the compelling nature of the data and the weakness, this study provides impetus for further exploration of the efficacy of Internet support. OECI

#### Acknowledgements

We thank the group of experts involved in the study for their help, suggestions and comments: Chiara Catania, oncologist, IEO; Elisabetta lannelli, patient representative, F.A.V.O.; Emanuela Omodeo Salè, pharmacist, IEO; Rosa Oricchio, psychologist, AlMaC; Annarita Sabbatini, dietician, IEO; Alberto Sbanotto, oncologist expert on palliative care, IEO.

We thank the librarian William Russell-Edu of the European Institute of Oncology for retrieving the literature.

#### REFERENCES

- 1. Huhmann MB and Cunningham RS. Importance of nutritional screening in treatment of cancerrelated weight loss. Lancet Oncol. 2005 May;6(5):334-43
- 2. Ravasco P, Monteiro-Grillo I, Camilo ME. Does nutrition influence quality of life in cancer patients undergoing radiotherapy? Radiother Oncol 2003 May;67(2):213-20
- 3. Hunter AM. Nutrition management of patients with neoplastic disease of the head and neck treated with radiation therapy. Nutr Clin Practice 1996 Aug;11(4):157-69
- 4. Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ, Filiberti A, Flechtner H, Fleishman SB, de Haes JCJM, Kaasa S, Klee MC, Osoba D, Razavi D, Rofe PB, Schraub S, Sneeuw KCA, Sullivan M, Takeda F. The European Organisation for Research and Treatment of Cancer QLQ-C30: A quality-of-life instrument for use in international clinical trials in oncology. Journal of the National Cancer Institute 1993;85:365-376
- Morasso G, Costantini M, Baracco G, Borreani C, Capelli M. Assessing psychological distress in cancer patients: Validation of a self-administered questionnaire. Oncology 1996;53:295– 302
- 6. Vachani C, Di Lullo GA, Hampshire MK, Hill-Kayser CE, Metz JM. Nursing resources: preparing patients for life after cancer treatment. Am J Nurs. 2011 Apr;111(4):51-5
- 7. Jemal A, Bray F, Center MM, Ferlay J, Ward E, Forman D. Global cancer statistics. CA Cancer J Clin. 2011 Mar-Apr;61(2):69-90. Epub 2011 Feb 4
- 8. Eng TR, Maxfield A, Patrick K, Deering MJ, Ratzan SC, Gustafson DH. Access to health information and support: a public highway or a private road? Journal of the American Medical Association 1998;280(15):1371-5
- Powell J and Clarke A. The WWW of the World Wide Web: Who, What, and Why? Journal of Medical Internet Research 2002;4(1):e4
- 10. Santoro E. Web 2.0 e Medicina. Roma: Il pensiero Scientifico Editore 2009
- 11. Chou WY, Hunt YM, Beckjord EB, Moser RP, Hesse BW. Social media use in the United States: implications for health communication. Journal of Medical Internet Research 2009;11(4):e48
- 12. Patrick K. How patients use the web for second opinions. West J Med. 1999 June; 170(6): 332–333.

- Williams P, Nicholas D, Huntington P, McLean F. Surfing for health: user evaluation of a health information website. Part one: Background and literature review. Health Information & Libraries Journal 2002;19(2):98-108
- 14. Nguyen H, Carrieri-Kohlman V, Rankin S, Slaughter R, Stulbarg M. Internet-based patient education and support interventions: a review of evaluation studies and directions for future research. Comput Biol Med 2004; 34: 95–112
- 15. Linsday S, Smith S, Bellaby P, Baker R. The health impact of an online heart disease support group: a comparison of moderated versus unmoderated support. Health Education Research 2009;24(4):646-654
- 16. Gustafson DH, Hawkins R, Pingree S, McTavish F, Arora NK, Menderhall J, Cella DF, Serlin RC, Apantaku FM, Stewart J, Salner A. Effect of computer support on younger women with breast cancer. Journal of General Internal Medicine 2001;16:435–45
- 17. Winzelberg AJ, Classen C, Alpers GW, Roberts H, Koopman C, Adams RE, Ernst H, Dev P, Barr Taylor C. Evaluation of an Internet support group for women with primary breast cancer. Cancer 2003;97(5):1164-1173
- Owen JE, Klapow JC, Roth DL, Shuster JL, Bellis J, Meredith R, Tucker DC. Randomized pilot of a self-guided Internet coping group for women with early-stage breast cancer. Annals of Behavioral Medicine 2005;30(1):54–64
- 19. EuroCancerComs funded under the EU FP7 "Science in Society". Project number: 230548 [www.eurocancercoms.eu]
- 20. Muscaritoli M, Preziosa I, Canelli A, De Leo S. La nutrizione del malato oncologico. Associazione Italiana Malati di Cancro. 2008
- 21. Rossi Fanelli F, Muscaritoli M, Laviano A, Gavazzi C. Neoplasia e perdita di peso. Che cosa fare? Federazione Italiana delle Associazioni di Volontariato in Oncologia. 2006
- 22. De Lorenzo F, Gnagnarella P, McVie JG, Del Campo L, Oricchio R. Contributo Italiano al Progetto Europeo Eurocancercoms (Supporto nutrizionale in soggetti con cancro: un sito internet dedicato) in Rapporti ISTISAN 2011/1 ISSN 1123-3117. 2011;227-229
- 23. Misotti AM, McVie JG, Milolidakis G, De Lorenzo F, Santoro L, Gnagnarella P. Supporto Nutrizionale in soggetti con cancro: un sito Internet dedicato. Proceedings of the XIII Congresso Nazionale ANDID, 12-14 May 2011, Milan 109
- 24. Gnagnarella P, Misotti AM, Santoro L, Akoumianakis D, Milolidakis G, De Lorenzo F, Lombardo C, McVie JG. A dedicated website for cancer subjects, the nutritional support study: preliminary results. In press www.ecancermedicalscience.com
- 25. Gnagnarella P, Misotti AM, Akoumianakis D, Milolidakis G, De Lorenzo F, Santoro L, Lombardo C, McVie JG. Nutritional support in cancer subjects: a dedicated website. AICR Annual Research Conference on Food, Nutrition, Physical Activity and Cancer 2011. American Institute for Cancer Research, November 3 & 4;Washington,DC
- Akoumianakis D, Milolidakis G, Akrivos A, Panteris Z, Ktistakis G. Clinical practice guideline management information systems: Cancer guidelines as boundary spanning transformable objects of practice, 2nd International Conference on Intelligent Networking and Collaborative Systems (INCoS 2010), November 24-26, Thessaloniki, Greece, IEEE Computer Society, pp. 230-237 (DOI: 10.1109/INCOS.2010.27)
- 27. American Cancer Society. Nutrition for the Person With Cancer During Treatment: A Guide for Patients and Families. 2010

- 28. National Cancer Institute. Eating hints: Before, During and After Cancer Treatment. 2009
- 29. Ministero delle Politiche Agricole e Forestali, Istituto Nazionale di Ricerca per gli Alimenti e la Nutrizione. Linee guida per una sana alimentazione italiana. 2003
- 30. World Cancer Research Fund and American Institute for Cancer Research. Food, Nutrition, Physical Activity, and the Prevention of Cancer: a Global Perspective. 2007;Washington,DC
- 31. Istituto Europeo di Oncologia. La Nutrizione durante il trattamento Oncologico. 2002
- 32. Scott NW, Fayers PM, Aaronson NK, Bottomley A, de Graeff A, Groenvold M, Gundy C, Koller M, Petersen MA, Sprangers MAG. EORTC QLQ-C30 Reference Values Brussels. 2008
- 33. Fayers PM, Aaronson NK, Bjordal K, Groenvold M, Curran D, Bottomley A. The EORTC QLQ-C30 Scoring Manual (3rd Edition) 2001, Brussels
- 34. Trijsburg RW, van Knippenberg FC, Rijpma SE. Effects of psychological treatment on cancer patients: a critical review. Psychosom Med. 1992 Jul-Aug;54(4):489-517
- 35. Fernsler JI and Cannon CA. The whys of patient education. Sem Oncol Nurs 1991; 7: 79–86
- 36. Mesters I, Van den Borne B, De Boer M, Pruyn J. Measuring information needs among cancer patients. Patient Educ Couns 2001; 43: 253–262
- De Lorenzo F, Ballatori E, Di Costanzo F, Giacalone A, Ruggeri B, Tirelli U. Improving information to Italian cancer patients: results of a randomized study. Annals of Oncology 2004;15(5):721-5
- 38. Alleanza Contro il Cancro, Associazione Italiana Malati di Cancro, Istituto Superiore di Sanità. Indagine su cancro e informazione: che cosa chiedono i malati. 2009
- 39. Eysenbach G, Powell J, Kuss O, Sa ER. Empirical studies assessing the quality of health information for consumers on the world wide web: a systematic review. Journal of the American Medical Association 2002;287(20):2691-700
- 40. Mayer DK, Terrin NC, Kreps GL, Menon U, McCance K, Parsons SK, Mooney KH. Cancer survivors information seeking Behaviours: a comparison of survivors who do and do not seek information about cancer. Patient Education and Counseling 2007;65:342-350
- 41. Høybye MT, Dalton SO, Deltour I, Bidstrup PE, Frederiksen K, Johansen C. Effect of Internet peer-support groups on psychosocial adjustment to cancer: a randomised study. British Journal of Cancer 2010;102:1348–1354
- 42. Demunter C, European Commission, Eurostat. How skilled are Europeans in using computers and the internet? Statistics in focus 17. 2006. Available from: http://epp.eurostat.ec.europa.eu/cache/ ITY\_OFFPUB/KS-NP-06-017/EN/KS-NP-06-017-EN.PDF. Accessed 23 September 2011
- 43. Hoey LM, leropoli SC, White VM, Jefford M. Systematic review of peer-support programs for people with cancer. Patient Education and Counseling 2008;70(3):315-37
- 44. Winkleby MA, Jatulis DE, Frank E, Fortmann SP. Socioeconomic status and health: how education, income and occupation contribute to risk factors for cardiovascular disease. American Journal of Public Health 1992;82:816–20
- 45. Elo IT and Preston SH. Educational differentials in mortality: United States, 1979–1985. Social Science and Medicine 1996;42:47–57
- 46. Pappas G, Queen S, Hadden W, Fisher G. The increasing disparity in mortality between socioeconomic groups in the United States, 1960 and 1986. New England Journal of Medicine 1993;329:103–9

- 47. Harper S and Lynch J. Methods for Measuring Cancer Disparities: Using Data Relevant to Healthy People 2010 Cancer-Related Objectives. NCI Cancer Surveillance Monograph Series, Number 6. Bethesda, MD: National Cancer Institute, 2005. NIH Publication No. 05-5777
- 48. Cutrona CE. Stress and social support: in search of optimal matching. Journal of Social and Clinical Psychology 1990;9:3–14
- 49. Cliff AM and MacDonagh RP. Psychosocial morbidity in prostate cancer. II. A comparison of patients and partners. British Journal of Urology International 2000;86:834–9
- 50. Mullen P, Smith R, Hill E. Sense of coherence as a mediator of stress for cancer patients and spouses. Journal of Psychosocial Oncology 1993;11:23–46
- 51. Dunn J, Steginga S, Rosoman N, Millichap D. Review of peer support in the context of cancer. Journal of Psychosocial Oncology 2003;21:55–67
- 52. Wortman CB. Social support and the cancer patient. Conceptual and methodological issues. Cancer 1984;53(suppl):2339-2362
- 53. Morasso G, Di Leo S, Caruso A, Decensi A, Beccaro M, Berretta L, Bongiorno L, Cosimelli M, Finelli S, Rondanina G, Santoni W, Stigliano V, Costantini M. Evaluation of a screening programme for psychological distress in cancer survivors. Support Care Cancer 2010;18(12):1545-52
- 54. Davison BJ and Degner LF. Feasibility of using a computer-assisted intervention to enhance the way women with breast cancer communicate with their physicians. Cancer Nursing 2002;25:417–24
- 55. Austoker J, Bankhead C, Forbes LJ, Atkins L, Martin F, Robb K, Wardle J, Ramirez AJ. Interventions to promote cancer awareness and early presentation: systematic review. British Journal of Cancer 2009;101(Suppl 2):S31-9
- 56. Eysenbach G. The impact of the internet on cancer outcomes. CA: A Cancer Journal for Clinicians 2003;53:365–71
- 57. Kroeze W, Werkman A, Brug J. A systematic review of randomized trials on the effectiveness of computer-tailored education on physical activity and dietary behaviors. Annals of Behavioral Medicine 2006;31(3):205–223
- Norman GJ, Zabinski MF, Adams MA, Rosenberg DE, Yaroch AL, Atienza AA. A review for eHealth interventions for physical activity and dietary behaviour change. American Journal of Preventive Medicine 2008;33(4):336-345.e16
- 59. Ryhanen AM, Siekkinen M, Rankinen S, Korvenranta H, Leino-Kilpi H. The effects of Internet or interactive computer-based patient education in the field of breast cancer: a systematic literature review. Patient Education and Counseling 2010;79:5-13
- 60. Zhang K and Peck K. The effects of peer-controlled or moderated online collaboration on group problem solving and related attitudes. Can J Learn Technol 2003; 29: 93–112

#### Appendix 1: Quality of Life questionnaire (QoL) (by EORTC QLQ-C30, version 3)

		Not at all	A little	Quite a bit	Very much
1.	Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2.	Do you have any trouble taking a long walk?	1	2	3	4
3.	Do you have any trouble taking a short walk outside of the house?	1	2	3	4
4.	Do you need to stay in bed or on a chair during the day?	1	2	3	4
5.	Do you need help while eating, dressing, washing yourself or using the toilet?	1	2	3	4
Duri	ng the past week:	Not at all	A little	Quite a bit	Very much
6.	Were you limited in doing either your work or other daily activities?	1	2	3	4
7.	Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8.	Were you short of breath?	1	2	3	4
9.	Did you have pain?	1	2	3	4
10.	Did you need to rest?	1	2	3	4
11.	Did you have trouble to sleep?	1	2	3	4
12.	Did you feel weak?	1	2	3	4
13.	Have you lacked appetite?	1	2	3	4
14.	Have you felt nauseated?	1	2	3	4
15.	Have you vomited?	1	2	3	4
16.	Have you been constipated?	1	2	3	4
17.	Did you have diarrhoea?	1	2	3	4
18.	Were you tired?	1	2	3	4
19.	Did pain interfere with your daily activities?	1	2	3	4
20.	Did you face difficulties in concentrating on things, like reading a newspaper or watching the television?	1	2	3	4
21.	Did you feel tense?	1	2	3	4
22.	Did you worry?	1	2	3	4
23.	Did you feel irritable?	1	2	3	4
24.	Did you feel depressed?	1	2	3	4
25.	Did you have difficulties in remembering things?	1	2	3	4
26.	Has your physical condition or medical treatment interfered with your family life	? 1	2	3	4
27.	Has your physical condition or medical treatment interfered with your social				
	activities?	1	2	3	4
28.	Has your physical condition or medical treatment caused you financial difficultie	s? 1	2	3	4
For 1	the following questions please circle the number between 1 and 7 that be How would you rate your overall health during the past week?	est applie	s to you	:	
29.	1 (Very poor) 2 3 4	5	6	7 (Fv	cellent)
30.	How would you rate your overall quality of life during the past week?	5	0	/ (LX	cellent)
50.	1 (Very poor) 2 3 4	5	6	7 / Г.	cellent)

#### Appendix 2: Psychological Distress Inventory (PDI) questionnaire

(by Morasso G. et al,1966)

1. Do you think your desire to speak with others has diminished?	
Not at all	
A little	
Quite a bit	٦
Much	
Very much	]
	_

# 2. Have you felt calm? Not at all A little Quite a bit Much Very much

#### 

Quite a bit	
Much	
Very much	

#### 4. Have you felt tired or lacking in energy?

Not at all	-	
A little	-	
Quite a bit	-	
Much	-	
Much Very much	-	

#### 5. Have you felt more alone?

Not at all	
A little	
Quite a bit	
Much	
Very much	

#### 6. Have you felt better?

Not at all	
A little	
Quite a bit	
Much	
Very much	

# 7. Have you experienced moments of dejection or depression? Not at all

A little	
Quite a bit	
Much	
Very much	

#### 8. Do you think that your illness might have created problems of self-image for you that did not exist before? Not at all\_\_\_\_\_

A little\_\_\_\_\_\_\_Quite a bit \_\_\_\_\_\_\_

#### 9. Have you felt worthless?

Not at all	
A little	
Quite a bit	
Much	
Very much	

10. Have you felt a lack of willpower?	
Not at all	
A little	
Quite a bit	
Much	
Very much	

# 11. Has your interest in the world that surrounds you diminished? Not at all A little Quite a bit Much Very much

# 12. Have you felt that your sexual desire has diminished? Not at all A little Quite a bit Much Very much

### 13. Has your illness negatively influenced your relationships with others?

Not at all	
A little	
Quite a bit	
Much	
Very much	

#### Appendix 3: Questionnaire on nutrition facts

#### 1) Which are the principles of healthy eating?

- O Do not eat much and increase vitamins consumption
- O Follow a balanced diet using also minerals and vitamins supplements
- Beware of weight, decrease fat, sugars and salt consumption, increase fruit and vegetables consumption
- ${\rm O}$  Privilege the proteins and fat consumption and complete with fruit and vegetable
- ${\rm O}$  Don't know

#### 2) What does a healthy lifestyle consist of?

- O Eat more fruit, vegetables, drink more water, decrease fat consumption, be more physically active
- O Be physically active, limit alcohol consumption, do not smoke and follow a healthy eating plan
- O Do not smoke, do not drink alcoholic beverages, be physically active
- O Do vigorous physical activity
- O Don't know

#### 3) What is the food pyramid?

- ${\rm O}$  A graphic where weekly suggested physical activity levels are placed in a decreasing order
- ${\rm O}$  A graphic that shows how many portions of every food groups have to be consumed per day
- ${\rm O}$  A guide for the population that suggests some recommendations on food to be consumed monthly
- ${\rm O}\,{\rm A}$  tool to be used from people that want to follow a healthy vegetarian diet
- O Don't know

#### 4) Does a diet to fight cancer exist?

#### ${\rm O}$ Yes

- O Yes, we need to add vitamins supplements
- O No, it doesn't
- O No, it is necessary to follow a healthy diet
- O Don't know

#### 5) It is common to lose weight throughout the course of cancer?

- O Yes, always
- O Yes, it happens often
- ${\rm O}$  No, never
- O No, otherwise there could be a weight gain
- O Don't know

#### 6) Do I have to reduce physical activity throughout the course of cancer?

• Yes, you'd better rest and lay in bed

- O Yes, you'd better rest
- O No, you'd better do even vigorous physical activity
- O No, you'd better do physical activity appropriated with your conditions (i.e. walk)
- O Don't know

#### 7) Can I use supplements?

- O Yes, always
- O Yes, but your physician should evaluate your conditions first
- O No, never
- O No, because supplements can cause some adverse effects
- O Don't know

#### 8) When Artificial Nutrition must be used?

Artificial Nutrition is a practice that allows the feeding of those patients that, for many reasons, are not able to introduce, even partially, by mouth liquid or solid foods.

- O Always throughout cancer
- O When the patient is no more able to feed himself autonomously
- O It is not suggested
- O Never, it is suggested only in cases when oral feeding is dangerous
- O Don't know

# 9) Are there foods that can reduce collateral effects due to chemotherapy and radiotherapy?

- O Yes, fruit and vegetables
- O Yes, meat and fish
- O No, none in particular
- O No, but a well nourished patient can better cope with the collateral effects
- O Don't know

# 10) Can I avoid changes in taste during cancer treatments (e. g. chemotherapy), without mouth soreness?

- $\ensuremath{\mathbf{O}}$  Yes, with some tricks like using soy sauce, lemon juice, vinegar or chewing gums
- Yes, by eating bitter foods
- No, because it seldom happens
- ${\rm O}$  No, because it is not possible to avoid changes in taste
- O Don't know

#### 11) If there is loss of appetite, what should I do?

- O Often drink water and carbonated drinks, eat many snacks
- O Eat many snacks, eat dry foods and always lay down to bed
- O Eat small and frequent meals, make food appetizing, eat slowly and rest after every meal
- O Cook meals by yourself, eat frequently, eat many snacks
- O Don't know

#### 12) What can I do to stop nausea and vomiting?

- Eat according to one's needs
- O Eat small and frequent meals, dry foods, do not introduce too many liquids
- ${\rm O}$  Do not eat anything and drink enough to stay hydrated
- O Eat fat foods and foods that slow down digestion
- O Don't know

#### 13) What can I do if I experience constipation?

- Eat small and frequent foods, preferring high-protein foods (meat, fish and cheese) and drink frequently
- O Use vitamin and mineral supplements, drink frequently and practice vigorous physical activity
- Add more fibre to the diet (fruit, vegetables, whole grain cereals) and help yourself with fruit syrups or juices, practice moderate physical activity
- O Address to a physician
- O Don't know

#### 14) What can I do if I have trouble in swallowing foods?

- O Address to a physician
- O Drink frequently, suck ice cubes, prepare a soft diet using sauces and liquids (broth, gravy)
- $\odot$  Eat small and frequent foods, drink frequently carbonated drinks, eat sweet and tasty foods
- O Eat high-calories foods and nutritional supplements, practice a moderate physical activity
- ${\rm O}$  Don't know

#### 15) What can I do if I have a dry mouth?

- O Drink frequently, eat sweets and chocolate
- O Drink low alcoholic beverages to avoid dry mouth
- O Drink frequently and hydrate lips, do not have snacks
- O Drink frequently, suck ice cubes, eat soft foods, hydrate lips
- O Don't know

#### 16) What can I do if I have mouth soreness?

- O Eat small and frequent quantities of foods
- O Drink plenty of liquids, avoid salty, spicy and acid foods, eat soft foods
- O Eat many snacks, drink frequently, hydrate lips
- O Consume nutritional supplements, drink frequently, hydrate lips
- O Don't know

### Next questions refer to your current eating habits. Please report consumptions that are closer to your current eating habits.

#### 17) How many fruit and vegetable servings do you eat daily?

- O Less than 1 a day
- O 2-3 a day
- O 4-5 a dav
- O More than 5 a day

#### 18) How much meat do you eat weekly?

- [1 meat serving is 70-100 g (raw weight); please include in your count also cold cuts,
- 1 serving = 50 g
- O Less than 2 servings per week
- ${\rm O}$  From 2 to 4 servings per week
- O From 4 to 8 servings per week
- O More than 8 servings per week

#### 19) How many alcoholic units do you consume daily?

[One alcoholic unit is 1 glass of wine, or 1 can of beer or in 1 shot of hard liquor (40 ml)]

- O I do not drink alcoholic drinks or less than 1 a day
- 1-2 a day
- O 3-4 a day
- O More than 4 a day

#### 20) Do you practice physical activity?

- O No, I don't
- O Yes, I practice soft physical activity (walking, climbing up the stairs)
- O Yes, I practice medium intensity physical activity (go cycling, gardening, housework)
- O Yes, I practice vigorous physical activity (more than 3 hours a week of sports)

### Nutrition and cancer: hints for patients

Patrizia Gnagnarella<sup>1</sup>, Laura Del Campo<sup>2</sup>, Francesco De Lorenzo<sup>2</sup>, Alessandro Maria Misotti<sup>1</sup>

- <sup>1</sup> Divisione di Epidemiologia e Biostatistica, Istituto Europeo di Oncologia, Milan, Italy
- <sup>2</sup> Federazione Italiana delle Associazioni di Volontariato in Oncologia, Rome, Italy

#### CANCER AND ITS POSSIBLE THERAPIES



# es of mo

NUTRITION AND CANCER: HINTS FOR PATIENTS

#### What is cancer?

Cancer cannot be considered as a single illness but represents a series of more than 100 different types of illnesses caused by distinct factors. In the majority of cases, a mutation of a genetic cell's information leads to the development of a tumour mass and to the invasion of surrounding tissues.

All tumours begin from a single cell that loses control during the growing phase. Actually a single cell's genetic mutation is not in itself a sufficient condition for the development of cancer; generally cancer originates from an accumulation of mutations. Inside each cell there are, in fact, mechanisms intended to prevent the survival of a tumour cell. The tumour process can also be triggered when these mechanisms fail. Due to this "failure" cells divide when they shouldn't, generating an enormous amount of other cells with the same regulating defect.

Tumours may either be benign or malignant. Cells, in benign tumours, have a slow growing rate and are not able to invade other parts of the body, but they could however put pressure on surrounding organs should their dimension and number grow. On the contrary, cells in malignant tumours, if not treated, can invade and destroy nearby tissues and also spread at a distance. They can in fact break away from the initial site of the tumour and spread to other sites through the blood and the lymphatic system until they hit and involve other vital organs such as lungs, liver, brain. Once reached a new area they may proliferate creating a new mass called "metastasis". This process is called **metastasization** and represents the most advanced phase of the tumour progression, determining the real cause of death by cancer.

#### What are the causes?

Many are the causes that can initiate cancer. Generally the gene's alteration responsible for the illness is determined by environmental causes, prolonged exposure to carcinogens of chemical, physical and viral origin. Some examples include smoking, asbestos, some substances generated by oil or coal combustion, drinking, an unhealthy diet, ultraviolet sun rays and chemical substances produced in industrial processes and in agriculture. To these external factors, hereditary genetic mutations that may cause the development of cancer can be added.

#### **Possible therapies**

Cancer, as previously described, cannot be considered as a single illness, as many different types of cancer exist. Each one of these originates in a type of tissue and has a proper name, a proper cause and a proper treatment. For this reason it is necessary for the oncologic therapy not to be standardised but in fact customised. Currently various therapies exist in the medical field to fight against cancer.

#### Chemotherapy

Chemotherapy works with the use of one or more medications called cytotoxic and antiblastic whose aim is to destroy cancer cells, preventing the dividing and the reproduction of tumour cells. A series of factors, among which the type and stage of the tumour, biological conditions (histological conditions of the neoplastic tissue) and clinical conditions (age, sex, pre-treatment, general conditions) of the patient affect the modalities and the dose of the treatment.

Chemo drugs can be delivered through the blood stream throughout the body and once in the tumour site, they work causing the death of neoplastic cells. These drugs could have the same effects on some healthy cells that still maintain their ability to heal the damage, but could induce a series of side effects. These effects are generally temporary, and in most cases, they disappear at the end of the treatment. The cells of certain areas are more prone to suffer from chemotherapeutic damage: the mouth lining, the bone marrow, hair follicles, the digestive system. Generally more than one course of treatment is needed and it will be followed by a rest period in order for the cells and the tissues to recover.

#### Radiotherapy

Radiotherapy is the use of high energy radiation in order to destroy tumour cells. The treated tumour cells are induced to die, due to the high energy used, blocking their multiplication and growth. Generally radiations are concentrated mostly in the affected area to avoid damaging healthy cells.

There are different ways of using radiotherapy:

- External beam radiation therapy (or transcutaneous radiotherapy) consists of radiating specific parts of the body from the outside using, in the majority of cases, a machine called linear accelerator (LINAC);
- Branchytherapy also known as internal radiotherapy, consists in placing the radiation source next to the area requiring treatment;
- Intraoperative radiation therapy (or IORT) in which a single high dose of radiation is delivered during surgery allowing the irradiation directly to the target area after the removal of the tumour;
- Metabolic radiotherapy consists in the use, for therapeutic purposes, of radiopharmaceuticals metabolised by the body. For radioactive protection purposes, this therapy will be carried out in a hospitalisation regimen, in rooms adequately prepared for radioactive protection purposes.

In the case of external beam radiation therapy, the radiation dose is given in more than one short term daily session, generally as an outpatient and over a period of many weeks. The radiation dose so divided, allows healthy cells not to get damaged so much. In fact, if the total dose was given in one session, healthy cells would become more damaged losing their ability to heal themselves.

#### Surgery

Surgery is the oldest of the cures used to treat cancer and still remains today a fundamental treatment. Surgical therapy entails the total removal of the neoplastic mass in the attempt to avoid surrounding tissues getting invaded. At times, to ease the scalpel's work, a preoperative chemotherapy is necessary to reduce the dimension of the tumour.

#### Hormonotherapy

This therapy alters the balance of certain hormones in the body, substances

that stimulate the cell's division in some organs. In fact, it has proven to be extremely effective on so called "hormone-sensitive" tumours such as some kind of breast, ovary, prostate cancer etc.

This type of therapy enables the patient, in certain cases, not to resort to surgery, even if it emerges to be only applicable to tumours that have proven to be dependent on hormonal factors.

#### Immunotherapy

Immunotherapy consists in the creation of vaccines that are able to "awaken" the immune system against tumour cells. Immunotherapy, in fact, is based on the conviction that the human immune system has the potential of protecting and healing itself also from diseases such as cancer. This therapy uses so called "sentinel cells" properly armed with drugs in order to fight tumours. These sentinel cells already exist in the blood; through immunotherapy they become in some way enhanced and trained to recognise tumour cells in order to fight them.

At the moment various antitumor vaccines are being studied to be used in conjunction with chemotherapy. Some of these are already used with success in suitable patients. The combination chemotherapy – immunotherapy could be the turning point of the fight against tumours.

#### Hyperthermia

Hyperthermia is a type of cancer treatment that through radiofrequencies causes an artificial rise of the body temperature in local areas (on certain organs) or also in the entire body. During treatment, tumour cells reach a high temperature (>  $43^{\circ}$  C) causing their death.

Obviously, the type of tumour and the affected organ can influence the effectiveness of hyperthermia over tumour cells. Furthermore, the heat sensitises tumour cells towards certain medications or radiations. Best effects of hyperthermia can be obtained in combination with other therapies (chemotherapy, radiotherapy, immunotherapy) in order to enhance beneficial effects and reduce toxic ones. Treatment can be repeated, but not more than three times per week.

#### NUTRITION PROBLEMS LINKED TO CANCER AND ITS THERAPIES

It is very important to follow a healthy diet if suffering from cancer or undergoing certain therapies, because these can influence the appetite, the ability to tolerate certain food or assimilate certain nutrients. It is normal not to feel well or to have gastrointestinal problems such as nausea, vomiting or diarrhoea, only to mention some. These symptoms can be



caused by cancer alone, by the organ or the part of the body involved, by the type of treatment and by the dose used. They can appear immediately, during the first treatment or subsequently. Certain medication used to ease some of the symptoms, for example the antiemetics (drugs used for the symptomatic treatment of nausea and vomiting), can lead to constipation; certain chemotherapeutics can lower immune defences inducing common infection of the oral mucous membrane, difficulty in chewing and in swallowing. Also anxiety and depression can influence or limit food intake.

An adequate diet, that supplies all substances needed by the body, allows maintenance of weight, a better tolerance for therapies, an improved resistance to the toxic effects of therapy and the possibility to fight infections that may arise. Restraining side effects and problems that could arise during the pathology determines a positive relapse on the pursuance of the treatment and on the quality of life. It is therefore important to continue eating in an adequate way in order to better tolerate such side effects until they disappear, before excessive weight loss could compromise the course of the therapy and of the disease.

It is important to notice, though, that the symptomatology remains very personal. Disorders that could arise, are generally temporary and gradually disappear at the end of the therapy.

According to the phase/stage of the disease and of the therapy in use, it is possible to organise a nutritional intervention that contemplates an adequate diet, the intake of nutritional supplements or oral integrators; if these first expedients are not sufficient the use of artificial nutrition (enteral or parenteral) in hospital or also at home will be necessary.

Although there is no evidence that a diet that cures cancer exists, it is certainly

true that an adequate diet can help to fight consequences, from a physical and psychological point of view.

Cancer and its treatments can, furthermore, weaken the immune system, damaging cells that have the function of protecting us from germs and viruses. This situation can occur during the course of chemotherapy, radiotherapy, or in the case of bone marrow transplant. Our body becomes more vulnerable, with a greater risk of becoming ill. Food can carry certain bacteria and germs. In this case it is important to pay attention to the choice of food consumption and its preparation. The handling, conservation and cooking of food, are important stages to restrain food contamination.

Below are the main side effects that can occur during the course of certain treatments.

#### Chemotherapy

Chemotherapy uses either single medication or a combination of more than one drug. These can be taken orally or they can be infused into the blood stream.

In relation to the type of drug, to the dosage and to the degree of the damage caused to healthy cells, nutritional disorders could arise such as:

- Loss of appetite
- Alteration of taste and smell
- Throat and mouth soreness
- Nausea
- Vomiting
- Diarrhoea
- Constipation
- Fatigue
- Weight gain
- Weight loss.

#### Radiotherapy

During this treatment, high energy radiation is given to the tumour to destroy tumour cells. Below are some common side effects that can occur during the course of the radiation therapy according to the treated area.

Radiation area	Side effects related to nutrition
Head and neck	Ulceration and soreness of the oral cavity
	Reduction of the salivary glands activity with consequent faucial dryness
	Altered taste perception
	Chewing and swallowing difficulties
	Nausea and vomiting
	Predisposition of dental decays
Chest	Alteration of the oesophageal mucosa and dysphagia
	Nausea with consequent loss of weight and appetite
	Heartburn
Pelvis and abdomen	Nausea
	Fatigue
	Diarrhoea
	Loss of appetite
	Flatulence
	Difficulty in tolerating milk and derivatives

#### Surgery

Surgery, according to the site of the operation, could compromise, alter or slow down normal food intake, digestion and metabolism of nutrients.

Problems are various and they sometimes overlap, according to the organ of the digestive system involved (mouth, oesophagus, stomach, intestine, colon and rectum):

- nausea
- vomiting
- precocious satiety
- loss of appetite
- chewing and /or swallowing difficulty
- weight loss
- diarrhoea
- constipation.

NUTRITION AND CANCER: HINTS FOR PATIENTS

#### Hormone therapy

Hormone therapy can cause, as per other therapies, some side effects related to nutrition:

- change in taste perception
- diarrhoea
- weight gain.

#### Immunotherapy

This kind of therapy can influence the interest towards food, but also feeding capability. Immunotherapy, together with flu-like symptoms (muscle pain, fatigue and fever) that tend to overlap, could cause the following symptoms:

- poor appetite
- taste alteration
- nausea
- vomiting
- faucial dryness
- oral cavity soreness
- diarrhoea
- weight loss.

#### Hyperthermia

Hyperthermia is a type of therapy that causes an artificial rise of the body temperature in local areas (on certain organs) or also in the entire body. Side effects are often caused by chemotherapy or radiotherapy associated with hyperthermia and in small proportion by hyperthermia itself, particularly if performed on the entire body. Disorders that can arise more frequently are:

- nausea
- vomiting
- diarrhoea.

#### **HEALTHY NUTRITION**

A specific diet that fights cancer does not exist. A healthy and balanced diet can reduce the risk of getting cancer and developing chronic diseases. A diet, to be considered healthy and balanced, must include all the important nutrients to our body: carbohydrates (mostly found in pasta, bread, rice, sweets), proteins



(mainly found in meat, fish, eggs, pulses), and fat (especially found in oil and vegetable fats) also completed by micronutrients, such as vitamins, minerals, trace elements (principally found in fruit and vegetables, either cooked or raw). A diet that excludes completely one or more ingredients of daily nutrition is contraindicated, if not even dangerous for our body. A balanced diet that meets the caloric – energetic requirements of the body, allows weight maintenance and the proper function of the immune defences.

The National Institute of Research for Food and Nutrition (INRAN) together with the Ministry of Agriculture, Food and Forestry Policies, published in 2003 the last review *Guidelines for a Healthy Italian Diet (Linee guida per una sana alimentazione Italiana)* that supplies a series of nutritional indications for all those who wish to follow a healthy diet. These recommendations are also meant for cancer patients who have not suffered important weight loss or who do not have other nutritional disorders. Thanks to this document everyone has a way of knowing which food to prefer and which to limit.

#### More grains, pulses, fruit and vegetables

Grains, pulses, vegetables and fruit are good sources of carbohydrates, vitamins, minerals, fibres and other bioactive elements of vegetal origin, and play an important role in our nutrition. Grains and pulses, apart from being good sources of carbohydrates, are also a good source of proteins and should supply 60% of daily calories, three quarters of which are in the form of complex carbohydrates (starch).



Fruit and vegetable consumption is recommended, because these foods present a low caloric density and a high filling power. Besides, they supply vitamins and minerals necessary to the body, useful fibres to maintain bowel function and they contain as well various bioactive ingredients (such as organic acids, polyphenols, oligosaccharides, etc). These components do not nourish, but they protect the body with many mechanisms that vary from antioxidant action towards free radicals and from the protection of polyunsaturated fatty acids, to privilege the development of healthy bacterial flora.

Several studies have shown that a nutrition rich in grains, pulses, fruit and vegetables provides protection from many diseases widespread in developed countries.

More cereals, pulses, fruit and vegetables		
How to behave		
Grains	Consume bread, pasta, rice and other grains (better if wholegrain), on a regular basis and avoid adding too many fatty sauces;	
	When possible choose products obtained with wholegrain flour and not with the simple adding of wheat or other fibre (read labels).	
Pulses	Increase consumption of fresh or dried pulses.	
Fruit and vegetables	Consume daily more portions of fresh fruit and vegetables.	

#### Fat: choose quality and limit quantity

Fat introduced into the diet can be found in condiments (e.g.: oils, butter, margarine) or in food, such as meat, eggs, fish, cheese and nuts. They are energy-dense foods (9 kcal/g), provide essential fatty acids (omega-6 and omega-3) and encourage the absorption of fat-soluble vitamins A, D, E, K and of carotenoids.



Fat should provide approximately 20 to 25% of total calories for sedentary subjects, to a maximum of 35% for subjects who are physically very active.

Regarding the nutritional quality of fats, daily use should prefer fats of

vegetable origin, as olive oil or oilseed, rich in unsaturated fatty acids, instead of animal ones rich in saturated fatty acids and cholesterol that increase the risk factors for obesity, cardiovascular diseases and tumours onset. In this regard, the suggested proportion of total calories is: not more than 7-10% of saturated fatty acids, to a total of 20% of monounsaturated and about 7% of polyunsaturated.

Fats: choose quality and limit quantity	
How to behave	
Fat condiments	Moderate the use of fats and oils used in cooking and seasoning. Possibly use non-stick pans, microwave, steam or wrapped cooking;
	Limit the use of condiments of animal origin: (butter, lard, suet, cream, etc);
	Prefer fat of vegetable origin: above all extra virgin oil and seed oil;
	Use oils preferably uncooked and avoid reusing already cooked fats and oils.
Fatty foods	Do not exceed in the consumption of fried food;
	Eat fish more often, fresh or frozen (2-3 times per week);
	Prefer lean meat and eliminate visible fat;
	If you like eggs you can eat them up to four per week distributed during the week;
	If you consume much milk, choose preferably skimmed or semi, that still maintains its calcium content;
	All cheese contains high quantities of fat: in any case choose low fat ones or consume smaller portions.

#### Sugar, sweets and sweet drinks: correct intake limits

Sugar is principally contained in sweet foods and drinks and also in honey and fruit; they all provide energy but have a different intensity of sweet taste (sweetening power). Sugar is made of simple molecules, that are able to be rapidly metabolised and available for energetic functions. In particular, simple sugars (for example sucrose) mainly influence glycaemia compared to complex sugars (starch found in pasta and rice).



For this reason it is advisable to maintain a consumption of simple sugars in the limits of 10-15% of daily total calories. Amongst foods rich in sugar it is better to prefer the so-called bakery products (such as biscuits, cakes without filling) that also provide complex carbohydrates and other nutrients, rather than sweets, chocolate and chocolate bars that mostly contain sucrose and fats.

Sugar, sweets and sweet drinks: in the correct dose	
How to behave	
Sweet foods and drinks	Moderate the use of bakery products (buns or pastries) and sweet drinks during the day, so as not to exceed permitted quantity of sugar;
	Amongst sweets prefer bakery products of Italian tradition, that contain less fat and sugar and more starch, such as biscuits, cakes without the filling, etc.;
	Consume occasionally sweet spreadable products on bread or melba toast (such as jams, honey and creams);
	Limit the use of products that contain a lot of sucrose, especially those that stick to your teeth, such as soft sweets, nougat, etc. Always clean teeth afterwards;
	If you want to eat low-calorie artificially sweetened food and drinks, always check the label for the kind of sweetener used and the instructions.

#### Drink plenty of water everyday

Our body is mostly made up of 55-60% of water, and water is essential to keep us alive, as it takes part in the majority of physiological reactions and in the structure of different substances. Water is continually lost or used by the body, so it is fundamental to reintegrate any possible liquid loss, in order to maintain an optimal water balance and to keep a good state of health.



The need for water however, can in some cases increase: during breast feeding, in case of fever, when temperature causes high perspiration and with diuretic increase. On the whole the daily water requirement is 1ml per kcal of energy expenditure (for adults), therefore the suggested daily intake for an adult is of

approximately 2 litres per day to be satisfied with food and drinks. One part of water is introduced with foods (approximately 600-800 ml) that have a high percentage of water, such as soups, milk, fruit and vegetables; the rest must be introduced with drinks (approximately 1200 ml) that correspond to 6-8 glasses of water per day.

Drink each day plenty of water	
	How to behave
Drinks	Always quench your thirst, rather try to anticipate it, with 1.5-2 litres of water per day;
	Drink often and in small quantities. Drink slowly, especially if water is cold: in fact an abrupt decrease of the stomach temperature could cause conditions for a dangerous congestion;
	Elderly people should get used to drinking often during the day, during and between meals, even if they do not feel the urge to drink;
	Water balance must be maintained by drinking mainly water, tap water as well as bottled water, both safe and controlled. Remember that different beverages (such as orange juice, cokes, fruit juices, coffee and tea) apart from providing water also supply other substances that contain calories (for example simple sugars) and are pharmacologically active (for example caffeine). These beverages must be consumed with moderation;
	It is incorrect to avoid drinking for the fear of excessively perspiring (perspiring is essential in order to regulate body temperature) or for the fear of gaining weight (water does not contain calories);
	During and after physical activity, drink to promptly replace water loss caused by perspiration, mainly drinking water;
	During certain diseases that cause a greater loss of water (for example fever or repeated episodes of diarrhoea), water loss should be adequately replaced as soon as possible.

#### Salt? The less the better

Bread and bakery products, such as biscuits, crackers and bread sticks, are the main sources of salt (sodium chloride) in our diet, because of their daily consumption. Other important sources of salt are cold cuts, cheese and sauces.

Sodium naturally contained in food is enough



to cover human requirements, without adding further. Excessive salt consumption can increase the risk of developing hypertension, cardiovascular and kidney diseases.

Consuming less than 6g per day of salt, (i.e. a tea spoon, which contains 2,4 g of sodium) could represent an important preventive treatment measure.

Salt? The less the better	
How to behave	
Salt	Gradually reduce the use of salt at the table as well as in cooking;
	lodine-enriched salt should be preferred to ordinary salt;
	Do not add salt in baby food at least during the first year of life;
	Limit the use of alternative condiments containing salt (stock cubes, ketchup, soy sauce, mustard, etc.);
	Season food with vegetables and herbs (such as garlic, onion, basil, parsley, rosemary, sage, mint, oregano, marjoram, celery, leek, thyme, fennel seeds) and spices (such as pepper, hot chilli, nutmeg, saffron, curry);
	Enhance food flavours by using lemon juice and vinegar:
	Choose, when available, low salt products (bread without salt, tinned low salt tuna fish, etc.);
	Ready packed food rich in salt (savoury snacks, crisps, olives, cold cuts, preserved meat and cheese) should be consumed only occasionally;
	During moderate physical activity simple replace with water liquids lost during perspiration.

#### Alcoholic drinks: if so only in controlled quantity

Water and ethyl alcohol are the primary ingredients in alcoholic beverages, in addition to small quantities of aromatic substances, antioxidants and vitamins. Our body can also live without ethyl alcohol, because it is not an essential element.

Our body, actually "bears" its presence without evident damages, as long as its



consumption is not excessive. A man should not consume more than 2-3 alcoholic units per day, while for a woman the dose should not exceed 1-2 alcoholic units per day. A single alcohol unity corresponds to the quantity of ethanol found in a glass of wine, in a can of beer (330 ml) or in a small glass of liqueur or super alcoholic beverage.

If we consume alcoholic beverages, it is advisable to introduce them in a small amount during a meal, as the presence of food inside the stomach slows the absorption of ethanol and limits the effects on the body, in particular in case of excessive amounts.

Alcoholic beverages: if so only in moderate amounts	
How to behave	
Alcohol	If you wish to consume alcoholic beverages, do it in moderation, during meals according to the italian tradition, in any case immediately before or after a meal;
	Amongst all alcoholic beverages, prefer those with a low content of alcohol (wine and beer);
	Avoid alcoholic beverages consumption during childhood, pregnancy and breast-feeding, and reduce it if you are elderly;
	Do not consume alcoholic beverages if you have to drive vehicles or if you have to use delicate/or dangerous machines, to maintain an intact attention span, self-criticism and motor coordination;
	If you take medication avoid or reduce alcohol consumption, unless explicitly authorised by your practitioner;
	Reduce or avoid alcohol consumption if you are overweight or have a predisposition to weight gain.

#### Vary your food choices

A healthy diet must respect the needs of either macronutrients such as proteins, carbohydrates and fats, or other components such as water, vitamins and minerals, that are essential to the body. A food that contains all substances in the correct quantities, does not exist, so it is advisable to diversify nutrition choices in order to guarantee all nutritive substances needed. Varying food choices can prevent you from imbalances and nutrition deficiencies.

#### **10 RECOMMENDATIONS FOR CANCER PREVENTION**

In 2007 "Food, Nutrition, Physical Activity, and the Prevention of Cancer: a Global Perspective" has been published by the World Cancer Research Fund (WCRF) and the American Institute of Cancer Research (AICR). This document collects, in a synthetic manner, the results of all scientific studies published in literature that have analysed the relation between nutrition, physical activity and tumours. Nutrition, analysed in terms of nutrients and foods, obesity and physical activity play an important role in the development of tumours. Evidence collected by experts is divided into four judgement degrees and has created recommendations for the population: eight are recommendations for individuals and the last two are for special conditions. Following these recommendations we should reduce the possibilities of getting cancer. Authors of this document, however, emphasise the importance of not smoking in the prevention of cancer, although it does not directly regard nutrition. Quitting smoking or avoiding exposure remains one of the fundamental behaviours to avoid getting not only lung cancer, but also tumours of many other organs.

#### **10 Recommendations**

#### 1. Keep slim

It is important to try to keep one's own weight between the limits. Scientific evidence indicates that overweight and obesity represent important risk factors for different types of tumours. One of the most important strategies to prevent cancer and many other chronic diseases, is weight maintenance in a recommended range during the course of life, starting from childhood until



adulthood. Particularly during adulthood, it is important to avoid weight gain and increase in waist circumference.

In order to know whether your weight is within an acceptable interval, it is possible to calculate the Body Mass Index (BMI), dividing your weight in kilos, per squared height. For example a person who weighs 70 kilos and is 1,75m high can calculate its BMI = 70/(1,75x1,75) = 22,8. To be in the range, BMI must be between 18,5 and 24,9. BMI values below 18,5 indicate a weight below the range (underweight). BMI values above 24,9 indicate weight above the range

(overweight).

To reach this goal it is important to:

- Keep physically active during the course of life (see recommendation n. 2);
- Prefer diets based on low caloric density food (see recommendation n. 4);
- Avoid the consumption of energy-dense and sugary beverages (see recommendation n. 3).

#### 2. Keep physically active everyday

Scientific evidence demonstrates that physical activity is a protective factor helping cancer prevention, weight gain control and, therefore, indirectly, all risks connected to overweight and obesity.

For this reason it is very important to try to "move" every day; one could start by fast walking for at least half an hour a day and gradually increase pace in order to reach an

hour's exercise or to practice any kind of sport. Here are some suggestions:

- Walk or cycle instead of using the car;
- Walk up and down steps without using the lift;
- Descend at an earlier stop if you use public transport;
- Spend time passed in front of the television in a better way.

# **3. Limit the consumption of energy-dense foods and sugary drinks**

Energy-dense foods, particularly processed ones, and sweet drinks, increase the risk of overweight or obesity. In weight control it is therefore important to avoid these foods, or at least to moderately consume them. The high





consumption of these foods inevitably results in a weight gain and indirectly in an increase of cancer risk linked to overweight and obesity. On the other hand, a low caloric density food consumption can help to control overweight and obesity; some examples are fruit, vegetables and foods rich in fibre.

Here are some suggestions:

- Consume in moderation energy-dense foods (with more than 225-275 kcal per 100 g of food) such as ready-made dishes, snacks, candies and sweets in general (vegetable oils are not part of this category);
- Increase consumption of low caloric density foods such as fruit, vegetables, grains and tubers (with 10 to 150 kcal per 100 g of product);
- Avoid sugary beverages replacing them with water or sugar-free drinks;
- Consume in moderation "fast food" such as hamburgers, chips, fried chicken.

#### 4. Consume mostly foods of plant origin

Evidences that indicate a protection of a diet rich in fruit and vegetables towards cancer, are less strong than in the past, nevertheless the use of these types of foods is strongly advised. In fruit and vegetables there are, in fact, certain protection factors towards different types of tumour.



Here is some general advice:

- Daily consume about 5 portions (400 gr) between fruit and vegetables;
- Consume whole grains and pulses at every meal;
- Limit the use of refined starchy foods such as bread, pasta, pizza and rice.

#### 5. Limit the consumption of red meat and avoid preserved meat

The consumption of red or preserved meat seems to increase the risk of certain forms of tumours, so it is recommended to limit their consumption, without completely eliminating them from our diet. In fact, important nutrients can be found in meat such as proteins, iron, zinc and vitamin B12. Recommendations are:

- Consume less than 500g of red meat (cooked weight) per week;
- Red meat includes: beef, pork, lamb, kid;
- Avoid consuming fatty parts of meat;
- Prefer the use of poultry and fish;
- Avoid, if possible, the use of preserved meat: salami, cold cuts, tinned meat, sausages and würstel.

The use of grains together with pulses and vegetables, allows the intake of the same nutrients found in meat (proteins and iron).

#### 6. Limit the use of alcoholic beverages

The use of alcoholic beverages is associated to a greater risk of getting cancer. There is no alcoholic dose below which the risk of getting cancer lowers. For this reason, even small quantities of alcohol should be avoided. It is quite true that modest quantities of alcohol can have a protective effect over cardio-vascular diseases. Below are some recommendations:



– Limit the use of alcoholic beverages to 2 units

(1 alcoholic unit is the equivalent of 1 glass of wine, 1 can of beer of 33cl or a small glass of liqueur) per day for men and 1 alcoholic unit per day for women;

- Avoid consuming large quantities of alcohol, concentrating the consumption (for example during week-ends);
- Children and pregnant women should not consume alcoholic beverages.



#### 7. Limit the use of salt and avoid mouldy grains and pulses

Certain food conservation methods, particularly the preservation with salt, the curing process, adding of preservatives, etc. can increase the risk of developing some kind of tumour. Salt is added to most foods during preparation and cooking. Most of us use more salt than the amount necessary to the body.



Another recommendation is to ensure the

correct state of preservation of food that we consume, in particular grains and pulses, by avoiding storing them in warm or humid places (dangerous moulds to our body could in fact develop). Among practical advice:

- Avoid preserved and salted foods such as cold cuts, aged cheese, crisps and savoury snacks, tinned and ready-to-eat food;
- Limit salt addition during meals and prefer the use of herbs, spices, lemon and balsamic vinegar to savour dishes;
- Preserve food avoiding salt addition;
- Limit the use of food with salt added during the preparation, such as bread and bakery products in general;
- Do not consume mouldy grains and pulses stored in warm or humid places.

#### 8. Meet nutritional needs through diet

Scientific evidence indicates that the use of vitamin supplements can modify the risk of cancer and, in some cases, they could increase it. It is henceforth advised to increase the consumption of nutrients only through foods and natural beverages. The use of supplements is recommended only if prescribed by a nutrition expert who can assess possible risks and benefits.



#### 9. Breast feeding

Scientific evidence indicates that breast feeding produces a sense of wellbeing and health and has a proactive effect both for the mother and the child. It is recommended to breastfeed until at least six months supplying only maternal milk, which remains the best nutrition during the first months of life. Then, from 6 to 24 months, the child can follow a complementary diet, in which other foods will be slowly introduced to maternal milk.

#### **10. For cancer patients**

For cancer patients the same prevention recommendations are true. In the absence of special indications from medical staff, it is advisable to follow previous recommendations regarding diet, weight maintenance and physical activity. Patients who have undergone surgery, chemotherapy or radiotherapy, could have special nutritional needs, it is therefore necessary to consult one's practitioner or a nutritional expert.

#### **WEIGHT LOSS**

An involuntary weight loss, not obtained as a consequence of restricted dietary intake, is a frequent phenomenon in cancer patients. It is often an alarm bell and creates worry either in patients themselves or among their friends and family, as the effects of a ponderal loss are visible. Weight loss must nevertheless be considered an avoidable or at least treatable condition; it depends, in fact, on the illness but also on the treatment followed.



#### Causes

Causes of cancer patient loss of weight are various; the most frequent are:

#### • 1. metabolism alteration;

In the presence of cancer, our body starts to produce substances that alter cellular metabolism and that in the medium to long term causes a decrease in appetite.

#### • 2. antitumoral therapies;

Chemotherapy and radiotherapy are effective, but very toxic to our body and can cause a series of nutritional disorders (reduction of appetite, fatigue, muscle weakness, nausea, vomiting, alteration of the mucous membrane).

#### • 3. mechanic obstruction;

If the disease is located at the oropharynx, the oesophagus and stomach level, tumour mass can obstruct food passage, with consequent swallowing difficulties (dysphagia), anticipate sense of satiety (precocious satiety), or cause nausea and vomiting.

#### Consequences

All these conditions can cause a difficulty in everyday feeding, and a progressive weight loss. When weight loss becomes consistent, negative physical effects can be felt. It should not be neglected, not even if the starting point is an overweight or obesity situation. Ponderal loss is, in fact, a risk factor as it could encourage the weakening of the immune system, muscular mass and slowing down of wound healing. All this could mean a lower tolerance to therapies, an accentuating of the fatigue syndrome and a greater risk of complications.

# What to do

To avoid weight loss and physical power loss, a series of nutritional therapies can be carried out, to begin with the prescription of an adequate diet, to the supplement of specific products (nutritional supplements), artificial nutrition, enteral and parenteral, in hospital or at home, when natural feeding is not sufficient. A reduced intake could represent an alarm bell and request an artificial nutrition action (that has to be valued and requested by a practitioner). The aim of the patient is therefore to maintain his own weight or to try to delay ponderal loss anyhow if this occurs, or once the weight is lost try to regain it in order to better tolerate therapies and the proceeding of the illness. It is a good thing however, to begin to maintain one's own weight and to monitor it, before big ponderal changes occur.

Useful advice	
Indication	Hints
Eat at pre stated hours	Eat at stated hours, rather than when hungry; it is important to eat also when not hungry to avoid losing weight.
Eat often and small portions	Consume small meals more than once a day (5-6) instead of the three traditional ones (breakfast, lunch and dinner), if one is not able to eat sufficiently during main meals. In this way one tries however to satisfy one's own caloric need.
Consume foods rich in calories and proteins	Consume high calorie and protein foods, in order to introduce necessary calories and proteins in a smaller volume of foods; Enrich dishes with protein condiments (such as milk, cheese, eggs) or with the adding of high energy foods (e.g.: oil, butter); Consume milk shakes, juices or soups as they can supply necessary vitamins, proteins and calories; Use milk as an added ingredient in the preparation of dishes (e.g.: sauces).
Keep active everyday	A short walk or a light physical exercise (climbing up the stairs, cycling) can stimulate appetite.
Consume supplements integrators	It is possible to introduce hypernutritive and hypercaloric beverages in order to compensate a possible poor nutrition intake. Chemists have a selection of products rich in calories to be consumed during the day, in the form of beverages, soluble powders, creamed products, milk puddings or simple prepared products to be added in the preparation of other foods. For this kind of products ask your practitioner who can advise you the more suitable product for your condition; If not able to eat in an adequate way concerning the caloric requirements, it is possible to start considering the possibility of artificial nutrition. Talk to your practitioner and/or specialist to decide the best solution.

# NAUSEA

Nausea is a sensation of discomfort and uneasiness in the stomach that can precede vomiting. It can appear above all during chemotherapy, and less frequently during radiotherapy over pelvic and abdominal regions. Its intensity can depend either on the type of medication taken, and/or by a subjective reaction to the cure. It can appear straight after the treatment, after a few days, after a few



therapy cycles or even before the therapy cycle. The patient feels bad simply by seeing or smelling something associated with the cure. This reaction is due to a conditioning phenomenon that will spontaneously clear up after the cure.

In some cases it can be very intense and cause exhaustion, it could prevent from eating and drinking or taking medicines. It is however advisable to talk to one's practitioner about the intensity of symptoms.

It is possible to control this symptom, this will help to better face the therapy. It must be kept in mind that the indications will not be effective for everyone, because each person can react to the therapies in a different way. Try to choose from the following advice, the more suitable ones.

	Useful advice
Indication	Hints
	Do not force yourself to eat when you don't feel like;
Do not force	Change meal hours, eat when you feel like, without time limitations;
yourself to eat	Consume between 6 to 8 small meals per day, instead of eating the normal 3 meals.
Consume dry food	Consume dry food such as toasted bread, crackers or melba toast, better in the morning even before getting up to avoid vomiting attacks.
Eat often and small portions	Generally one has to chew properly and slowly every mouthful, to avoid excessive swelling of the stomach and to ease digestion;
	Drink between meals and take small sips.
Consume cold foods	Avoid foods which are too hot or too sweet, prefer savoury and cold ones (for example water-ice).
	Sip small quantities of fizzy beverages during the day, such as mineral water, ginger ale, tonic water, lemonade, soda drinks, etc;
Sip a fizzy drink	Try to drink slowly with a straw small quantities of cool drinks;
	Avoid coffee for its strong flavour, substitute it perhaps with tea.
Alcoholic	It is advisable not to consume alcoholic drinks: wine, beer and spirits such as liqueurs and whisky;
beverages	Certain medicines can react to alcohol worsening the condition;
	Ask information to one's practitioner.
	Strong smells can cause nausea, so it is advisable to breathe through the mouth in order to avoid the smells detected through the nose which could increase nausea sensation;
Do not stay in the kitchen	Prefer a well ventilated room, remain near an open window, or walk in the open air before and after meals;
	Ask for help during the preparation of meals in order to rest and avoid cooking smells. Perhaps consume ready-to-eat or frozen dishes.
	A friend can be a valid help over the treatment period;
Be accompanied when going for	Conversation distracts and helps one think about other things than the disease;
treatment	Silence and solitude encourage emotional tension and consequently nausea.
	Do not eat 1 or 2 hours prior to therapy;
During	Lie down and rest if needed;
chemotherapy days it is better	Read a book, listen to music, take a hot bath;
to rest	If taking antiemetics (medicines for the treatment of nausea and vomiting), it is best to rest as they can cause sleepiness.

#### **FAUCIAL DRYNESS**

Dryness of the mouth is a common disorder during the course of chemotherapy or of the head-neck area radiotherapy; this can damage salivary glands with a consequent modification of saliva production. This condition establishes a reduction of saliva production, or its own modification, becoming thicker. The need to breath with an open mouth, in certain cases where breathing is difficult or complicated, could worsen the condition, especially in a dry atmosphere.



This condition is often accompanied also by an inflammation of the oral cavity and by the presence of small ulcers, that could cause pain, a burning sensation and swallowing difficulties.

Symptoms could in any case be restrained by following a series of the indications below, in order not to compromise food intake.

74

Useful advice	
Indication	Hints
To prevent faucial dryness	Drink often, small sips during the day, in order to maintain the mouth humid, consuming water or fizzy drinks (they can be more refreshing). It is better to take a bottle of water if going out;
	To encourage salivation it is best to suck ice cubes, consume popsicles, small pieces of pineapple or chew gum.
	Avoid consuming dry foods that can irritate the mucous, such as bread crust, preferring the soft part, avoid dry and hard food such as crackers, bread sticks, melba toast, popcorn and crisps as they could cause swallowing difficulties; limit the use of raw vegetables;
Dry/soft consistency of foods	Cooked food is softer and easier to chew and swallow. Soft food can be easily prepared with the use of a mixer, adding a good amount of non piquant sauces;
	It is advisable to consume soft foods such as scrambled eggs, omelettes, soups and vegetable soups, fresh and soft cheese, fish, minced chicken and meat, creams made of milk and eggs, ice creams and milk puddings.
Acidic/sour foods	Lemon juice stimulates saliva production, but attention must be paid if inflammation of the oral cavity is present. In this case it is best to avoid food which is too acidic/sour: spices, aromatic herbs, high salty or smoked food, alcoholic and fizzy beverages, citrus fruits, tomato juice and sauce, pineapple, yogurt and fruit juices.
Avoid sweets and confectionery	Avoid consuming sweets and chocolate as they stick to the palate, thicken the mouth and make chewing and swallowing difficult.
Avoid smoking and alcohol	Do not consume wine, beer or spirits as they can worsen faucial dryness;
	Avoid tobacco-made products as they could inflame the mouth and throat.
	Wash the mouth every evening and after every meal, using a soft toothbrush and a non-abrasive toothpaste;
Mouth hygiene	Rinse the mouth well, after brushing teeth, in order to clear any remains of toothpaste as it could make the mucous drier;
	Do not use mouthwashes that contain alcohol as they could worsen the condition (read the label);
	Remove and clean dentures.
Lips hydrating	Always keep your lips humidified with the use of lip balm and vaseline; if lips are well humidified, it is easier to chew and to taste food.

### INFLAMMATION OF THE ORAL CAVITY

The cells of the oral cavity are among the most hit by antitumor medications and become inevitably damaged in the case of radiotherapy in the head-neck area. Most common problems are small ulcers on the tongue, the gums, the pharynx and oesophagus. These disorders can cause pain, burning, difficulties in swallowing, bleeding and pus.



These symptoms can be controlled with some behavioural and nutritional advice, but it is necessary to talk to a practitioner if:

- Temperature rises above 37°;
- Ulcers on lips, gums, or mouth lining or swollen tongue appear;
- The oral mucous turns red or fills up with small white spots (mouth ulcer or thrush fungus).

We quote here below some advice in order to diminish or control pain, but also to treat mouth diseases that can also cause pain; it is important to follow the advice below at the first signs of oral cavity inflammation in order to be effective.

	Useful advice
Indication	Hints
To ease pain	Suck ice cubes, it has an anaesthetising effect on pain of the mucous.
	Consume food in small portions (mouthfuls), to avoid chewing too much;
Soft and	Prepare pureed or liquid foods; a light sauce (such as white sauce, gravy) or boiled potatoes can be added to soften foods;
blended food	Soften breakfast cereals with milk and prepare vegetable puree with broth;
	Prefer food of soft consistency (e.g. fresh cheese, milk pudding, semolina, meat balls), butter or cream may be added.
Cold or warm	Serve food at room temperature;
food	Add crushed ice to drinks, eat ice creams and fruit or milk jellies.
Avoid hard or rough food	Avoid bread crust and dry foods such as crackers, bread sticks, melba toast, popcorn and crisps as they might scratch already inflamed mucous;
Tough toou	Limit the use of raw vegetables; by cooking food it becomes softer and easy to eat.
	Avoid the use of acidic or sour tasting foods: condiments, spices, aromatic herbs, high salt and smoked food, alcoholic and fizzy drinks, lemon juice, citrus fruits, sauce and tomato juice, pineapple;
Avoid sour and irritating foods	Try to consume white yogurt and if this might be acidic try the fruit ones;
	Limit fresh juices, that may cause a burning sensation, and prefer less acidic juices such as blackcurrant or wild rose syrup, apple and pear/peach juices.
	Drink at least one or one and a half litres of water a day;
Beverages	Drink a lot of milk, a good source of nutrients and energy;
Develages	Avoid alcoholic drinks, alcohol can worsen burning sensations and inflammation.
	Wash your mouth after every meal, avoiding abrasive toothpastes and mouthwashes containing alcoholic substances;
	In case of pain, rinse your mouth with analgesic or soothing substances prescribed by the specialist;
Mouth hygiene	Clean your tongue with a cotton bud dipped in a solution of bicarbonate of soda (a spoon of bicarbonate every 50cl of water) to alleviate inflammation, remove food residues and make the oral mucous softer;
	Keep your dentures in an appropriate solution during the night. Try to use dentures as little as possible during the day as this can irritate the gums more.
Avoid smoking	Do not smoke because smoke can worsen the burning sensation and inflammation.

# **TASTE ALTERATION**

During an oncological treatment dysgeusia can occur. This technical term is used to describe taste alteration. In most cases it is a temporary condition, that disappears at the end of the therapy. This side effect entails:

- Disliking certain foods;
- Perceiving changes of flavour in certain foods which did not previously occur prior to the treatment;



- Eating food that leaves a metallic taste in your mouth;
- Feeling normal food is insipid and not sweet enough;
- Feeling food more bitter than normal.

This alteration can also be associated with smell alteration. The causes may be different:

- Chemotherapy (e.g. Cisplatin, a chemotherapeutic agent) can cause alteration and loss of taste buds;
- Deficiency of some very important trace elements (e.g.: zinc), for normal taste perception;
- A reduced salivation;
- Alteration of brain mechanisms that elaborate taste sensation received from the tongue.

This condition can cause difficulties in eating in an adequate and correct way and can influence appetite.

However certain possible solutions exist in order for food to be tastier and more pleasant.

	Useful advice
Indication	Hints without oral cavity inflammation
	Prefer favourite foods and avoid momentary unpleasant ones. Try to reintroduce them some time after, as taste could have gone back to what it was before;
	According to one's own situation and sensitivity the following foods could be preferred:
Food choices	Strong flavoured food, refreshing to the mouth and leaving a good taste (e.g.: fresh fruit, bitter juices and sweets);
	Neutral flavoured food (pasta, rice, etc);
	Cold or room temperature food;
	Refreshing infused tea or fizzy cold drinks;
	Fresh and sour fruits (e.g: grapefruit, oranges, lemons etc).
Red meat	Red meat flavour is often changed (metallic taste). Substitute it with other meat: chicken, turkey, rabbit.
Food preparation	Flavour food using spices and aromatic herbs (e.g.: rosemary, basil and mint); marinate meat or fish prior to cooking by using: an acidic ingredient (e.g. wine, beer, vinegar or lemon juice), oil and flavours (herbs and spices). In certain cases various sauces (soy, yogurt, Worcester sauce) can be added. Cover meat and /or fish with these ingredients and leave to rest for several hours.
Plastic utensils	Prefer plastic utensils rather than metal ones;
Plastic utensils	Chop sticks could also be useful.
	Drink using a straw;
Avoid fastidious	Keep drinks covered;
smells	Choose foods that don't need to be cooked;
	Avoid eating in closed or hot rooms.
Mouth hygiene	Rinse your mouth well after every meal, avoiding abrasive toothpaste, toothbrushes and mouthwashes that contain alcoholic substances;
	Cleanse your tongue with cotton wool soaked in a bicarbonate of soda solution (1 teaspoon of bicarbonate in 50 cl of water). This solution helps to ease inflammation, removes food residues and makes oral mucous softer.

# **CONSTIPATION**

Constipation is a disorder that occurs when defecation happens less frequently than usual, stools are hard and defecation is painful. There are different causes for this disorder: bad lifestyles and eating habits are the base of this discomfort, that can be amplified during the course of antitumor or analgesic therapies, and often linked to big emotional stress.



Constipation can cause discomfort, abdominal pain and other side effects that include: a coated tongue, bad breath (halitosis), loss of appetite, headache, dizziness, nausea, acne spots and mouth ulcers, pain in lower back area, heartburn and insomnia.

If constipation is occasional, the advice of a practitioner is not needed. However it is necessary to contact him if:

- Defecation does not occur for about 3-4 days, when it normally happens every day;
- Defecation is difficult or it comes with abdominal pain;
- Having resorted to the previous advice, the disorder persists.

Two of the elements that condition defecation are: liquid intake and the consumption of fibre. Liquid intake is often inadequate and the intake of fibre insufficient. These two factors have a synergetic effect on the volume and consistency of the stools: fibre increases faecal mass promoting bacterial fermentation at colon level, stimulating in this way intestinal mobility, and stools tend to expand calling for greater water quantity.

	Useful advice
Indication	Hints
Liquid intake	Drink at least a litre and a half (8-10 glasses) of beverages per day preferring water; liquids hydrate stools and prevent constipation;
	Do not exceed the use of fizzy drinks as they increase intestinal gas and can worsen constipation.
Fibre	Insert in the diet a greater amount of fibre: prefer wholegrains and possibly bran. These fibres stimulate intestinal mobility, but require heavy quantities of water, as they could in fact have an opposite effect (favouring constipation) if not accompanied with water;
	Prefer fresh fruit with high sugar levels, fruit with high fibre content and, generally, all fruit with skin, dry and dehydrated fruit;
Physical	Regular physical activity prevents constipation, stimulating bowel peristalsis (which are bowel movements that push the stools outwards);
activity	It can also be useful to walk, even in one's house, cycling or practicing a sport;
	On the bed, exercise muscular relaxation and contraction.
Somo natural	Figs syrup, plums, plum juice, cooked apples;
Some natural remedies	Consume hot beverages such as coffee, tea and soups, either on an empty stomach or straight after a meal.
	Try to eat every day at the same hours, to give the bowel a new rhythm;
Useful advice	Do not talk much at the table and do not chew gums in order to limit air intake that can worsen constipation;
	Drink in the morning on an empty stomach.
Specific products	Talk to your practitioner in order to choose the most suitable product;
	Use <i>psyllium</i> fibre-based products (which can be found at the chemist), glycerine suppositories or micro-enemas;
	If using a supplement, choose a fibre-enriched one.
To be avoided	The methodical use of enemas can prevent regular bowel function;
	Enemas should be used with caution and only in exceptional cases;
	Evaluate the possibility of taking, as a preventive measure, light laxatives or stool softeners.

# DIARRHOEA

Diarrhoea is described as an increase in the quantity and passing of stools, with a diminishing consistency (liquid or semiliquid stools) that is associated with frequent evacuation. It can be caused by chemotherapy or abdominal radiotherapy, but also by infections, by ingestion of cold food or by emotional stress. During this disorder, foods and their nutrients are not absorbed by the intestine due to the high speed of transit. This



can cause a loss of nutrients, water in particular, with consequent dehydration, general discomfort with poor appetite and fatigue. For this reason it is important to know what to eat in order to contain losses and avoid dehydration. In order to control this problem the use of anti-diarrhoeal medicines can be useful, but only after consulting a practitioner. These medications reduce motions and slow down bowel movements, diminishing the number and the intensity of diarrhoeal evacuations. If diarrhoea lasts for up to more than a day, if blood is found in the stools or fever is above 38°, it is better to talk to one's own practitioner.

Useful advice	
Indication	Hints
	Drink plenty of liquids sipping, during the course of the day (e.g.: tea, fruit or vegetable centrifuged, water, fruit or citrus juices) to avoid dehydration;
Boueregee	Drink at least 1 glass of liquid after every evacuation;
Beverages	Consume beverages at room temperature;
	Avoid coffee and iced beverages, as these can irritate the intestine;
	Defizz fizzy drinks before drinking them.
	Avoid rich sauces, fried, spicy and hot foods;
Follow a light	Limit the use of fat and consume only small quantities of olive oil, preferably uncooked;
diet	Limit the use of cold cuts and preserved meat (salami, bologna, sausage);
	Consume lean cuts of meat, fish and eggs, cooking in a simple way: steaming, wrapped or cooked on the griddle.
	Avoid the use of milk and milk-based beverages;
Milk and dairy products	Consume yogurt in order to restore intestinal flora;
producto	Consume cheese if tolerating it and in small doses.
Eat often and	Consume small, frequent and light meals (5-6 per day);
small portions	If not able to consume a whole meal, eat small portions often, chewing slowly every mouthful.
Fibre reduction	Avoid wholegrains (bread, pasta, melba toast), pulses and vegetables or foods that contains fibre (soups and vegetable cakes), as they are subject to fermentation by colon bacteria and favour gas production;
	Limit the use of fresh fruit.
Reintegrate mineral loss	In order to reintegrate mineral loss eat bananas, fish, boiled potatoes, which are naturally rich in potassium and minerals;
	Consume mineral rich beverages (e.g. sport drinks, fruit nectars and juices, vegetable broths).

# VOMITING

Vomiting consists in the expulsion from the mouth of food or non food material. During the course of neoplastic disease, this can be a side effect of the treatment (chemotherapy or radiotherapy of the gastrointestinal tract) or a direct consequence of the illness, where the tumour puts pressure on the abdominal cavity or prevents food passage. It could also be caused by the stimulation, by certain tumour cells, of the "vomiting centre" in the brain. It is a transitory



effect, if caused by chemotherapy or by radiotherapy. The use of antiemetic medications could be useful, if prescribed by a practitioner. It is however better to consult a practitioner when vomit is very dark or contains blood, if one is unable to take medication, in the presence of a strong fatigue feeling or dizziness or if one is eating or drinking very little.

It is possible to control this symptom, by following some advice.

Useful advice	
Indication	Hints
	Eat often and small portions;
Solid foods	Eat slowly and chew well every mouthful;
	In the morning, before getting up, consume dry food (toast, crackers or melba toast).
	Drink mostly between meals and take small sips to avoid an excessive filling of the stomach;
Beverages	Defizz fizzy drinks by shaking them with the use of a spoon or leave them open as gas could again disturb the stomach;
	Limit the use of strong tea or coffee.
Alcoholic beverages	Limit the use of wine, beer, spirits such as liqueurs and whisky as some medication could react to alcohol and worsen the condition.
In case of	It is important to reintroduce minerals lost by vomiting;
vomiting rehydrate liquids	Drink light teas, vegetable soups (also with salt), sport drinks, water and non carbonated and cold beverages in small sips.
It is necessary to rest during the days of treatment	Try to lie down (antiemetics cause sleepiness), change the air in the room, avoid strong smells (breathe through your mouth) and do not eat 1 or 2 hours prior to the therapy;
	Ask help for the preparation of food.

NUTRITION AND CANCER: HINTS FOR PATIENTS

# DIFFICULTIES IN SWALLOWING AND MASTICATION

Dysphagia is the condition in which the passage of food through the mouth, from the oesophagus to the stomach is difficult or does not occur in a correct way. This problem can be caused by neurologic and non neurologic pathologies, such as tumours of the oral cavity, or by surgery. The main risk represents food passing through the airways, with the possibility of causing pneumonia.



The first symptoms that could alert or that could require medical assistance, are the following:

- cough, also a light one, straight after or within 2-3 minutes from swallowing the mouthful;
- appearance of hoarseness after swallowing the mouthful;
- leaking of food or liquids from the nose;
- fever, even a weak one;
- frequent ejection of catarrh.

If difficulties in swallowing prevent proper feeding, artificial nutrition will be necessary: enteral nutrition is the preferred choice in this case, but the best approach has to be decided by the practitioner. This happens in severe cases of dysphagia, in which any type of oral nutrition is not recommended. Levels of light and moderate dysphagia also exist, in which it is necessary to use compensatory strategies. In cases of a more serious dysphagia, it is recommended to consult a specialist (practitioner and speech therapist).

Useful advice	
Indication	Hints
	Consume small meals more times per day, up to 5-6 meals per day, instead of the 3 traditional ones (breakfast, lunch and dinner) with which the caloric requirement would not be met;
Eat often and small portions	Eat slowly and chew well every mouthful as much as possible;
onian por dono	Drink with a straw;
	Serve dishes at room temperature, avoiding foods which are too hot or too cold.
	The blender can be an indispensable device for food preparation particularly, if a liquid and/or soft food diet is necessary;
Consume soft	Prepare finely chopped foods or small mouthfuls and always well mixed with sauces (white sauce and gravy), semolina, soft cheese or mayonnaise;
or blended food	Prepare soft meat balls mixing minced meat or fish with eggs, milk, cheese, spices, breadcrumbs or boiled potatoes;
	Prepare omelettes enriched with cheese, milk and eggs;
	Consume puddings (such as crème caramel, custard creams, milk puddings, tiramisu etc);
	Prepare fruit shakes enriched with yogurt, milk, ice cream, sugar or honey to be consumed as a snack;
	Baby food can also be used.
Add to dishes high calories and protein	If it is necessary to increase caloric intake, it is possible to soften and enrich dishes adding foods such as butter, oil, fresh cream, cheese, sugar, yogurt and milk;
foods	Prefer whole milk instead of broth, to prepare vegetable puree.
	Consume only the soft part of the bread, or soft sandwich bread;
Avoid rough or hard food	Avoid dried foods such as crackers, melba toast popcorn and crisps;
	Limit raw vegetables as they are hard to chew and they can break into small pieces;
	Cook or boil dry foods, making them softer and easier to swallow, for example dry bread can be softened with water either/or broth, and vegetables can be boiled in water.

# FATIGUE AND TIRING EASILY

Fatigue and tiredness are common conditions and are caused either by the illness or the treatments. Frequently fatigue is a consequence of anaemia (a diminution in red blood cells that carry oxygen to tissues), that is caused by the tumour or by chemotherapy. To prevent anaemia it is possible to take iron supplements or medications that stimulate red blood cells. Poor appetite and poor nutrition can also cause fatigue and increase tiredness.



A way to keep the situation under control is partly by trying to foresee when fatigue can occur, for example after a session of radiotherapy, or after a medical visit or a session of chemotherapy.

Medical advice is necessary if, together with fatigue, the following factors occur:

- a frequent and serious loss of balance;
- a sudden fall with contusions and fainting;
- difficulties in waking;
- a lack or difficulties in breathing.

You can find below some advice in order to control fatigue.

Useful advice	
Indication	Hints
Prepare food when feeling	Cook when you feel well and freeze food in single portions to be able to use them when fatigue occcurs or when a medical visit or a radiotherapy session has been programmed;
well	Stock up on frozen, canned and precooked food to be consumed in those days when you are not strong enough to cook.
Ask for help to family and friends	Avoid shopping or cooking when you are not able to: ask for the help of a friend or a family member.
Consume ready-to-eat meals	Consume ready-to-eat meals, canned, frozen or deli food being very careful to their conservation or preparation (heat them well) to avoid bacteria contamination and food poisoning;
	Avoid meals rich in carbohydrates as they can caused fatigue and sleepiness.
	Being active during the day makes you sleep better at night;
Between activities it is important to	It is important to rest, take a break, between an activity and the other after a bath, after getting dressed or after a walk;
	Carry out activities for short periods (taking a bath, reading, listening to music);
rest	Move slowly to avoid loss of balance or falls;
	Try to cope with stress.
Use high nutrient drinks (supplements and integrators)	If due to fatigue, there is no strength for cooking or eating, consume high energy drinks (integrators). Chemists have a wide selection of high calorie products to be consumed during the day, after having consulted a practitioner.

NUTRITION AND CANCER: HINTS FOR PATIENTS

# **POOR APPETITE**

Poor appetite is a common condition during the course of illness and during the course of treatments. It often creates a sense of worry and is associated with the worsening of the disease in itself. The patient loses appetite and reduces feeding compared to his normal conditions. It is very important to correctly inform patients and their families, about this disorder in order to avoid unjustified anxiety and incorrect interpretations. The loss of appetite can occur following fatigue,



pain, stress, depression or anxiety. It is necessary to be alarmed, but it is advised to consult a practitioner if:

- one has eaten or drunk too little;
- a considerable weight loss has occurred over the last week;
- mastication is painful and swallowing difficult.

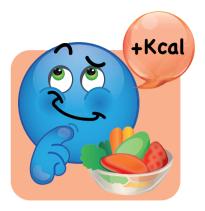
Ultimately it is very important that patients try to eat and drink adequately in order to satisfy their own requirements in terms of energy, water and nutrients.

	Useful advice
Indication	Hints
	Consume small meals more times per day, up to 5-6 meals per day, instead of the traditional three (breakfast, lunch, dinner) with which it would be difficult to reach caloric requirements. Get used to eating many snacks during the day allowing the consumption of a bigger amount of food in the 24 hours;
Eat often and small portions	Try to eat something every 2 hours;
	Always keep various snacks at hand, to eat during the day: fresh or dehydrated fruit, pieces of cheese, fruit or cereal yogurt, crackers, bread sticks, melba toast, crisps, peanuts, olives;
	Eat slowly, chew well every mouthful and relax at the end of the meal.
	Prepare or organise pleasant and relishing meals;
	Prepare on a plate small quantities of food, garnish with lemon slices, tomatoes, parsley and other vegetables;
	Dress food using herbs and flavours to make meals taste better;
Stimulate taste and appetite	Avoid eating alone: eating with family and friends can help to regain appetite;
	Laying the table in an accurate way and in a pleasant atmosphere makes meals tempting;
	Sometimes smelling food can be pleasant, or otherwise sickening: regulate according to your own sensations;
	Exercising or even only walking can stimulate the appetite.
Substitute water with milk in food preparation	During a meal or between meals, favour the use of milk, as it contains proteins, calories and fats and helps to meet protein and energy requirements. Remember that milk can substitute water (or a part of it) in the preparation of any dish (for example soups, semolina and vegetable creams).
Consume high nutritive beverages (supplements and integrators)	If due to fatigue one cannot find the strength to eat, or to prepare a meal, one can resort to the use of energising beverages (integrators). Chemists have a wide range of products rich in these to be consumed during the day, prior to a specialist's advice;
	It is however preferable to enrich one's own diet with high protein (milk, cheese, eggs, meat, fish and pulses) and caloric foods (adding a good quantity of oil or other fats to food).
Medications	Medications that increase appetite also exist (progestagens). Their intake must be prescribed by a practitioner, as they can have side effects.

# **INCREASE ENERGY INTAKE**

Cancer and its therapies can lead patients to eat insufficiently to cover their own nutritional needs. Fatigue and tiredness can also contribute to a decrease in food intake. If these conditions persist they can cause an involuntary and sometimes important weight loss.

To face an eventual weight loss or to prevent it, it is appropriate to try to increase caloric intake only with the consumption of food. If



necessary, it is possible to get help from specific products found at the chemist. Your practitioner can advise you on the most suitable hypercaloric supplement.

Follow the advice below in order to stimulate appetite.

	Useful advice
Indication	Hints
	Cook when you feel well and freeze meals in single portions to consume them when you feel tired, or when a medical visit or radiotherapy session has been programmed;
Prepare food	Stock up on frozen, canned or ready made food to consume them when you don't have the strength to cook;
when feeling well	If you use ready-to-eat, canned, frozen or deli food, be very careful about their conservation or preparation (e.g. heat them up properly, check expiry dates) in order to avoid bacteria contamination and food poisoning;
	Avoid high carbohydrate meals, as these can cause sleepiness and accentuate fatigue and tiredness if present.
Ask help from family and friends	Avoid shopping or cooking when not feeling able to do so: ask for the help of a family member or a friend;
Chimulata	Walking in one's house, cycling or practicing a sport even for small intervals can also be helpful;
Stimulate appetite	It is important to create a relaxing atmosphere during meal times;
	Choose or experiment new recipes;
	Eat out.
Eat often and small portions	Consume small meals many times a day, up to 5-6 meals per day, instead of the traditional three (breakfast, lunch, dinner) with which probably caloric intake could not be reached;
	Getting used to consuming various snacks during the day allows you to eat a bigger quantity of food during the whole day; eating every 2 hours could be useful;
	Always keep at hand small snacks: dried and dehydrated fruit, pieces of cheese, fruit or cereal yogurt, crackers, bread sticks, melba toast, crisps, peanuts, olives, milk puddings, milk shakes, ice creams, jams, pieces of cake, biscuits, confectionery, sweets;
	Eat favourite foods at different times of the day (e.g.: breakfast food at dinner).
Eat at pre- arranged times	Try attempting to eat at pre-established times, rather than when hungry; it is important to eat even if not feeling like it in order to avoid losing weight.
Drink between meals	Drink between rather than during the meals. Drinks can cause a satiety sensation and can prevent from eating.

### **PRECOCIOUS SATIETY**

Precocious satiety is a common disorder, that occurs when one feels quickly satiated, even when consuming a small meal. This condition is often a consequence of surgery with a partial or total resection of the stomach, that determines a decrease in stomach capacity. This discomforting sensation of fullness often reinforces poor appetite, and can induce to eating less, compromising one's own weight. Some advice is listed below.



Useful advice	
Indication	Hints
Eat often and small portions	Consume small meals more than once a day, up to 5-6 meals per day, instead of the traditional three (breakfast, lunch, dinner) with which caloric intake could not be satisfied. The habit of consuming numerous snacks allows eating a greater quantity of food in the 24 hours.
Eat and chew slowly	Eat slowly and chew well every mouthful;
	Avoid lying down after meals in order to avoid reflux.
Drink between meals	Drinking between rather than during meals can decrease satiety sensation and allows greater eating.
Beverages	Substitute most part of water drunk during the day with more substantial liquids; water in fact increases precocious satiety sensation without supplying energy; prefer milk, fruit juices and citrus juices;
	Avoid fizzy drinks.
Avoid fat and fried food	Consume light and slightly seasoned food;
	Avoid fried and fatty food, as very fat foods extend times of digestion and worsen symptoms;
	Prefer "light" food cooked by grilling, steaming or wrapping;
	Avoid enriched fibre foods such as wholegrains and derivates, fruit vegetables and pulses; they can worsen satiety sensation.
Physical activity	A moderate physical activity between meals can promote digestion and helps to empty the stomach; walking and cycling are recommended.

#### REFERENCES

American Cancer Society. Nutrition for the Person With Cancer During Treatment: A Guide for Patients and Families 2010

Antimi M, Vanni A M. Consigli alimentari durante il trattamento oncologico. Fondazione Federico Calabresi 1997

Binetti P, Marcelli M, Baisi R. Manuale di nutrizione clinica e scienze dietetiche applicate. Società Editrice Universo 2006

Calista F, Battistini NC, Ghinelli C, Palazzi C. Alimentazione post gastrectomia. Università degli Studi di Modena e Reggio Emilia 2006

Cannella C, del Balzo V, Dernini S. Piramide alimentare italiana: guida settimanale per uno stile di vita salutare. A Cura della Sezione di Scienza dell'Alimentazione, Dipartimento di Fisiopatologia Medica, Sapienza Università Di Roma, 2005

Cimeli T, Feuz A, Guggisberg E, Gwisdek G, Gygli C, Lanz S, Rechsteiner M, Schwizer V, Soldati-Guerrini C. Difficoltà di alimentazione legate al cancro. Lega svizzera contro il cancro 2005

Collegio Italiano Primari Ospedalieri di Oncologia Medica. La chemioterapia. La collana del Girasole, n° 2. Editing: Claudia Di Loreto. AlMaC 2009

Crotti N, Zaninetta G, Sculati O, Staffieri E, Mariano M, Murru L, Lucchini D, Alghisi A. Consigli utili per l'alimentazione nel paziente oncologico adulto in trattamento e in fase avanzata. Casa di cura S. Anna 1998

Gruppo di esperti costituito presso l'Istituto Nazionale di Ricerca per gli Alimenti e la Nutrizione (INRAN). Linee guida per una sana alimentazione italiana. Ministero delle Politiche Agricole e Forestali e INRAN, 2003

Gruppo di lavoro. Elaborazione del tipo di dieta verso cui indirizzare il cittadino, consigliando le opportune variazioni. Relazione conclusiva, 2004

Gruppo di Studio della Disfagia. Guida ai pasti della giornata. Dieta di 1° e 2° livello per disfagia. Rete delle UO di Dietetica e Nutrizione Clinica – Regione Piemonte 2005

Gruppo di Studio della Disfagia. Guida ai pasti della giornata. Dieta di 3° e 4° livello per disfagia. Rete delle UO di Dietetica e Nutrizione Clinica – Regione Piemonte 2005

Istituto Europeo di Oncologia. Come aumentare l'apporto calorico alla dieta. IEO Booklets 2010

Istituto Europeo di Oncologia. La Nutrizione durante il trattamento Oncologico. Our Booklets 2002

Meyer D. Niente paura della nausea e del vomito. Mepha http://www.mepha.ch/

Muscaritoli M, Preziosa I, Canelli A, De Leo S. La nutrizione del malato oncologico. La collana del girasole. Editing: Claudia Di Loreto. AlMaC 2008

Muto P, Muscaritoli M, Preziosa I, Brusadin G, Penduzzu G, Gardes M P, Menghini A. La radioterapia. La collana del Girasole, n°3. Editing: Claudia Di Loreto. AlMaC 2010

National Cancer Institute. Eating hints: Before, During and After Cancer Treatment. U.S. Department of Health and Human Services. National Institutes of Health 2009

Rossi Fanelli F, Muscaritoli M, Laviano A, Gavazzi C. Neoplasia e perdita di peso. Che cosa fare? F.A.V.O. 2006

World Cancer Research Fund. Food, Nutrition, Physical Activity and the Prevention of Cancer: a Global Perspective. American Institute for Cancer Research 2007

# WRITE THE FUTURE

#### **CENTRAL OFFICE**

**OECI - EEIG** c/o Fondation Universitaire 11, Rue d'Egmont B-1000 Brussels, Belgium Phone: +32 2 512 0146

oeci@oeci.eu <u>ww</u>w.oeci.eu