Clinical Nutrition Guidelines and Summaries for Patients

Clinical nutrition is a discipline which deals with the prevention, diagnosis and management of nutritional and metabolic changes related to acute and chronic diseases and conditions caused by a lack or excess of energy and nutrients. Any nutritional measure, preventive or curative, targeting individual patients is clinical nutrition.

30 October 2018

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1. Introduction

1.1 WHAT IS THIS DOCUMENT ABOUT?

This document is about the development of clinical nutrition guidelines and the importance of summaries of these for patients as well as the need for patient involvement in the development processes, the importance of health literacy and informed decision-making concerning food and nutrition.

The importance of food and nutrition for patients as well as the need for good information to patients on food and nutrition is highlighted in EPF's position statement on information to patients on food and nutrition.[1] Please consider EPF's statement when reading this document.

Clinical nutrition is a discipline which deals with the prevention, diagnosis and management of nutritional and metabolic changes related to acute and chronic diseases and conditions caused by a lack or excess of energy and nutrients. Any nutritional measure, preventive or curative, targeting individual patients is clinical nutrition. Clinical nutrition includes the nutritional care of people with cardiovascular disease, obesity, diabetes, dyslipidaemias, food allergies, intolerances, inborn errors of metabolism as well as any disease where nutrition plays a role such as cancer, stroke, cystic fibrosis and many more.[2]

This document explains existing clinical nutrition guideline development processes as well as outlining shortcomings in existing processes and proposes how patient involvement in the guideline development process can be improved.

It explains why patient summaries of clinical nutrition guidelines are needed and highlights the importance of patient involvement in the development of guidelines and patient summaries alike.

This document aims to inform organisations developing clinical nutrition guidelines how to better involve patients in this process. This document is also written to provide European and national patient groups information on scientific nutrition guidelines available for specific disease areas as well as existing examples of patient friendly summaries of this information. Where necessary, relevant resources are mentioned where further information can be found.

The objectives of this document are to:

- Underline the importance of information to patients on food and diet choices
- Emphasise the importance of health literacy and informed decision-making concerning nutrition;

[1] http://www.eu-patient.eu/globalassets/policy/nutrition/epf-position-statement---nutrition.pdf
[2] ESPEN guidelines on definitions and terminology of clinical nutrition: http://www.espen.org/files/ESPEN-guidelines-on-definitions-and-terminology-of-clinical-nutrition.pdf

- Provide an overview of existing nutrition guideline development processes;
- Highlight evidence based scientific nutrition guidance available for specific disease areas, while giving examples of existing examples of patient friendly summaries of this information and nutrition guidance developed by patient organisations;
- Explain why patient summaries of clinical nutrition guidelines are needed and inspire scientific societies and guideline developers;
- Provide recommendations for improving existing guideline development processes, improving patient involvement and the development of patient summaries.

1.2 HOW WAS THIS DOCUMENT DEVELOPED?

Based on the outcomes of the EU Patient Group Conference on Nutrition[3] which took place in Brussels in June 2017 and in line with EPF's position statement on information to patients on food and nutrition[4], in February 2018, EPF set up an EU patient task force on nutrition[5], made up of volunteers from the EPF membership as well as other EU patient organisations. The task force is facilitated and co-led by the EPF Secretariat and EGAN (Patients Network for Medical Research and Health).

The main objective of this task force was to enhance the development of comprehensive summaries of recognised nutrition guidelines for patients, following the request of the patient community, in cooperation with scientific societies and guidelines developers. This document has also undergone consultation with the wider EPF membership.

This document will be presented at the 2018 edition of the Optimal Nutritional Care for All (ONCA) Conference taking place in Sintra, Portugal in November 2018.

1.3 WHO IS THIS DOCUMENT INTENDED FOR?

This document is primarily intended for patient and carer organisations and also scientific societies and organisations developing clinical nutrition guidelines. Healthcare professionals who are called upon to give advice may also find this document useful.

DISCLAIMER

This document has no intention of providing individual patients and their caregivers with nutritional advice. It only describes general situations. For personal advice on nutrition one should consult a dietitian. Furthermore, the information included in this document is not exhaustive.

[3] http://www.eu-patient.eu/globalassets/policy/nutrition/report-nutrition-conference-june-29-2017.pdf
[4] http://www.eu-patient.eu/globalassets/policy/nutrition/epf-position-statement---nutrition.pdf
[5] http://www.eu-patient.eu/whatwedo/Policy/nutrition/eu-patient-task-force-on-nutrition/

2. Nutrition in the prevention and management of chronic and long-term conditions

Nutrition plays an important role in both health and chronic disease management. Indeed, for many people attaining good nutrition is not a simple question of having good eating habits or choosing the 'right' foods. Some medical conditions mean that even when a person makes good nutritional and lifestyle choices, achieving nutritional health remains challenging. It is also important to keep in mind that in some cases, foods or food elements can also trigger the onset of specific diseases, for example food allergies and intolerance and/ or food poisoning and infections.

Making good choices about one's diet is not just an important way to reduce the risk of the onset of chronic conditions and maintain health. Nutrition also has a key part to play in the management of a chronic condition and health outcome as well as in secondary prevention and prevention of multimorbidity. Appropriate nutrition can prevent certain symptoms, delay the onset of complications, and improve health outcomes for some patients. Eating the right kinds of foods can improve well-being and physical strength, whereas poor nutrition can lead to reduced immunity, impaired physical and mental development, and reduced productivity.[6] Moreover, depending on a patients' condition, treatment, lifestyle, ability, age and environment, certain foods will be more appropriate for some patients. In these cases, nutrition should also be adapted according to the patient's needs. This is very relevant when a disease affects taste, often as a side-effect of the use of medication.

For some types and phases of disease it is not possible to maintain a normal nutritional status and/or avoid disease symptoms with personalised diets and standard foods alone. In such cases **specialised nutritional products (medical nutrition)** are needed to supplement the diet, or to replace food. In these cases, patients are partially or entirely dependent on medical nutrition. Medical nutrition products have been designed specifically to meet these medical needs, providing energy and nutrient-dense solutions in easily delivered forms. Medical nutrition may be oral (oral nutritional supplements), enteral (via the stomach or intestine) or parenteral (via the vein). Such nutrition formulas are given through a special feeding tube (enteral) or intravenous

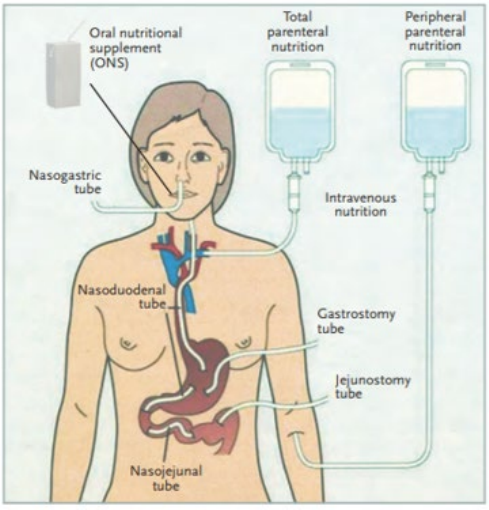


Figure - Different forms of medical nutrition

[6] ESMO (European Society for Medical Oncology). Handbook on Nutrition and Cancer. Lugano: ESMO Press; 2011. ECPC (European Cancer Patient Coalition). Living Well During Cancer Treatment. Brussels: ECPC; 2017.

catheter (parenteral). Most often this can be done in a patients' own surroundings (at home), however it is sometimes given in hospitals, especially in more critical periods.

The examples below provide disease-specific explanations of the important role nutrition plays in the management of certain chronic conditions.

Coeliac disease is a lifelong autoimmune disorder where gluten - a protein found in wheat, rye, oats and barley triggers an abnormal response of the immune system which causes damage to the small intestine and left untreated can lead to malabsorption and malnutrition. The immune reaction may affect other organs also, therefore coeliac disease may manifest with various symptoms outside the digestive system. The only available treatment for coeliac disease is a strict and lifelong gluten-free diet. Therefore, good nutritional counselling is essential. Under the gluten-free diet, symptoms will improve in most cases, the antibody levels will gradually normalise, and the intestine will mostly recover.

Cancer patients are at a particularly high risk of malnutrition because both the disease and its treatments threaten their nutrition status (state of nourishment of a patient). Yet cancer-related nutritional risk is sometimes overlooked or under-treated by clinicians, patients, and their families. Depending on the type of cancer and stage of treatment, guidance can differ. Additionally, cancer patients' taste and ability to eat can also be significantly affected. Sometimes disease conditions malnutrition, due to lack of appetite, problems in swallowing, increased catabolism or caused by treatment; known as "malnutrition related to the disease". For instance, people with throat cancer can have serious swallowing problems.[7]

There are two main types of **diabetes, type 1 and type 2**. There are some other types of diabetes too, such as gestational diabetes. Type 1 diabetes is a lifelong condition where the blood glucose (sugar) level is too high because the body cannot make a hormone called insulin. In Type 2 diabetes the blood glucose level is too high because the body does not produce enough insulin, or the body cannot effectively use the insulin it produces. Insulin allows the glucose in the blood to enter cells and fuel our bodies. In addition to symptoms of diabetes, over a long period of time, high glucose levels in the blood can seriously damage the heart, veins and arteries, eyes (neurological complications), feet and kidneys. These are known as complications of diabetes. A key requirement in preventing complications is maintaining good blood glucose (glycaemic) control, blood pressure and cholesterol. Comprehensive nutritional information, education and training is imperative in order for people with diabetes to be able to adequately manage their condition. This may include calculating the amount of carbohydrates, recognizing hidden sugar within food ingredients and knowing the amount of salt and fats.

Good nutritional care is a fundamental element of the management of **Huntington disease**, a hereditary, degenerative neurological condition. Weight loss is a well-known and common

[7] http://www.eu-patient.eu/contentassets/3998bf037bca4ddc890b934a3d1b460d/patient_perspectives_on_nutrition_-1.pdf

problem experienced by many patients with Huntington disease. Many patients lose weight unnoticed due to high energy needs and other food or diet problems therefore guidance on diet is essential.[8]

Mucopolysaccharide Diseases (MSP) are rare or very rare hereditary metabolic diseases which require a certain medical nutrition, a medical diet, which in most of these diseases is the only way of treating them to avoid or at least delay damage of organs, mental and physical disabilities and premature death. These diets must be prescribed and monitored by expert healthcare professionals. Regular information and counselling to patients and their families are indispensable to enable patients to follow these very strict diets and encourage their continuous adherence.

The so-called western lifestyle with changing nutrition, gut flora, air pollution, chemicals and processed food have been studied a lot in connection with the development of **allergy and asthma**. For **food allergy**, the only treatment is avoidance and people and families with food allergy rely on food labelling. For some people with food allergy their diet is so restrictive that clinical food supplements are needed to ensure good nutrition. Management of food allergy always requires a mandatory nutritional guidance by a dietician or other healthcare professional. Severe food allergy can be highly limiting for patients and families and requires education of all actors in the food chain, including schools, catering, and restaurants.

Asthma and **chronic obstructive pulmonary disease (COPD)** cause a chronic (systemic) inflammation of the airways, impaired lung function, airflow obstruction, morbidity and mortality. People with COPD can be at risk of fragility, because the disease, and the lack of oxygen also consumes muscles. Therefore, and especially in severe COPD, clinical nutrition is needed to ensure proteins, vitamins and minerals are provided. The disease also 'consumes more' of these and therefore nutrition and professional support on diet is needed. Often people with COPD have other chronic diseases like diabetes or heart disease which also come with a specific dietary guidance.

Chronic kidney disease can require a kidney friendly diet to prevent more kidney damage. People living with chronic kidney disease may need to limit fluids, eat a low protein diet, limit salt, potassium, phosphorus and other electrolytes. This can prevent certain minerals building up in the body.

Cardiovascular disease - Consumption of long chain omega 3 polyunsaturated fatty acids, fish, fruit and vegetables, nuts, fibre and replacing saturated fats with polyunsaturated fatty acids are associated with beneficial heart effects while consumption of saturated fatty acids, trans fatty acids and salt are associated with an increased risk of cardiovascular events. A Mediterranean dietary pattern is often recommended.

Inflammatory bowel disease (IBD) (predominantly **Crohn's disease and ulcerative colitis**) is increasingly common and potential dietary factors have been suggested to be at cause.

[8] https://topaz.nl/media/191480/nutritional-care-for-hd-patients.pdf

Malnutrition is highly prevalent in IBD, especially in Crohn's disease. Increased energy and protein requirements are observed in some patients. These patients may need medical nutrition in different phases throughout their lives, especially during the acute phase of their disease.[9]

Chronic intestinal failure (CIF) is the long-lasting reduction of gut function, below the minimum necessary for the absorption of macronutrients and/or water and electrolytes, such that intravenous supplementation is required to maintain health and/or growth. Even though it is very important that these patients maintain some ingestion of food and nutrients adapted to the characteristic of their intestine, they depend on parenteral nutrition (or iv fluids) to support their life.[10]

Further detail on the importance of nutrition in the context of different chronic conditions is highlighted in EPF's position statement on information to patients on food and nutrition.

2.1 MEDICAL NUTRITION: THE PATIENT-PROFESSIONAL PARTNERSHIP

Patients and caregivers must be involved in decisions taken, together with healthcare professionals, regarding the need for nutritional assistance as well as medical nutrition. To maximise positive outcomes and to ensure patient safety, healthcare professionals, who are experts in this area should make recommendations about initiating, monitoring and cessation of medical nutrition. EPF supports the notion of a Nutrition Support Team (NST), which is a multidisciplinary team consulted to manage the complex nutritional needs of patients (e.g. enteral and parenteral) which serves the primary responsibility of assuring that patients receive optimal nutrition support. Core members can include doctors, dietitians, nurses and pharmacists. Activities range from direct patient care to the development of guidelines and protocols for implementation by other healthcare workers.

Healthcare professionals should use evidence-based guidelines to assist them in selecting the most appropriate method of nutritional support for their patient, taking account of a wide variety of factors including:

- the goals of care, in a shared-decision making context
- patient's nutritional needs and wishes
- ability to take, digest, absorb, metabolize or excrete foods, nutrients or metabolites
- diagnosis and prognosis
- patient's ability to adhere to the intervention

[9] http://www.espen.org/files/ESPEN-guideline_Clinical-nutrition-in-inflammatory-bowel-disease.pdf
[10] http://www.espen.org/files/ESPEN-Guidelines/1__ESPEN_guidelines_on_chronic_intestinal_failure_in_adults.pdf

• patient safety and patient reported outcome measures (PROMs) and patient reported experience measures (PREMs) where relevant

It is essential that healthcare professionals combine their clinical experience and practical experience with a sound knowledge of the evidence base in making a recommendation or in the provision of nutritional support, e.g. a patient with a poor appetite may not be able or willing to consume extra food or may lack the energy or ability to prepare it. A patient who has lost the ability to swallow may need enteral (via the stomach) addition of nutrition and a patient with intestinal obstruction may need parenteral nutrition (via the vein). Similarly, financial aspects such as adequate equipment to prepare food and / or cost of concentrate food should not be neglected.

2.2 HEALTH LITERACY AND INFORMED DECISION-MAKING

Reliable, understandable, relevant and easily accessible information is the cornerstone of individual patient empowerment, quality of life, diseases management and meaningful patient involvement in health policy.

Health literacy is a key determinant of health.[11]

"Health literacy is linked to literacy and entails people's knowledge, motivation and competencies to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course."[12]

Being health literate empowers patients to understand information about their health and make more informed decisions. Low health literacy, or the lack of health literacy-friendly information can make daily life choices difficult for patients.

In the nutrition arena, health literacy-friendly measures recommended by WHO include making relevant and understandable information available from reliable sources.[13]

It is important that research, guidelines, care standards, recommendations and good practices concerning nutrition reach patients and citizens. Research and guidelines should be explained and disseminated in a patient-friendly way, and their communication and dissemination should be improved. Patient organisations, healthcare professionals, governments and the wider education system, all have their specific roles to play in this area if we are to improve health awareness and maximise impact upon the health and lifestyle choices of future generations.

According to the Value+ project definition, meaningful patient involvement means that patients take an active role in activities or decisions that will have consequences for the

[11] http://www.eu-patient.eu/globalassets/policy/healthliteracy/health-literacy-infographic.pdf
[12] https://bmcpublichealth.biomedcentral.com/articles/10.1186/1471-2458-12-80
[13] Health Literacy. The solid facts. WHO Europe, 2013, page 41-42, link

patient community, because of their specific knowledge and relevant experience as patients.[14] Patients and patient organisations are best placed to advise on what matters most to patients, how to define messages, in what form these should be delivered, through which channels they should be communicated, and finally on accessibility issues for patients with disabilities.

3. Clinical nutrition guideline development

3.1 GUIDELINE DEVELOPERS

Accurate information on specific nutritional needs is often not easy to find and sometimes patients and their caregivers do not receive appropriate guidance or answers to their questions from health care professionals. In addition, patients also sometimes find it difficult to get a referral to a specialised dietitian for their questions on food and nutrition. Insufficient time and material dedicated to this in educational curricula of health care professionals can be an important cause for this lack of information. There is progress, but it is the complexity of the issue in particular that is underestimated.

However, there is increasing interest from health care professionals in the topic of food and nutrition. Also, there is a growing number of professionals trained on matters of food and nutrition and their impacts on human health. Qualifications and professional terminology (i.e. nutrition scientist, public health nutritionist, dietitian, nutritionist, clinical nutritionist, and sports nutritionist) are different in different countries as is the level of education they receive.[15] In this document, we refer to all qualified nutrition professionals. [16]

Nutrition guidelines are very often developed by national scientific bodies, societies and institutions considering national circumstances, regulations, stakeholders etc. and making recommendations on the national level. At a European level, several societies and organisations work with national affiliates to develop European nutrition guidance. Consequently, patients seeking information about nutrition are advised to also consult national guidelines because they may vary or complete higher-level guidelines according to national regulations. It is not possible here to provide examples and links for every country here, however the following section aims to give an overview of some of these guideline developers.

The **European Society for Clinical Nutrition and Metabolism (ESPEN)**[17] is one of the scientific organisations that aims to encourage the rapid diffusion of knowledge and its

[14] http://www.eu-patient.eu/globalassets/projects/valueplus/doc_epf_handbook.pdf
[15] Doctors receive on average 25 hours of nutrition education in Europe (Eu J Cin Nutr 2014) compared to dietitians who spend over 3 years studying nutrition and diet.
[16] Please consult professional registers to find qualified professionals for advice.
[17] www.espen.org

application in the field of clinical nutrition. One of its core activities is the organisation of consensus papers and guidelines about clinical nutritional care. National level ESPEN-like organisations[18] have a similarly important role.

Another important professional organisation is the **European Federation of the Associations of Dietitians (EFAD)**.[19] EFAD has developed a Life Long Learning (LLL) Strategy to promote the development of the dietetic profession and developing dietetics on a scientific and professional level. One of EFAD's members, the British Dietetic Association (BDA) has developed several lay fact sheets for citizens and patients as well as family members and caregivers.[20]Another important resource is the Nutrition and Diet Resources UK website[21], a not-for-profit provider of nutrition and diet resources to support patient-centred care.

Disease-specific professional organisations or research networks such as **United European Gastroenterology (UEG)**[22], the **European Society for Paediatric Gastroenterology Hepatology and Nutrition (ESPGHAN)**[23]**,** the **European Crohn´s and Colitis Organisation (ECCO)**[24]**,** the **European Society for Medical Oncology (ESMO)**[25] **and the European Huntington's Disease Network (EHDN)**[26] also have an important role in developing therapeutic guidance, protocols and evidence-based clinical guidelines.

In **Germany**, the **Association of the Scientific Medical Societies** (**AWMF)** (German equivalent to NICE), is "a network of Scientific Medical Societies, which advises the government of the Federal Republic of Germany as well as the governments of the German federal countries ("Bundesländer") in all topics of scientific medicine and medical research and classification." They do this in many ways, including the publication of clinical nutrition guidelines with specific indications.[27]

The **National Institute for Health and Care Excellence (NICE)** in the UK is an independent public body that provides national guidance and advice to improve health and social care in England. NICE guidance offers evidence-based recommendations made by independent Committees on a broad range of topics. The NICE clinical guidelines recommend how healthcare professionals should care for people with specific conditions. They can cover any aspect of a condition and may include recommendations about providing information and

[18] www.espen.org/societies.
[19] www.efad.org
[20] https://www.bda.uk.com/foodfacts/home
[21] www.ndr-uk.org and more general information at www.nutrition.org.uk
[22] https://www.ueg.eu/quality-of-care/
[23] http://www.espghan.org/
[24] https://www.ecco-ibd.eu/publications/ecco-guidelines-science.html
[25] https://www.esmo.org/
[26] http://www.ehdn.org/
[27] https://www.awmf.org/en/awmf.html; https://www.awmf.org/en/clinical-practice-guidelines.html;

advice, prevention, diagnosis, treatment [28]and longer-term management. These guidelines are also important for health service managers and commissioners of national health system services. A general overview of developed guidelines can be found on their website.[29]

Nutrition is also referred to in guidelines pertaining to specific environments, such as in **surgery** for example.[30] Although malnutrition accompanies many chronic diseases, it is also important to recognise situations such as surgery where nutrition has an important impact on the recovery of patients. The Enhanced Recovery After Surgery (ERAS) Society[31] has in some cases published guidelines as a joint effort with other medical societies such as ESPEN and the International Association for Surgical Metabolism and Nutrition (IASMEN). [32]

Disease-specific patient organisations also publish guidance and information for patients. Many of which work with dietitians and medical doctors to check and verify the information provided. Some patient organisations have also developed evidence-based nutrition guidelines for health care professionals.[33]

3.2 GUIDELINES ON CLINICAL NUTRITION

This section gives a couple of examples of European and national guidelines on clinical nutrition. This section on guidelines is illustrative, rather than exhaustive.

Guidelines on the use of clinical nutrition[34] that aim to prevent, manage and treat different chronic diseases and improve patient outcomes have been developed by **The European Society for Clinical Nutrition and Metabolism (ESPEN)** since 1997. These guidelines are intended for health care professionals and should be used as guidance for taking decisions about a patients' nutritional care. See the figure below for a selection of published ESPEN guidelines[35] and guidelines in progress[36].

- **Nutrition in dementia (2015):** published
- **Ethical aspects of artificial nutrition and hydration (2016):** published
- **ESPEN-ESPGHAN-ECFS guidelines on nutrition care for infants,**
- **children, and adults with cystic fibrosis (2016):** published
- **Chronic intestinal failure in adults (2016):** published
- **Nutrition in cancer patients (2017):** published

[28] https://diabetes-resources-production.s3.eu-west-1.amazonaws.com/resources-s3/2018-03/1373_Nutrition%20guidelines_0.pdf
[29] https://www.nice.org.uk/
[30] http://www.espen.org/files/ESPEN-guideline_Clinical-nutrition-in-surgery.pdf
[31] http://erassociety.org/patients/
[32] https://www.ncbi.nlm.nih.gov/pubmed/23052794
[33] Evidence-based nutrition guidelines for the prevention and management of diabetes, Diabetes UK, link.
[34] ESPEN guidelines on definitions and terminology of clinical nutrition: http://www.espen.org/files/ESPEN-guidelines-on-definitions-and-terminology-of-clinical-nutrition.pdf
[35] ESPEN guidelines and consensus papers: http://www.espen.org/guidelines-home/espen-guidelines
[36] ESPEN guidelines in progress: http://www.espen.org/guidelines-home/guidelines-in-progress

- **Recommendations for action against cancer-related malnutrition (2017):** published
- **Clinical nutrition in inflammatory bowel disease (2017)**: published
- **Clinical nutrition in surgery (2017):** published
- **Neurology (2018):** published
- **Clinical nutrition and hydration in Geriatrics (2018):** published
- **ESPGHAN/ESPEN/ESPR/CSPEN guidelines on pediatric parenteral nutrition (2018):** published
- **Nutritional support for polymorbid internal medicine patients (2018):** published
- **Clinical nutrition in the intensive care unit (2018):** published
- **Liver Disease:** work in progress, close to publication
- **Home Enteral Nutrition:** work in progress
- **Home Parenteral Nutrition:** work in progress
- **Pancreas Disease:** work in progress
- **Nephrology:** work in progress
- **Hospital Nutrition:** work in progress

Figure 1: ESPEN Guidelines published and in progress since 2015

The **National Institute for Health and Care Excellence (NICE) in the UK** have developed clinical guidelines on 'Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition', published in February 2006 and last updated in August 2017. This guideline covers identifying and caring for adults who are malnourished or at risk of malnutrition in hospital or in their own home or a care home. It offers advice on how oral, enteral tube feeding and parenteral nutrition support should be started, administered and stopped. It aims to support healthcare professionals identify malnourished people and help them to choose the most appropriate form of support.[37] NICE has developed a user-friendly interactive flowchart which brings together everything NICE says on the topic of 'Nutrition support in adults' and provides a summary of the recommended pathway.[38] This guideline is accompanied by a 'Nutrition support in adults' quality standard which was also last updated in August 2017. PINNT (Patients on Intravenous and Naso-gastric Nutrition Treatment) and the Motor Neurone Disease Association have worked with NICE to promote this quality standard to commissioners and service providers.[39] NICE clinical nutrition guidance can also be found in NICE's condition-specific guidelines.[40]

[37] https://www.nice.org.uk/guidance/cg32
[38] https://pathways.nice.org.uk/pathways/nutrition-support-in-adults#content=view-node%3Anodes-indications-for-nutrition-support
[39] https://www.nice.org.uk/guidance/qs24
[40] https://www.nice.org.uk/guidance/conditions-and-diseases

3.3 GUIDELINE DEVELOPENT PROCESSES

THE ESPEN PROCESS FOR GUIDELINE DEVELOPMENT

Since 1997, the European Society for Clinical Nutrition and Metabolism (ESPEN) publishes guidelines and position papers on a regular basis in the journal *Clinical Nutrition*[41]. The details of the methodology used to develop and publish guidelines is presented in a standard operation procedure[42]. The procedure consists of 10 milestones and is described in the figure below. This process is lengthy and takes 2 – 3 years till publication.

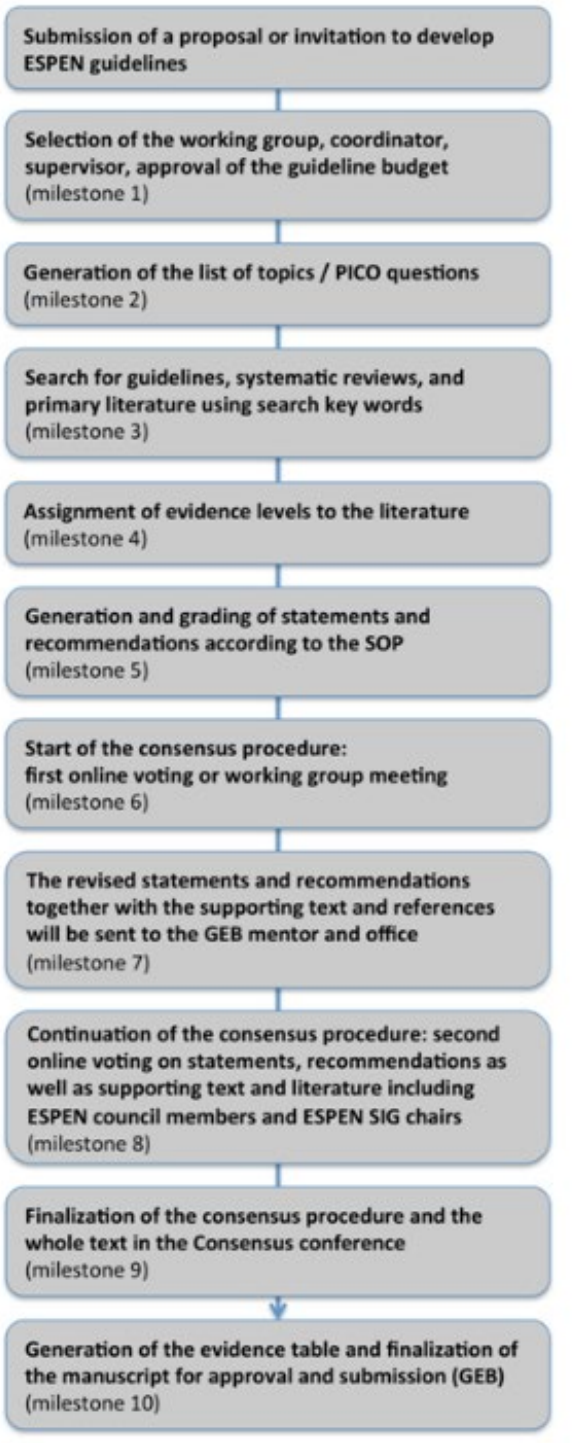


Figure - Flow chart indicating the structured generation of an ESPEN guideline.

[41] https://www.clinicalnutritionjournal.com/

[42] Standard operating procedures for ESPEN guidelines and consensus papers, January 2015, http://espen.org/guidelines/ESPEN_GuidelinesSOP.pdf

As part of the dissemination and implementation phase of the guideline development process, ESPEN intends to carry out the following activities.[43]

1. Careful examination of the guideline for clarity of language and format.
2. Review by a representative from a patient's organization. This does not automatically mean that the guideline is also a lay version of the guideline.
3. Presentation of the guideline in different formats (full format for experts, short format for practitioners, lay version format for patients) and media (print and website).
4. Inclusion of the guideline with algorithms, care pathways, and electronic decision support tools to complement the guideline.
5. Linking the guideline with relevant organisations and stakeholders.
6. Dissemination of the guidelines via slide sets, oral presentations, and teaching sessions (e.g. national conferences, LLL education, etc.).

To ensure that ESPEN guidelines are up to date and state of the art, they are revised at regular intervals (usually every 3–4 years, latest after 5 years).

The need for ongoing additions and updating of a guideline does not only reflect the availability of new and emerging scientific knowledge, but also depends on the results obtained from an analysis of the guideline's previous usage. The latter helps to identify opportunities for improvement.

Although this is an objective of ESPEN, so far, not all steps are achieved systematically. The lay version format of these guidelines for patients and caregivers are considered by both patients and ESPEN to be a high priority for future work.

Recent progress has been made to this end. In 2018, ESPEN was attributed a 2 year grant from the United European Gastroenterology (UEG) which is dedicated to the improved dissemination of existing clinical practice guidelines and standards and implementation into practice. This comprises 4 components: shortened versions of the guidelines for practitioners, translation of shortened versions into national languages, guidelines apps and lay versions of the shortened guidelines in an accessible format for patients.

EPF and ESPEN have recently confirmed a formal collaboration in the context of this project with respect to the development of patient versions of guidelines and to ensure strong patient involvement in the review of new guidelines.

[43] ESPEN guideline implementation and update: http://www.espen.org/files/ESPEN-Guidelines/0__Standard_operating_procedures_for_ESPEN_guidelines_and_consensus_papers_2.pdf

4. Patient involvement in guidelines development

4.1 THE EXTENT OF PATIENT INVOLVEMENT IN GUIDELINE DEVELOPMENT TODAY AND THE NEED FOR BETTER GUIDANCE FOR PATIENTS, E.G. PATIENT SUMMARIES OF GUIDELINES

Although scientific societies are working hard on the topic of guidelines and consensus papers, the feeling is that most of this knowledge is insufficiently available for patients and their caregivers. One of the objectives of this document is to ensure this knowledge is disseminated to European patient organisations and their members and through them to individual patients and their families.

It appears that in many EU countries patients and patient organisations do not have a role in co-developing clinical guidelines with health care professionals.

Systematic patient involvement has however significantly developed over the past years, although not in a consistent or equal manner across Europe.

Positive examples of **patient involvement in nutrition guidelines development** are experienced in several countries however there are fewer known good practices of patient involvement in central and eastern European countries. In the **UK**, BAPEN[44] (the UK ESPEN national association) and the Association of British Dietitians (BDA)[45] cooperate strongly with PINNT UK (Patients on intravenous and nasogastric nutrition therapy)[46] in developing lay-versions of educational material. Similarly, in **Germany**, the scientific departments of several patient organisations collaborate with societies like the above-mentioned AWMF, for example in developing specific indication-oriented guidelines. AWMF online provides patient information which intends to support the physician-patient-relationship.[47] Several scientific societies also produce patient information as part of their clinical practice guidelines. In **the Netherlands**, the Dutch Association for Allergology (NVvA) has designed a Nutrition Provision Guideline (Richtlijn Voedselprovocatie)[48]. The idea behind this guideline is that, in practice, various medical disciplines are involved in the treatment of people with (suspected) food allergies, therefore, in the case of this guideline, several associations are involved in its development. Representatives of the patient association, Dutch Anaphylaxis Network (NAN) and the Food Allergy Foundation (SVA) were also involved in the development of this guideline. The intended users of this guideline are medical specialists, nurses, dietitians and doctor's assistants working in the 2nd or 3rd line who are involved in

[44] https://www.bapen.org.uk/about-bapen/our-partners/espen
[45] https://www.peng.org.uk/publications-resources/resources-for-patients-hcps.php
[46] https://pinnt.com/Home.aspx
[47] https://www.awmf.org/en/clinical-practice-guidelines/patient-informations.html
[48] http://www.nvdv.nl/wp-content/uploads/2014/08/Richtlijn-voedselprovocatie-29-09-2015.pdf

any way whatsoever in the indication or supervision of patients before, during or after a food allergy.

At a European level, the **Association of European Coeliac Societies** (AOECS) was involved in the development of the **European Society for Paediatric Gastroenterology Hepatology and Nutrition** (ESPGHAN) nutrition guidelines for the diagnosis of coeliac disease as a full member of the working group. ESPGHAN is currently in the process of revising this guideline and has once again invited AOECS to be involved in this review, bringing the patient perspective to this exercise.

Similarly, **ESPEN** has started to include patient representatives in this process also, notably regarding guidelines on liver disease, intensive care and home enteral and parenteral nutrition. ESPEN has also began to work on translating guidelines on clinical nutrition in IBD and chronic intestinal failure into lay version guidelines for patients with **the European Federation of Crohn's & Ulcerative Colitis** (EFCCA) and **the European CanCer Organisation** (ECCO). ESPEN will also soon start to work with EPF with respect to the development of new lay versions of guidelines for patients.

In addition to good practices of patient involvement in the development of nutrition related guidelines, there are several examples of **good practices of patient involvement in guideline development** that is not necessarily related to nutrition. These should also be considered when developing meaningful patient involvement processes for nutrition guideline development.

In **Germany**, the National Care Guidelines Programme (Nationale VersorgungsLeitlinie NVL) is a joint initiative of the German Medical Association (Bundesärztekammer), National Association of Statutory Health Insurance Physicians (Kassenärztliche Bundesvereinigung**)** and the Association of Scientific Medical Societies for the Promotion of Quality in Medicine (Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften zur Qualitätsförderung in der Medizin).[49] The National Care Guidelines, are supplemented by a booklet on Patient Guidelines, which serve as companion information for patients to National Care guidelines on asthma, COPD, diabetes, heart failure, coronary heart disease etc. On behalf of the German Cancer Society, the Medical Centre for Quality in Medicine (Ärztliches Zentrum für Qualität in der Medizin - ÄZQ) has also developed patient guidelines on cancer (including breast cancer, colon cancer, cervical cancer, gastric cancer and prostate cancer). These are available online in full text.[50] In addition to information that is identical in content to the corresponding health care guidelines but rewritten in lay terms, these patient guidelines contain additional information that meet patients' needs. They explain the optimal care structures, provide background information on the functioning of the

[49] https://www.leitlinien.de/nvl/
[50] https://www.leitlinienprogramm-onkologie.de/index.php?id=8&type=0

respective body organ or system and its pathological change, initiate self-management and support the doctor-patient communication (e.g. through checklists).

In **Spain**, the Spanish society of parenteral nutrition (SENPE) together with health professionals and health councils of the different autonomous communities have created the framework document of the National Health System on the approach to malnutrition related to the disease. After the mediation of the Spanish Patients' Forum, it was approved by the Ministry of Health and its follow-up was recommended to the autonomous communities within the national health system.

The **Guidelines International Network** (G-I-N PUBLIC) is an international working group of researchers, health professionals and patient/public representatives that aims to support effective patient and public involvement in the development and implementation of clinical practice guidelines around the world and has developed a toolkit[51] to this end.

Patient and public involvement in guideline development has three main rationales, namely more patient-centred health care provision, more democratic health care policy-making and quality improvement of care and policy. Being aware of these different rationales for patient and public involvement can be helpful to manage divergent expectations that public and patient involvement participants may hold.[52]

4.2 PATIENT EXPERTISE AND EXPERIENCE

Living with a condition provides patients with unique expertise of a condition and experience of health care and services. In this sense, the unique position of patients provides valuable insights to healthcare guidance. There are many examples where patients have influenced the recommendations made as mentioned above. A concrete example of this is in Spanish guidelines on psoriasis for example, where experts and researchers focused on percentage coverage of the body in psoriasis whereas the patients said that the location of psoriasis matters more to them, such as the hands or face.

Furthermore, patient involvement has been shown to contribute to a more transparent and democratic health policy making process.[53]

Another important reason why patient versions of guidelines are needed is to give individual patients and family members a better understanding of why certain nutritional advice is given and to improve adherence and concordance[54] to nutritional advice.

[51] https://www.g-i-n.net/working-groups/gin-public/toolkit
[52] https://www.g-i-n.net/working-groups/gin-public/toolkit
[53] http://www.eu-patient.eu/globalassets/projects/valueplus/doc_epf_handbook.pdf
[54] EPF Position paper on adherence and concordance: http://www.eu-patient.eu/globalassets/policy/adherence-compliance-concordance/adherence-paper-final-rev_external.pdf

In all medical and prevention situations adherence is a crucial issue. But it is also known that adherence is also difficult to tackle adequately. We will not go in detail here about these issues. Especially for patients being dependent on medical nutrition for 24 hours per day, peer support and support from family members plays an important role in terms of starting the therapy and to continue with it. Improvement can also be seen in terms of increase in body weight, a vital sign for patients who are below ideal body weight.

Image of a placemat with normal healthy food and a plate with a plastic bag with medical nutrition, Appetite for Life

The figure on the right shows the contrast of two different food regimes, often within one family. This also illustrates that where daily meals are a social and mostly pleasant event, some family members are unable to fully participate in these meals and sometimes may feel isolated. This happens not only in family situations, but also in societal events with friends, at work or in sport events.

Patient groups in disease areas where (medical) nutrition plays an important role have a lot of expertise on the practical obstacles patients and families experience, such as the lack of understanding and facilities at emergency hospital units, or ignorance and mistrust while traveling through customs and reimbursement issues. For more information see the International Alliance of Patient Groups for Chronic Intestinal Failure and Home Artificial Nutrition (PACIFHAN)[55] and the websites of PACIFHAN members[56].

4.3 PATIENT GENERATED NUTRITION DATA – AN UNTAPPED RESOURCE

The way ESPEN and most other professional organisations develop guidelines is a highly scientific process, which is very evidence-based. From practice, we know that many patients and families are experimenting with varying individual diets. Most of the time this will not lead to scientific advice which can be used for guideline development. An interesting approach to this problem has been undertaken by several patient advocates together with health institutions in The Netherlands in a project called BeyondRCT[57] which is exploring the collection of data via a 'Practice Based Evidence Building'[58] method.

Biomedical research and Randomized Controlled Trials (RCT's) have generated a lot of very valuable insights but have severe limitations as well. One of those limitations is that patient inclusion criteria are often very strict, thereby excluding the complexity of multiple chronic conditions that people suffer from, and the diversity of lifestyles that people lead.

[55] http://pacifhan.org/
[56] http://pacifhan.org/pacifhan-members/
[57] http://www.beyondrct.net/
[58] http://www.pennutrition.com/index.aspx

Furthermore, the research setting is highly controlled, severely limiting the ability to translate the results to the environment of daily life. Citizens, and especially patients, increasingly question the usefulness of proposed health approaches to their specific conditions. They demand more inclusive research strategies, in which their highly contextualised experiences tangibly impact the generation of knowledge'.[59] A study on prostate cancer and nutrition is also being conducted by the Rotterdam Erasmus Medical Centre and organized by the Dutch platform Patients and Food[60].

5. Existing clinical nutrition guideline summaries developed by patients for patients

This section highlights summaries of recognised clinical nutrition guidelines and guidance developed by patient groups and organisations for patients.

Patient organisations have, to date, developed several initiatives of existing guidance on nutrition and different chronic conditions in a multitude of different formats. The initiatives listed and explained below are intended for patients and serve as a guide and inspiration to scientific societies and guideline developers. These examples are far from exhaustive and we welcome receiving more examples.

Developing summaries of recognised nutrition guidelines for patients is a complex exercise. Nutrition relates to different chronic conditions in very different ways, be it coeliac, diabetes, allergies or cancer to name a few. Furthermore, the way in which nutrition relates to different subsets of these diseases and different patients also varies greatly, adding to the complexity of such guidance.

Further detail on the importance of nutrition in the context of the different chronic conditions addressed below is highlighted in EPF's position statement on information to patients on food and nutrition.

Coeliac Disease and Nutrition

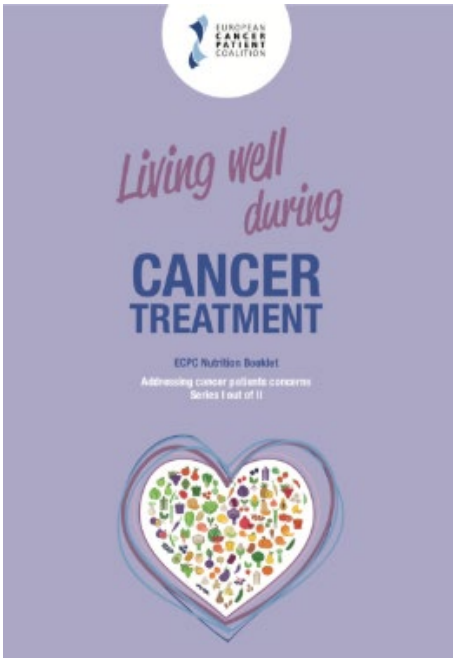
There are several clinical guidelines and publications on nutrition and coeliac disease. People living with coeliac are considered as experts and the professionals very much depend on the education they receive from expert patients or patients' associations. Information for patients is developed by patient organisations such as the **Association of European Coeliac Societies (AOECS)**[61].

[59] http://www.beyondrct.net/wp-content/uploads/2018/10/Executive-Summary-BeyondRCT-2018.pdf
[60] https://patientenvoeding.nl/studie-prostaatkanker-en-voeding-2018/
[61] https://www.aoecs.org/coeliac-disease

AOECS is currently working on two eLearning tools (one for patients and one for HCPs) on lay languages and with practical hints on model basis, in the context of a 'FOCUS IN CD Interreg Central-Europe' funded project.

The **Hungarian Coeliac Society (HCS)**, a member of AOECS, is currently working within an Interreg CE project on "Innovative patient-centred health care services - advantages of establishing a close CE network in coeliac disease patient healthcare" together with 11 other project partners (from Hungary, Slovenia, Croatia, Italy/Trieste and Germany/Munich). One of the main aims of the project is to develop 2 **eLearning tools** (one for patients and one for HCPs) and one App for family doctors to become more familiar with coeliac disease, to comply with the lifelong rules, increase the ratio of diagnosed patients and shorten the diagnostic time. The eLearning tool for patients (in English, German and Hungarian) is currently undergoing beta testing. Other translations are also in progress. The project will end in May 2019.

Cancer and Nutrition



The **European Cancer Patient Coalition (ECPC)** performed a European Survey[62] of 907 people with cancer about the importance of nutrition, of which more than 90% did not receive any information about weight loss because of cancer (cachexia) from their health professionals. Almost 70% reported that they lost weight after the cancer diagnosis and more than 70% of the respondents did not know the meaning of the term 'cachexia'. ECPC therefore believes that there is a need to empower individual patients and patient associations by producing more information on cancer patients' nutritional needs. Therefore, in 2018 ECPC published a **booklet entitled 'Living well during cancer treatment'**.[63] This booklet is based on the ESPEN guidelines on nutrition in cancer patients[64] and the ESMO handbook of Nutrition and Cancer.[65] Within this booklet, ECPC have also developed a 'Cancer Patient's Charter of Rights for Appropriate and Prompt Nutritional Support'.

The ECPC 'Living well during Cancer Treatment' Nutrition Booklet (2018) addresses common questions patients might have about diet, nutrition and physical activity during

[62] https://academic.oup.com/annonc/article/28/suppl_5/mdx385.007/4109504
[63] http://www.ecpc.org/edu/nutrition
[64] http://www.espen.info/wp/wordpress/wp-content/uploads/2016/11/ESPEN-cancer-guidelines-2016-final-published.pdf
[65] https://oncologypro.esmo.org/Education-Library/Handbooks/Nutrition-and-Cancer

cancer treatment, and provides essential patient information regarding nutrition and cancer, based on recognised guidance on nutrition and cancer.

Breast Cancer and Nutrition

As a growing body of evidence shows the link between healthy choices and a lower risk of developing breast cancer, **EUROPA DONNA** - The European Breast Cancer Coalition (ED) established **Breast Health Day** (BHD) on 15 October 2008. The BHD campaign stresses the importance of being active, eating a well-balanced diet and maintaining a normal body weight. While studies have not linked specific diets to breast cancer risk, nutrition is still important, with excess body weight and physical inactivity accounting for 25-33 percent of breast cancer cases.[66] In this respect, Europa Donna have recently launched a new section of their website dedicated to prevention providing information on primary and secondary prevention as well as preventing recurrence.[67]

Diabetes and Nutrition

Several materials and guidance on nutrition and diabetes have been developed by patient organisations and societies to support newly-diagnosed patients or patients at risk of developing type 2 diabetes.

In the context of a project called MANAGE-CARE[68], the **European region of the International Diabetes Federation (IDF Europe)** has developed a **patient empowerment booklet**[69] which includes guidance on nutrition. This booklet is available in 10 different languages.[70]

"There is not a one-size-fits all approach when it comes to making food choices, so these new guidelines take this into account. It is important that people with diabetes, and those at risk, are supported to choose the right foods for them to help them to achieve their specific treatment goals and improve their health and quality of life." Douglas Twenefour, Deputy Head of Care and co-chair of the guidelines group, Diabetes UK

[66] IARC (2002). IARC Handbooks of Cancer Prevention, Volume 6, Weight control and physical activity. Lyon, France: International Agency for Research on Cancer, link.
[67] https://prevention.europadonna.org/
[68] http://www.managecare-project.eu/
[69] https://www.idf.org/images/English_web.pdf
[70] https://www.idf.org/our-network/regions-members/europe/eu-research-projects/14-manage-care-patients-empowerment-booklet.html

Diabetes UK has been publishing dietary guidelines[71] since 1982, with updates and revisions issued at regular intervals. Each revision reflects advances in the available evidence that impacts changes in approaches to dietary management of diabetes. In March 2018, Diabetes UK published a comprehensive guide[72] intended for health care professionals on **evidence-based nutrition guidelines for the prevention and management of diabetes type 2**. Diabetes UK have also developed materials intended for patients and their carers together with registered dietitians who translate the latest public and scientific research into practical guidance.[73] Furthermore, Diabetes UK have also developed **advice and tips** on everything from healthy swaps, understanding food labels, how to cook healthier meals, meal planning and shopping on a budget.[74]

Allergy and Respiratory diseases and Nutrition

Food Allergy

The **Finnish patient association Allergy, Skin and Asthma Federation** produces patient education material together with the top experts in the country and including the patient perspective. For food allergy, there is patient guidance on food allergy in adults[75] and for food allergy in children[76]. These include causes, managing food allergy, including diet, emergencies, psychosocial factors and tips. They have also helped co-create with professionals a web portal called **ERIMENU** ('different menu') in which you can insert your diet whether its allergy, coeliac disease or other and receive information on food products and recipes that are suitable for you.[77]

Building on a long patient organisation tradition, all Nordic allergy and asthma associations and heart and lung associations have such materials and guidance, but also educational resources both for patients and their families and professionals and do important work

[71] Example: https://onlinelibrary.wiley.com/doi/full/10.1046/j.1464-5491.2003.01104.x
[72] file:///C:/Users/Katie/Desktop/Perso/Health%20Insurance/DKV/4.%20Remboursement_24Mars-3Ao%C3%BBt2018/1373_Nutrition%20guidelines_0.pdf
[73] https://www.diabetes.org.uk/guide-to-diabetes/enjoy-food/our-dietary-advice-explained
[74] Helping families with diabetes shop, cook and eat, Diabetes UK: https://www.diabetes.org.uk/Guide-to-diabetes/Managing-your-diabetes/Healthy-eating
[75] https://www.allergia.fi/site/assets/files/1231/aikuisten_ruoka_allergia_web_pages_2803-2018.pdf
[76] https://www.allergia.fi/site/assets/files/1210/lasten_ruoka_allergia_opas_web_spreads.pdf
[77] https://www.erimenu.fi/

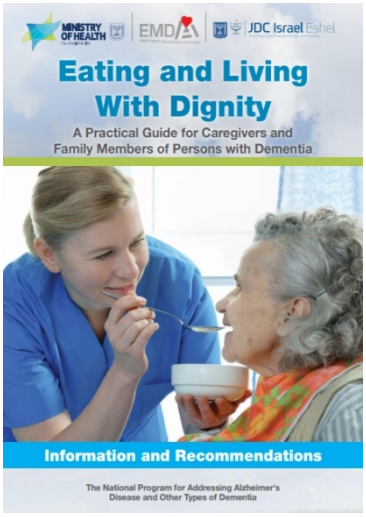
through national helplines and peer support groups organised by their local and regional member associations.[78]

Chronic Obstructive Pulmonary Disease (COPD)

COPD Support Ireland, a charity set up to support all those living with chronic obstructive pulmonary disease has developed a **leaflet entitled "Nutrition & Chronic Obstructive Pulmonary Disease"**[79] which provides guidance for people living with COPD on how to eat well, tips to encourage eating, for losing weight and eating a balanced diet and for gaining weight or improving nutritional intake.

In the Netherlands, "Zorgstandard Asthma- Goede zorg voor iedereen met astma" ("**Care Standard Asthma- Good care for anyone with asthma**)[80] is a patient version of the Zorgstandaard astma voor volwassenen[81] (Care Standard for Asthma for adults), which is based on medical guidelines. The purpose of the booklet is to help patients cope with their disease in the best possible way, it includes a chapter on nutrition for asthma. In this booklet patients can find information about their disease, which care they can receive and what they can do themselves to manage their disease. This book also states what care the caregivers should provide, allowing patients to know exactly what they can do themselves and what they can expect from a physician. The patient version has been developed by Longfonds ('Lung Fund'), a health foundation that includes patient organisations.

Nutrition and Neurological Diseases



Many people and especially older people live with neurological diseases, such as dementia or Alzheimer's disease. Professional guidelines exist, but more importantly there is a guide available for patients, family members and caregivers. The guide **'Eating and Living with Dignity: A Practical Guide for Caregivers and Family Members of Persons with Dementia'**[82] was developed by the Israel Ministry of Health in collaboration with the Alzheimer's Association of Israel and JDC Israel ESHEL.

Another important neurological disease is Huntington's disease. Although there are no European nutritional guidelines available to date, the **European Huntington's Disease Network Standards of Care Dietitians Group** has brought together expert dietitians from across Europe to produce

[78] http://www.efanet.org/who-we-are/members
[79] http://copd.ie/wp-content/uploads/2014/10/Nutrition-and-COPD.pdf
[80] https://bestellen.longfonds.nl/product/patientenversie-zorgstandaard-copd/
[81] http://www.longalliantie.nl/files/4113/7335/4473/Zorgstandaard_Astma_Volwassenen.pdf
[82] https://www.health.gov.il/PublicationsFiles/Dementia_Nutrition_en.pdf

nutrition guidelines to promote optimal nutritional screening, assessment and management of individuals throughout all stages of the disease[83].

In addition, the Australian organisation Huntington's New South Wales has developed **guidelines for meeting the nutritional needs of people with Huntington disease**[84]and a **booklet entitled 'Eating and Swallowing Difficulties in Huntingdon Disease'**[85] which provides practical advice for carers.

Nutrition and Neuromuscular disorders

Patients with neuromuscular disorders are fully aware that optimal and personalised diets are one of the cornerstones of wellbeing and quality of life.
The Treat-NMD Neuromuscular network has developed standards of care for spinal muscular atrophy (SMA) for example which include guidance on nutrition. These are also available in multiple languages.[86] **Cure SMA** have also developed support and care publications including a publication specifically related to nutrition.[87]

Medical nutrition

Lay information on Medical Nutrition can be found on the website of the **International Alliance of Patient Organisations for Chronic Intestinal Failure and Home Artificial Nutrition (PACIFHAN)**[88].

ESPEN released guidelines on enteral nutrition in 2006 and parenteral nutrition in 2009. Since 2010, ESPEN changed the focus to disease-specific guidelines. Currently ESPEN is working on a guideline for home enteral nutrition (HEN) and home parenteral nutrition (HPN). In this guideline review process patient's experts are included.

Very relevant information and resources, including a video library and online education[89] can also be found on the website of the OLEY Foundation, an American organisation who strives to enrich the lives of those living with home intravenous nutrition and tube feeding through education, advocacy, and networking.

Nutrition and Pre-conception care and early life

The Early Nutrition Academy[90] has developed an **Early Nutrition eAcademy**, an e-learning platform, which consists of different modules, each focusing on one defined topic within the

[83] https://www.futuremedicine.com/doi/pdf/10.2217/nmt.11.69
[84] https://www.huntingtonsnsw.org.au/sites/default/files/Nutrition%20Guidelines.pdf
[85]https://www.huntingtonsnsw.org.au/sites/default/files/Eating%20and%20Swallowing%20Difficulties%20April%202012.pdf
[86] http://www.treat-nmd.eu/care/sma/family-guide-translations/
[87] http://www.curesma.org/documents/support--care-documents/nutrition-basics.pdf
[88] www.pacifhan.org
[89] https://oley.org/page/MyHPN_Modules
[90] https://www.early-nutrition.org/en/

field of early nutrition. Although these modules are developed for professionals, patient representatives can also use them. To date the following modules are available online:

- Nutrition and Lifestyle During Pregnancy
- Breastfeeding
- Infant Formula Feeding
- Complementary Feeding

One of the partners of the Early Nutrition Academy is the European Foundation for the Care of Newborn Infants (EFCNI)[91]. EFCNI has developed numerous information materials such as factsheets in lay language for families. Another organisation specialised in this field, is Preparing for Life[92].

Nutrition and Persons in Older Age

The European Nutrition Health Alliance (ENHA), of which EPF is a partner, has spent the last ten years advocating for more attention to be given to nutritional problems in older age. In several EU countries, national steering committees promote screening of people in older age for their nutritional status.[93] ENHA has in recent years broadened its scope to promote optimal nutritional care for all, throughout the lifecycle.[94]

The European Federation of the Associations of Dietitians (EFAD) has a specific working group of dietitians working with older adults. They have special knowledge, skills and attitudes which underpin gerontology and geriatric nutrition. Especially sarcopenia (the loss of skeletal muscle mass and strength as a result of ageing) and age-related frailty is an issue in less active older adults as compared to those older adults who are healthy and active. Although osteoporosis is an issue for all age groups, it can be of specific concern for older adults. The International Osteoporosis Foundation for example has developed a brochure which contains a lot of information.[95]

6. Recommendations

6.1 RECOMMENDATIONS FOR GUIDELINE DEVELOPERS

Recommendations for improving guideline development processes, developing patient summaries of guidelines for patients and patient involvement:

[91] https://www.efcni.org/
[92] https://preparingforlife.net/
[93] https://www.fightmalnutrition.eu/
[94] https://european-nutrition.org/
[95] https://www.iofbonehealth.org/good-nutrition-healthy-bones

- EPF recommends societies developing clinical nutrition guidelines to also develop lay summaries of guidelines for patients in a systematic and transparent way, through co-design, together with patients, consulting patient organisations throughout the process with formal cooperation agreements and appropriate compensation.
- EPF recommends guideline developers to involve patients and their organisations throughout the development of evidence based clinical nutrition guidelines; in the scoping, prioritisation, drafting and patient summary development stages, with appropriate compensation, in accordance with the Value+ project principles.[96]
- EPF recommends that the outcome of the process (patient summaries and clinical nutrition guidelines- be easily available ("on one site with one click"), in plain language and available in as many languages as possible.
- EPF recommends that food based dietary guidelines be introduced as well as person-centred recommendations relating to food and diet choice in evidence based clinical nutrition guidance. 'People do not eat nutrition, but they do eat food'.

6.2 RECOMMENDATIONS FOR PATIENT ORGANISATIONS

- EPF invites patient organisations to develop strategies on how their involvement in the development of clinical guidelines, care standards and patient versions of these materials could be enhanced. The development of these materials could also enhance shared-decision making and adherence.
- EPF invites patient organisations to cooperate with professional societies in the development of nutrition guidance for patients, in the format of patient summaries of guidelines for example.
- EPF invites its members to disseminate this document widely to their networks and to inform their members of existing clinical nutrition guidance, summaries for patients and patient-led initiatives highlighted throughout.

7. Conclusion

Patients and their organisations have many questions when it comes to chronic conditions and relevant food and nutrition guidance. Similarly, there is growing interest to communicate on this topic, providing patients and their families with guidance and good information which meets the needs of patients. Given that nutrition plays an important role in the prevention, treatment and management of many diseases, many patient organisations have identified nutrition as a key topic of activity.

There is unfortunately however a lot of inaccurate and even dangerously misleading information on nutrition and chronic disease on the internet. Fighting against "fake

[96] http://www.eu-patient.eu/globalassets/projects/valueplus/doc_epf_handbook.pdf

information" is a challenge. Therefore, when exploring or developing information for patients, it is wise to consult a well-recognised expert specialised in the disease area for advice.

Over the past years, EPF has amplified its activities on the topic of food and nutrition. Activities such as EPF's recent Position Statement on Information to Patients on Food and Nutrition[97] published in February 2018 sparked the interest and active input of many EPF members.

In 2019, EPF will publish an executive summary of this document for patients and patients' organisations to use in their advocacy activities and to facilitate translation.

EPF and EGAN will continue to work closely with societies and guideline developers such as ESPEN, EFAD and ENHA to improve awareness on the importance of nutrition in the prevention and management of diseases and the inclusion of nutritional needs in care standards. Similarly, we will continue to encourage the development of patient summaries of recognised guidelines, highlighting the importance of patient involvement throughout the guideline development process. In this regard, EPF hopes to work with guideline developers on the realisation of patient summaries, how these could be used by patients, what they would look like and on the dissemination of these.

The process of better patient involvement is not a bottom-down process but depends on mutual interrelation between patient organisations on the one hand and readiness to accept patients' involvement by scientific societies and bodies on the other hand. EPF can support by describing and providing guidance on the frame which facilitates and enhances patient involvement but not the specific detailed work and interaction, which very often has to consider disease specific, or national contexts and circumstances. With this, EPF looks forward to working closely with its membership to improve clinical nutrition guidance for patients in Europe.

[97] http://www.eu-patient.eu/globalassets/policy/nutrition/epf-position-statement---nutrition.pdf

8. Acknowledgements

EPF would like to thank the members of the EU patient task force on nutrition for their work throughout 2018.

- Albert Counet, Ligue Huntington Francophone Belge
- Lana Crnjac, European Liver Patients' Association
- Katie Gallagher, European Patients' Forum (EPF)
- Caroline Heilpern, European Federation of Allergy and Airways Diseases Patients' Associations (EFA)
- Robert Johnstone, National Voices, UK
- Ernest Karuranga, International Diabetes Federation European Region (IDF Europe)
- Winne Ko, International Diabetes Federation European Region (IDF Europe)
- Tunde Koltai, Hungarian Alliance of Patient Organisations
- Marek Lichota, Appetite for life Association and the International Alliance of Patient Organisations for Chronic Intestinal Failure and home Artificial Nutrition (PACIPHAN)
- Isabelle Manneh-Vangramberen, European Cancer Patient Coalition (ECPC)
- Virginie Potbury, Association of European Coeliac Societies (AOECS)
- Lala Rabemananjara, International Diabetes Federation European Region (IDF Europe)
- Roberta Savli, European Federation of Allergy and Airways Diseases Patients' Associations (EFA)
- Sarah Sleet, Association of European Coeliac Societies (AOECS)
- Cees Smit, Patients Network for Medical Research and Health (EGAN)
- Cathalijne Van Doorne, European Federation of Neurological Associations (EFNA)

EPF consulted the following organisations during the development of this document and would also like to thank them for their expertise and valuable contributions.

- European Federation of the Associations of Dietitians (EFAD)
- European Society for Clinical Nutrition and Metabolism (ESPEN)