

A still life painting of several pears and green leaves, viewed through a window frame. The pears are rendered in shades of yellow, green, and brown, with visible brushstrokes. The leaves are vibrant green. The background shows a glimpse of a landscape with trees and a blue sky. A semi-transparent purple rectangular box is overlaid on the center of the image, containing the title text.

**PATIENT PERSPECTIVES
ON NUTRITION**

Human beings do not eat nutrients, they eat food.

Mary Catherine Bateson

If you really want to make a friend, go to someone's house and eat with him...
the people who give you their food give you their heart.

César Chávez

PATIENT PERSPECTIVES ON NUTRITION

A booklet produced by EPF, EGAN and ENHA

COLOFON

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The case studies in part 1 of this booklet are fictitious and are intended to reflect common real-life patient experiences in the area of nutrition. The case studies in part 2 of this booklet reflect real patient experiences.

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PREFACE

*Una mela al giorno toglie il medico di torno. . . Ein Apfel am Tag hält den Doktor fern. . .
Kto jada salatkі, ten jest piękny i gładki. . . Който зеленчуци не яде, той голям не ще да
нопасне. . . Ett äpple om dagen håller doktorn borta. . . An apple a day keeps the doctor away.*

An old proverb that exists in many cultures, languages and variations. It is a saying that certainly holds some truth to it and today is backed up by research and activities carried out by healthcare authorities such as the World Health Organisation (WHO). Indeed, well-balanced diets that are high in fresh fruits and vegetables and low in trans and saturated fats, high-fat dairy and meat products, sugars and salt can play a role in the onset of chronic conditions. Therefore healthy diets and lifestyles are increasingly encouraged by policy makers, patient groups, educators and healthcare professionals. However, less well-known is the important role that nutrition plays in both health and disease management. This booklet focusses specifically on the importance of nutrition in relation to chronic disease management, and does not address other factors such as genetics, social determinants, literacy, all of which influence health and disease.

Indeed, for many people attaining good nutrition is not a simple question of having good eating habits. Some medical conditions mean that even when a person makes good nutritional and lifestyle choices, achieving good nutritional health remains challenging. That is the topic of this book. It's a combination of the knowledge of patient experts and groups who explain what impact their diseases have on their nutritional needs. And it is the experience of the nutritional scientists who explain what the relationship is between nutrition and health, medical nutrition options and what the extra impact of malnutrition on diseases could be. At the same time, it is one of the first booklets where the collective experience of patient experts and nutritional scientists is shared. The first part of this booklet is written by nutritional scientist - Dr. Ceri Green - and the second part is material from EU Patient Groups.

There is growing recognition of the burden to healthcare systems caused by malnutrition, both due to poor identification of nutritional risk in patients and because of a lack of inclusion of nutritional care plans when it comes to disease management. The importance of this issue was first brought forward at the first conference on "The relevance of nutrition for EU patient groups", held on July 4, 2012 in Brussels. At this meeting patient groups and nutritional scientists shared their knowledge and

presented their needs. This meeting was jointly organized by the European Patients' Forum (EPF), the European Nutrition for Health Alliance (ENHA) and the European Genetic Alliances Network (EGAN). The recommendations of this meeting can be found at the end of this booklet.

From this meeting came a wish to make the presentation of Dr. Ceri Green: *Nutrition: a vital part of health and disease management* available for a wider audience of patient groups and treating physicians. And at the same time, to combine her presentation with the realities on the ground, the insights kept within patient groups about their knowledge on food and nutrition during health and disease management. A more holistic approach to tackling these issues, where everyone, i.e. governments, policy makers, healthcare professionals, patients and carers, understands his or her role, is crucial on the road to success.

The booklet is a joint production from three groups, namely two EU patient groups (the European Patients' Forum (EPF) and the European Genetic Alliances Network (EGAN) together with the European Nutrition for Health Alliance (ENHA). ENHA is a multi-stakeholder group working especially on a screening process for malnutrition. Grouped together, the political agenda from these three groups show a variety of needs and demands.

We hope this booklet, which is the result of excellent collaboration with our partners will contribute to closing the knowledge gap when it comes to nutrition and disease management. This will, in turn, contribute towards better healthcare and quality of life for Europe's patients.

We are delighted this publication is presented for the first time during the 10th Annual Meeting of the European Patient's Forum (EPF) in Dublin on May 24, 2013 under the Irish presidency of the EU.

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Food provides much more than just nutrition. It is a fundamental part of our cultures and social interactions. The role of food in this context is, however, not the topic of this book. Instead, what we will look at is a well-known but often forgotten or overlooked aspect of food: what we eat and therefore the nutrients we consume can play a critical role in ensuring health or managing outcomes in disease.

NUTRITION: A VITAL PART
OF HEALTH AND DISEASE
MANAGEMENT



1. THE LINK BETWEEN NUTRITION AND HEALTH

The World Health Organisation (WHO) has for many years provided guidance to its member countries on the link between nutrition and health.

Based upon research carried out after World War II, the WHO highlights the important correlation between poor diets and the onset of non-communicable diseases (NCDs). Poor diets are high in saturated fats, high-fat dairy and meat products, sugars and salt, and low in fruits and vegetables. Such diets cause overweight and obesity; the main nutritional problems over the last 30 years that are now the fifth leading risk for global deaths. In addition, poor diets contribute to the development of NCDs, with statistics from 2008 showing that 44% of the diabetes burden and 23% of the ischaemic heart disease burden is attributable to overweight and obesity and therefore to poor nutrition. Other NCDs which individuals are at particular risk of developing include cardiovascular (heart) disease, cerebrovascular disease (stroke), and certain cancers.¹

With these findings, the WHO began to dedicate a great wealth of resources to fighting NCDs by fostering a holistic approach to the problem, including how to address the crucial role that nutrition plays when it comes to improving a country's primary health service and fighting the development of chronic diseases.

2. PRINCIPLES OF A BALANCED DIET

As part of the Countrywide Integrated NCD Intervention programme (CINDI), the WHO developed food-based guidelines that can be adapted to national situations. Because of the significant role that cultural factors play in dictating diets, the WHO encourages countries to adapt these guidelines depending on local dietary patterns, particularly when this is shown to have an impact on the prevalence of a particular NCD. This approach has proved innovative in that it departed from the previous nutrient-based guidelines that were not targeted at the general public.

The CINDI guidelines propose twelve steps for healthy eating in adults and recommend a daily energy intake of 1500 to 2800 kcal² which varies depending on the level of physical activity and weight.

Food provides energy and nutrients which are essential to allow growth and development, and for maintaining optimal body function. The essential macronutrients needed are protein, fat and carbohydrate. Dietary fibre is also an important part of a balanced diet. These nutrients are present in the diet in quite substantial amounts. Micronutrients include vitamins, minerals and trace elements, which are present in the diet in rather small amounts. Water can also be considered as a nutrient, and is found in drinks, but also in many foods. A typical adult needs around 1500-2000ml of water per day to maintain adequate hydration levels. Table 1 gives some more information.

Food component	Structure	Provides tot the body
Protein	Chains of essential and non-essential amino acids	Building blocks of cells, tissues, organs and enzymes, energy source
Fat	Triglycerides containing different essential and non-essential fatty acids	Energy source, taste, normal structure and function of membranes
Carbohydrate	Starches, chains of sugars and single sugars	Energy source
Dietary fibre	Various plant materials which are not digested in the small intestine	Normal bowel structure and function, influences satiety and nutrient absorption, energy source
Vitamins	Organic fat or water soluble substances	Key components for many metabolic processes, e.g. chemical reactions that convert food to energy
Minerals and trace elements	Inorganic elements	Various functions including bone formation, oxygen transport, blood clotting, fluid and electrolyte balance, function of hormones and enzymes, cellular function, neurotransmission
Water		Solvent, transport, excretion, lubrication, control of body temperature

Table 1 – Nutrients in the diet³

Different foods contain different types and amounts of macro- and micro-nutrients and dietary fibre. Some foods contain only a single macronutrient (e.g. table sugar) but most foods contain a variety of nutrients. To ensure a healthy and well-balanced diet, it is important to eat a range of different foods. Table 2 gives a few examples of some common foods and the types of nutrients they contain.

Food examples	Protein	Fat	Carbohydrate	Fibre	Vitamins	Minerals and trace elements
Milk, yoghurt	++	+	+		++	++
Meat, fish, eggs	++	+			++	++
Nuts	++	++	+	++	++	++
Pulses	++		+	++	++	++
Wholegrain cereals, bread	+		++	++	++	++
Rice, potatoes	+		++	+	+	+
Fruit, vegetables			++	++	++	++
Oil, butter		++			++	
Sugar, sugary drinks			++			

Table 2 – Nutrients found in different foods ³

* This table is to give a general impression only - different foods will vary greatly in absolute levels and types of the various nutrients.

Most countries have developed their own approaches to describing a healthy balanced diet as part of their national public health messages, e.g. using food wheels, plates or pyramids. An example is shown here (see Figure 1).⁴



Figure 1 – Irish Food Pyramid

3. NUTRITION THROUGH THE LIFECYCLE – FROM PRECONCEPTION TO OLDER PEOPLE

Nutrition plays a vital role in the life of an individual at all ages. However, the composition of healthy nutrition varies according to age. In addition to the basic rules of nutrition, each age group has specific nutritional needs that have to be met in order to ensure good health. These needs are reflected in international and national dietary recommendations. Furthermore, there are some critical periods when adequate nutrition is even more important than at other times, such as in the preconception period and during pregnancy, in early childhood, in older people and in situations of acute or chronic illness. Inadequate nutrition during these periods can be even more detrimental than at other life stages.

Some of the different nutritional needs during the lifecycle are considered below.

PRECONCEPTION NUTRITION AND NUTRITION DURING PREGNANCY

Nutrition is important even before the very earliest stages of life – before a woman becomes pregnant. General recommendations are that a woman who wants to become pregnant should adopt healthy dietary habits in order to minimise health risks both for herself and her future child. Although the impact of obesity on birth outcomes has yet to be studied extensively, obesity should be avoided. Women are advised to seek nutritional counselling when in the preconception phase and during pregnancy.

During pregnancy, it is important to consume a diet made up of high quality food with high nutrient density. A generous intake of fruits and vegetables is important along with consumption of products rich in iron and calcium, protein and folic acid.⁵ Folic acid is considered a key component of preconception and pregnancy nutrition because of its role in preventing neural tube defects such as spina bifida.⁶ For more specifics on nutrition needs to help prepare for pregnancy, please see the section which details “Preconception care” (page 74).

NUTRITION DURING THE EARLY YEARS OF LIFE

For the first years of life, the WHO recommends that mothers breastfeed their children and introduce safe and adequate complementary foods from the age of about six months. As children grow, their nutritional needs evolve and their food intake diversifies. An adequate and balanced diet that meets nutritional needs at each stage is key to ensuring that children grow and develop properly.

Although easier said than done, teaching children to eat healthy, regular and balanced meals will help them to enjoy better health when they become adults, and decrease the risk of developing obesity and chronic diseases. Parents should therefore be encouraged to provide meals that promote the principles of a healthy diet whilst taking into account their nutritional needs for growth.⁷

NUTRITION IN OLDER PEOPLE

Ageing is accompanied by changes in nutritional needs. Energy needs tend to decline as people get older but the needs of nutrients remain the

same or even increase. In particular, attention needs to be paid to micro-nutrients such as calcium, vitamin D and vitamin B₁₂ as well as dietary fibre, types of fat and fluid intake. This means that older people need to eat good quality foods with a high nutrient density to ensure that their needs are met, and to help to reduce the risk of developing or accelerating age-related conditions such as osteoporosis (brittle bones) and sarcopenia (muscle wasting).⁸

NUTRITION AND DISEASE

1. THE ROLE OF NUTRITION IN PATIENT CARE

In the first part of this section, the influence of nutrition on maintaining health was addressed. In the next part, the effect of disease on nutritional needs is considered.

Making good choices about one's diet is not just an important way to help prevent the onset of chronic conditions and maintain health. For people that suffer from certain types of diseases, it can mean the difference between feeling well or feeling very ill, or even sometimes between life and death. For example, people with type 2 diabetes or those with lactose intolerance are in many cases able to stay well by avoiding certain types of foods. Proper nutritional counselling will enable them to maintain a healthy balanced diet. Appropriate food will ensure that their nutritional needs can be met despite their condition, allowing them to maintain a normal nutritional status.

INABILITY TO EAT A BALANCED DIET

However, in some types and phases of disease it is not possible to maintain a proper nutritional status and/or avoid disease symptoms with standard foods alone. In such cases specialised nutritional products are needed to supplement the diet, or to replace food. Specialised dietary products may be needed temporarily because of an acute health threat. With such products the nutritional gap is closed until a person is able to return to their usual diet. In other cases, specialised products may be needed for the long term, sometimes even permanently, and will become an integral part of disease management throughout life.

CASE STUDY:

EXTREMELY LOW BIRTH WEIGHT PRETERM INFANT

Sophie was born by caesarean section at a gestational age of 29 weeks and 4 days. Sophie's mother experienced hypertension (high blood pressure) during pregnancy which led to intrauterine growth restriction; with a birth weight of 880g, Sophie was smaller than expected for the number of weeks of pregnancy. Sophie experienced some breathing problems after birth and initially needed mechanical ventilation to support her breathing.

Because of her prematurity Sophie required early and appropriate specialised nutritional support as she was at high risk for malnutrition. She had not only very limited reserves and an immature gastrointestinal tract, also her suck and swallow coordination was not developed yet. In order to support normal growth and in order to prevent the long-term effects of malnutrition during the early stage of her life Sophie needed to be fed intravenously. On the first two days parenteral feeding was provided through an umbilical catheter before a peripherally inserted central venous catheter could be placed at day 3.

As Sophie did not tolerate enteral feeding during the first 3 days parenteral nutrition represented the only route for nutrient supply during this period.

On day 4 minimal enteral feeding with human milk was introduced and during the following period slowly increased according to tolerance until full enteral feeding was possible.

CASE STUDY:

PHENYLKETONURIA

Jane is 17 years old and was diagnosed with phenylketonuria (PKU) within a week after being born.

Jane has to follow a low protein diet for optimal brain development. The diet restricts foods with high levels of protein which contains phenylalanine such as

meat (red or white), fish, dairy produce, nuts, pulses and any soft drinks containing aspartame. Her diet is very low in natural proteins, and mainly consists of vegetables, fruits, and special low-protein products such as bread and pasta. Jane will more than likely have to follow this diet for the rest of her life to keep her phenylalanine levels low and on track.

To ensure that she gets sufficient protein to grow, develop and function, Jane needs a special low phenylalanine protein supplement that also contains additional vitamins, minerals and amino acids, because her diet alone is inadequate to fulfil her nutritional needs. The protein supplements need to be taken daily (preferably split over mealtimes) in order to mimic normal protein intake.

Throughout her childhood, Jane had to be regularly in contact with her specialist in order to ensure her nutritional needs were met and she was growing normally. Counselling is critical for Jane's condition, as growing up having to adhere to this very restricted diet has proved challenging for her and her family.

Many diseases, disorders and conditions make it very difficult or impossible to maintain a food intake which is sufficient to meet nutritional needs. These challenges arise for a variety of reasons;⁹ some examples are given below.

1. Some conditions give rise to dysphagia (impaired swallowing), e.g. head and neck cancer surgery, chemotherapy and radiotherapy, stroke, and other neurological conditions such as motor neurone disease and amyotrophic lateral sclerosis (ALS). In these circumstances it may only be possible to eat foods whose texture, thickness and fluid content has been changed in order to facilitate swallowing. In other cases swallowing may be completely impossible in which case feeding via a tube into the gastrointestinal tract may be necessary.
2. Loss of appetite, mucositis, nausea, vomiting and/or diarrhoea are frequent problems in some cancers, inflammatory bowel diseases such as Crohn's disease and ulcerative colitis, or severe infection and inflammation such as in complications after severe injury or extensive surgery. Oral nutritional supplements, feeding via a tube or feeding intravenously (parenteral nutrition) may be necessary to ensure that nutritional needs can be met.

Additional information on this condition can be found in the section of the booklet provided by the European Federation of Crohn's and Ulcerative Colitis Associations (see page 67).

3. Respiratory (lung) disorders such as chronic obstructive pulmonary disease (COPD) can impair breathing and are often associated with early satiety (feeling full quickly) which can make eating enough a challenge.
4. In some situations, an acute problem such as a severe injury can mean that patients are kept sedated and ventilated for days or weeks - tube feeding or parenteral nutrition would be needed in these circumstances.

CASE STUDY: GI DISEASE

Mark is a 26 year old computer programmer who has been suffering from Crohn's disease since he was a teenager. He has had frequent hospital admissions with severe episodes of diarrhoea and pain due to inflammation in the bowel. He was admitted to hospital again and following assessment by his medical team and the surgeons he underwent surgery to remove part of his bowel that had become narrowed due to ulceration and scarring.

Mark has always struggled to keep his weight stable during 'flare-ups' of his Crohn's disease. On admission he weighed 58kg; he is 1.79 m tall which meant his Body Mass Index (BMI) was 18kg/m² (underweight). He is now four days post-op and is eating and drinking very small amounts again. Although he was screened for malnutrition on admission, his nurse did not refer him to a dietitian thinking that because he was fasting for tests on some days there was little they could do. Since admission he has lost a further 4 kg (7% of his body weight) due to fasting for tests and surgery, his BMI is now 17 kg/m² and he is classed as at high risk of malnutrition. He has now been seen by the dietitian who has recommended he take oral nutritional supplements (ONS) to increase his energy and nutrient intake in an effort to stabilise his weight.

5. Some diseases may result in gastrointestinal obstructions, e.g. oesophageal or gastrointestinal cancer, and make the patient dependent on intravenous feeding (parenteral nutrition).
6. Other problems can occur that make meeting nutritional needs from normal foods alone impractical or impossible due to problems of digestion, absorption and/or metabolism. For example, digestion and absorption are impaired in cystic fibrosis which may mean that additional nutrition via oral nutritional supplements or tube feeding may be needed, sometimes in combination with enzyme replacement therapy. In people who have undergone extensive bowel surgery resulting in excision (removal) of large parts of their small intestine resulting in short bowel syndrome, there may be insufficient length of intestine for sufficient digestion and absorption, and nutritional support via tube feeding or intravenous nutrition may be needed. In diseases such as phenylketonuria (PKU) and other inherited metabolic disorders, the body does not provide specific enzymes in sufficient quantity and thus foods cannot be metabolised fully, leading to a build-up of substances or metabolites which can have harmful consequences. In this case, special supplements are used to ensure that nutritional needs can be met in a safe way. Other diseases such as cow's milk allergy and coeliac disease mean that to avoid severe and detrimental symptoms, certain foods must be avoided. Specialised products may be needed to ensure that nutritional needs can be met. For more information on coeliac disease, the Association of European Coeliac Societies has contributed a section to this book and will go into further detail as to the specifics of the condition (see page 44).
7. General physical disability can hamper normal nutritional intake. Imagine a person who has difficulties in moving and/or handling food or cutlery e.g. due to arthritis or a fracture, or has poor dentition (teeth) – it is obvious that food intake will not be easy and help with preparing food and eating may be needed.

CASE STUDY: CANCER PATIENT

John is 57 years old and was enjoying an active work and social life until three months ago, when he started to notice weight loss, difficulty swallowing and pain in his throat. He consulted his general practitioner (GP) and was referred to a specialist at the hospital and was subsequently diagnosed with cancer of the oesophagus (the gullet).

John has had surgery to remove the tumour and has just started radiotherapy as an outpatient every day for several weeks to ensure that the cancer does not come back.

Before his operation John had lost about 6kg in weight. His normal weight 90kg and being 1.83m tall, John had always been a bit overweight with a BMI of 27kg/m². Since his operation he has lost more weight; he wasn't allowed to eat before some of the tests and although he was fed via a tube for a short time after the operation his appetite has not really returned to normal. At his hospital appointment this morning the nurse checked his weight which is now 78kg.

Although this is still in the normal healthy range, he has lost 13% of his body weight since his illness began. He is managing to eat very little and his throat is likely to become sore with the radiotherapy making eating more difficult in the coming weeks. Further weight loss is likely and concerns the nurse.

John's wife is an excellent cook and prepares all of John's favourite foods, but he just can't manage them. She is upset and doesn't know how to help and John feels guilty. He feels under constant pressure to eat more.

The nurse gives John and his wife some advice about eating small amounts regularly, choosing energy and protein-rich foods to maximise his intake without increasing the volume of food he needs to eat and recommends to take oral nutritional supplements (ONS). He can drink these or his wife can use them to make easy to swallow, high energy foods such as smoothies, puddings or soups.

They agree that the aim is to try and keep John's weight stable during radiotherapy.

MALNUTRITION AND RISK OF MALNUTRITION

People like Sophie, Jane, Mark, John and others are potentially at risk of or may already be malnourished or more specifically undernourished.

“Malnutrition” in its broadest sense means poor nutrition and encompasses both undernutrition and overnutrition. Scientists have been struggling for years to agree on a universally accepted definition of malnutrition. One definition that is commonly used is ‘a state of nutrition in which a deficiency, excess (or imbalance) of energy, protein, and other nutrients causes measurable adverse effects on tissue/body form (body shape, size and composition) and function, and clinical outcome.’⁹

In the case of disease and its impact on nutritional intake and status, the term malnutrition generally means undernutrition. But undernutrition should not be confused with underweight, as even overweight people can suffer from insufficient nutritional intake, weight loss and poor nutritional status. Indeed, high BMI can be misinterpreted as an indication that a patient is getting all important nutrients, when in many cases they might not be due to some of the conditions which have already been described.

Because of the difficulties in defining (and therefore measuring) malnutrition, and also in recognising the fact that due to disease, people may be in a declining nutritional state but may not (yet) be designated as undernourished according to BMI, the concept of “risk of malnutrition” is often used. Screening tools which have been developed to identify malnutrition and risk of malnutrition often categorise people into low risk, moderate risk or high risk groups. Detailed nutritional assessment might then be needed to further clarify the nature of the risk and to define an appropriate course of action.

THE CONSEQUENCES OF MALNUTRITION

When nutritional requirements are not met, the impact on individuals and on society can be high.

On an individual level, inadequate nutritional intake can have numerous consequences. In early life, this can result in failure to thrive; growth and development may be delayed or impaired. In adults consequences include

muscle weakness, weight loss, depression or reduced quality of life, increased risk of infections and other complications. Recovery can be delayed, e.g. after surgery. Not surprisingly, these consequences have implications for healthcare systems, resulting in more frequent visits to the doctor, increased use of medications, increased admission to hospital, and longer stays when in hospital. Care needs also increase, especially for older people who may no longer be able to look after themselves. In a number of countries in Europe, the financial costs associated with managing the consequences of under-nutrition have been calculated and these amount to billions of euros.¹⁰⁻¹³

MEDICAL NUTRITION

Medical nutrition is a term used to describe products for nutritional intervention. These include products which are designed for oral use, products which are designed to be administered via a tube into the gastrointestinal tract, and products that are designed to be given intravenously. These products will vary in terms of format and composition depending on their purpose and must be used under medical supervision for the dietary management of a particular disease or condition. Although specific vitamin and mineral supplements such as calcium and vitamin D are also often prescribed by doctors to address specific nutritional deficiencies, these are not generally included within the description of medical nutrition.

In many cases, medical nutrition will be used to supplement intake of normal foods. In other cases, medical nutrition may be a patient's sole source of nutrition and thus nutritionally complete products may be used.

2. THE DIFFERENT FORMS OF MEDICAL NUTRITION

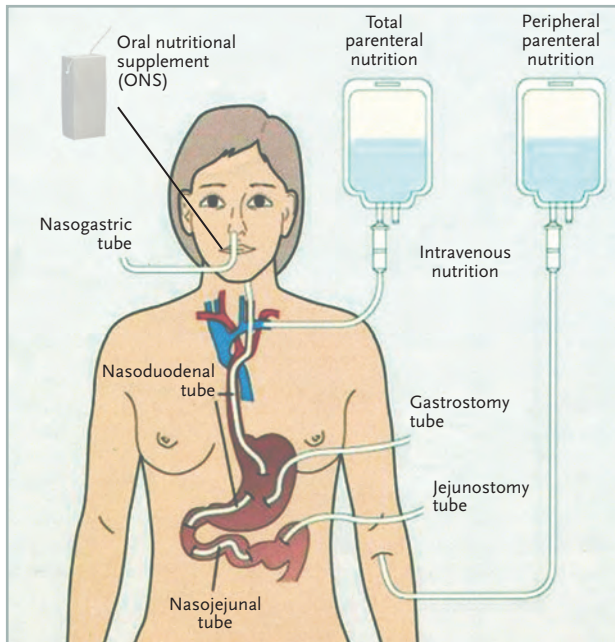


Figure 2 – Different forms of medical nutrition

Medical nutrition can broadly be divided into two main types:

- Enteral nutrition – to be administered via the gastrointestinal tract
- Parenteral nutrition – to be administered into the veins

The conditions in which they are used differ depending on what is preventing the patient from eating normal food, which differs according to the patient's specific condition and nutritional needs (as described in the section on nutrition and disease and as elaborated in Figure 2).

ENTERAL NUTRITION

The word “enteral” comes from the Greek “enteros” meaning intestine. Enteral nutrition refers to nutrition that is absorbed through the gastrointestinal tract. This encompasses medical nutrition products that are given orally (by mouth) or via a tube into the gastrointestinal tract.¹⁴

ENTERAL NUTRITION – ORAL ADMINISTRATION

Some medical nutrition products are specifically designed for oral use. Broadly these can be divided into two categories. The first category include those with a standard nutrient composition which contain macro- and micronutrients and are designed to be used to manage nutritional risk across a variety of disease areas and conditions. Medical nutrition products for oral use with a standard nutrient composition are often known as “oral nutritional supplements” or ONS. These are not to be confused with food or dietary supplements in pill formats that provide vitamins, minerals, etc.

The second category include those which have a specialised composition which are designed to be used in a particular disease, disorder or condition (e.g. renal disease, phenylketonuria, cow’s milk allergy). Depending on the balance of nutrients contained in these products, they may or may not be suitable as a sole source of nutrition. For more information on certain renal diseases please see information provided by the European Kidney Patients’ Federation (see page 70).

In most cases medical nutrition products for oral use are used as a supplement to normal foods. They are most often liquid, ready to use products, e.g. in a small bottle with a straw. Some products are available in powder form, whereby they may be added as a fortifier to other foods, or may be made up into a drink with water or milk. Some oral products are thickened for use by people who have swallowing difficulties, e.g. following a stroke. In all cases, these products should be used under medical supervision after an evaluation of individual circumstances, to ensure that the right type of product is used at the right time to meet predefined nutritional goals.

ENTERAL NUTRITION – TUBE ADMINISTRATION

In some cases, medical nutrition via the oral route is not possible, e.g. in some severe cases of cystic fibrosis or cerebral palsy, or after major surgery. As noted previously, swallowing can also be impaired due to acute stroke or to head and neck surgery. Provided that the gastrointestinal tract is at least partially functional, feeding via a tube may be advisable. This can be supplementary to oral intake (e.g. an overnight feed to top up what is consumed orally over the course of the day), or can be the sole source of nutrition.

CASE STUDY: OLDER PERSON IN POST-OPERATIVE HOSPITAL CARE

Rose is a 77 year old lady admitted to the acute orthopaedic trauma ward from home following a fall. She had a fractured hip and it is now a week since her emergency operation to repair her hip.

Rose was living at home with her husband who is her main carer; she relied on him heavily as she has dementia and is unable to care for herself. They have help twice a day to get Rose up in the morning and back to bed in the evening. Rose's husband does all the shopping and cooking and generally Rose eats well at home with a lot of encouragement.

Since being in hospital, Rose has become even more confused and is not eating or drinking. The physiotherapist has been unable to get her out of bed to start rehabilitation and Rose's hip wound is not healing well.

On admission, routine nutritional risk screening with a tool called 'MUST' showed that Rose was at 'medium risk' of malnutrition since, although her body weight was stable at 50kg, at 1.64m tall Rose had a BMI of 18.5 kg/m² (underweight). Now on repeat screening her risk has increased to 'high' due to weight loss of 5 kg (which equals a loss of 10% of her body weight) since admission.

The ward nurse takes action to ensure that Rose gets the nutritional care she needs. Using the hospital nutritional screening and care planning policy she orders a special high energy, high protein menu for Rose, starts a chart to record her food and drink intake, offers her oral nutritional supplements (ONS) between meals, and ensures that one of the nurse assistants feeds Rose at lunchtime and regularly prompts her to drink her ONS.

When Rose's husband visits, the ward nurse explains the nutritional care plan to him and asks him what Rose likes to eat at home, asks him to encourage Rose to take the ONS and shows him where to record what she drinks and eats.

This form of medical nutrition may be required temporarily for a few days or weeks, for a more prolonged length of time, or sometimes even permanently.

There are different ways of accessing the gastrointestinal tract as shown in Figure 2. A nasogastric tube is the most common approach for shorter term use. In case longer periods of tube feeding are needed, then other routes of administration might be preferred such as via a gastrostomy (a tube placed directly through the abdominal wall into the stomach) or a gastrojejunostomy (a tube placed directly through the abdominal wall into the stomach, and by means of an extension tube allows feeding into the jejunum).

Enteral products for tube feeding are usually nutritionally complete and serve as the sole source of nourishment. Some products have a standard nutrient composition and would contain all of the macronutrients and micronutrients that are contained in a normal healthy diet in a balance that is consistent with scientific recommendations and guidelines. Such products are often available in different energy and nutrient densities, allowing healthcare professionals to choose the most appropriate way of meeting individual nutritional needs.

Some products for tube feeding have a modified nutrient composition to enable them to better meet specific nutritional requirements in particular diseases, disorders or conditions. For example, people who have gastrointestinal problems which don't allow full digestion and absorption of whole proteins may require pre-digested, already split (hydrolysed) protein.

PARENTERAL NUTRITION

The term parenteral comes from the Greek para meaning “besides” and enteros meaning “intestine”, i.e. besides the intestine. Parenteral nutrition thus refers to a means of bringing nutrition into the body other than through the gastrointestinal tract, in other words, intravenously.

When enteral nutrition is contraindicated, not feasible or insufficient, patients need to receive their nutrients and energy either completely or partially by the intravenous route. Examples of indications for parenteral nutrition include gastrointestinal failure occurring mostly after surgery or in extremely ill hospitalised patients, short bowel syndrome, intestinal obstruction, a fistula in the gastrointestinal tract (an abnormal connection leading to leakage of stomach or intestines). Other examples are cancer patients with severe mucositis (inflammation of the mucous membranes that line the digestive tract) or infants and children who are unable to tolerate adequate enteral feeding to sustain their nutritional requirements e.g. premature infants.

Depending on the clinical situation, parenteral nutrition may be required for short term nutritional support, for the longer term or even for life. The term total parenteral nutrition refers to the provision of nutrients and energy solely by the parenteral route, while supplemental parenteral nutrition complements either oral or enteral nutrient supply.

Parenteral nutrition is delivered via a catheter inserted into a peripheral or central vein (venous access). The expected duration and kind of therapy drives the choice of venous access. With peripheral venous access the parenteral nutrition solution is usually administered via a catheter inserted into a superficial peripheral vein in the upper extremities, e.g. the hand or arm. Such peripheral parenteral nutrition is only suitable for short term or partial parenteral nutrition. In contrast for central venous access a central venous catheter is placed into a large vein close to the heart. Central venous access is required to administer concentrated parenteral nutrition solutions designed to cover all nutritional needs of the patient.

Parenteral nutrition solutions are usually provided as an “all-in-one system” with all required macro- and micronutrients mixed in one bag and infused simultaneously through only one intravenous line. These bags can be compounded and mixed from the single components e.g. in the hospital pharmacy or by an external service company, a compounding laboratory. In addition industrially manufactured multi-chamber bags with two or three compartments are also available in different formulations and formats in order to meet the specific needs of diverse patient groups. These bags are heat

sterilised and can be stored at room temperature. Just before use the contents in the different compartments are mixed, the mixture is supplemented with vitamins and trace elements, and other nutrients might be added to adapt them to the individual patient's needs.

3. USE OF MEDICAL NUTRITION

Medical nutrition encompasses a variety of products with unique compositions of specific nutrients which are designed to respond to the diverse nutritional needs of patients. To be effective, medical nutrition should be recommended by a healthcare professional in the context of an individual's needs and related to other circumstances, such as the nature of the problem which has led to malnutrition. Furthermore, careful monitoring is needed during the course of intervention, to ensure that it is administered safely and that goals are met. In some cases, it may be appropriate to change the type of medical nutrition or to stop it – this also needs to be carefully considered by a healthcare professional, taking into account the evolving circumstances.

Medical nutrition is often used in hospitals; however its use is by no means confined to this setting. Many people benefit from medical nutrition which allows them to enjoy full and active lives. It may also be used in care settings such as nursing homes and other long stay institutions.

BENEFITS TO PATIENTS

Medical nutrition can improve nutritional intake and status, which in turn leads to improvements in functional and clinical outcomes. Perhaps most importantly, it may improve the patient quality of life.⁹

Figure 3 shows examples of how medical nutrition may impact specific patients' and disease outcomes.¹⁵⁻¹⁷

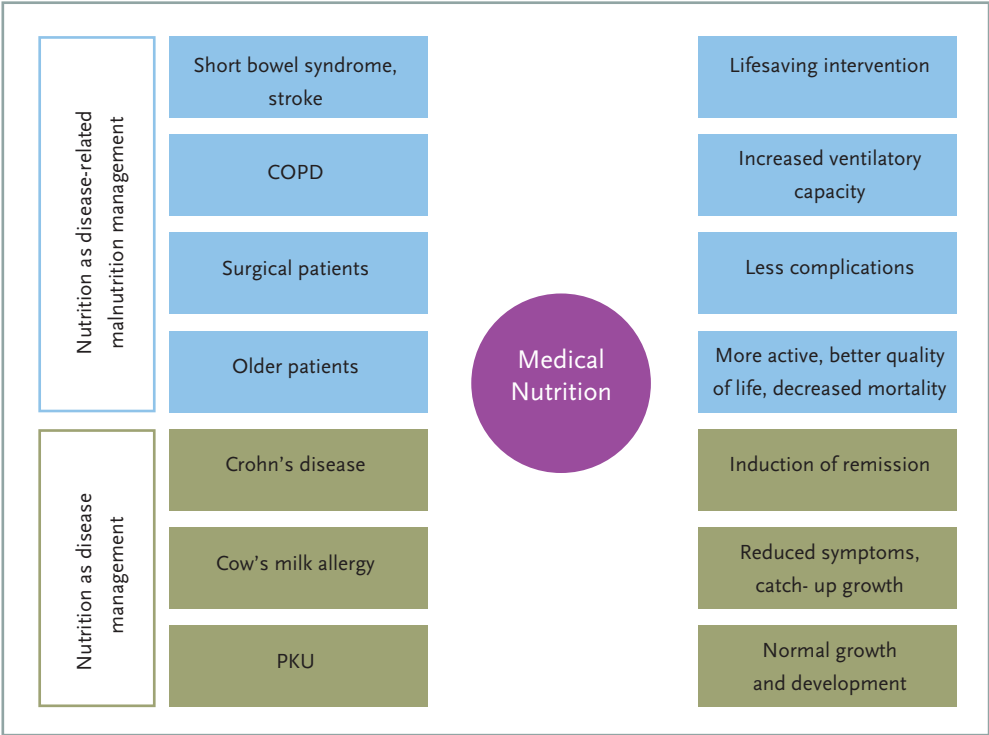


Figure 3 – Impact of medical nutrition

BENEFITS TO HEALTHCARE SYSTEMS FROM MALNUTRITION MANAGEMENT

There is an increasing need to demonstrate economic benefits of healthcare interventions. Recently several studies in Europe have demonstrated the economic benefit of oral nutritional supplements (ONS).²⁰⁻²⁴

PROFESSIONAL GUIDELINES

Professional guidelines on the use of medical nutrition in managing risk of malnutrition and improving patient outcomes have been developed by the European Society for Clinical Nutrition and Metabolism (ESPEN)²⁵⁻²⁷ and should be used by healthcare professionals as guidance for taking decisions about a patient's nutritional care.

Some countries have developed national guidelines to address the specific situation in their countries. For example, in 2006, the National Institute for Clinical Excellence (NICE) in England published guidelines on the use of oral, enteral and parenteral nutritional support in hospitals and the community.²⁸ (see Figure 4)

Nutritional intervention to manage risk of malnutrition is likely to be most effective and efficient when a screening programme exists which should include follow up and monitoring. In other words, risk populations such as those being admitted to hospitals, nursing homes or with chronic conditions should have a quick check of their nutritional risk status, so that if needed, further assessment can be carried out and medical nutrition prescribed if necessary.

This will help to identify early on whether people are at risk of malnutrition and take appropriate action. Comprehensive nutritional risk screening should also avoid inappropriate use of medical nutrition in those who do not require it. Regular re-screens through the course of a patient's journey can help to keep track of progress and make adjustments as necessary.

International guidelines are available in the case of some diseases where medical nutrition may play a crucial part in the avoidance of disease symptoms, such as cow's milk allergy.²⁹⁻³⁰ For many rare diseases, international guidelines are not yet available, although national guidelines may be available, such as PKU.³¹

AT ALL STAGES OF CARE:

- Consider cultural, ethical and legal issues of providing nutrition support
- Provide patients with information about their treatment
- Ensure that there is a care pathway with clear treatment goals

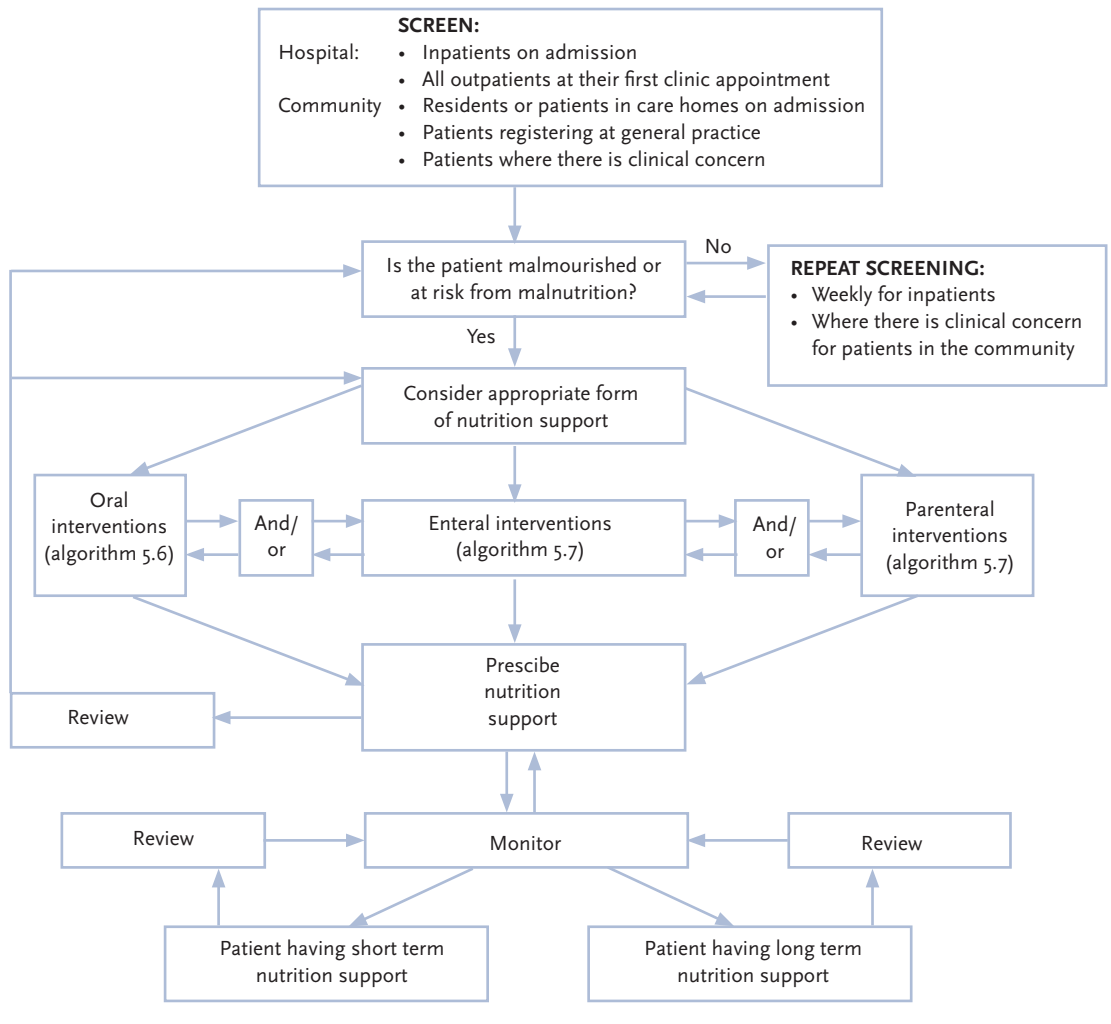


Figure 4 – Patient Pathway Algorithm²⁸

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MEDICAL NUTRITION: AT THE INTERFACE BETWEEN FOOD AND PHARMACEUTICALS

4. DISTINGUISHING MEDICAL NUTRITION FROM PHARMACEUTICAL MEDICATIONS AND FOOD

Although composed of nutrients, medical nutrition differs from food because its primary goal is to meet the nutritional needs of patients and it is intended to be used under medical supervision. Indeed, medical nutrition must be prescribed by a healthcare professional. Medical nutrition is intended to improve nutritional intake and status and impact patient outcomes, and it is clinically tested to validate these benefits.

This nutrient-based formulation and mixture of nutritional components is also what makes these products distinct from traditional pharmaceutical medications. Moreover, medical nutrition can have a broad spectrum of effects on patients. Side effects should be minimal when medical nutrition is used appropriately, particularly in the case of enteral nutrition. However, it is worth noting that while the ultimate goal of medical nutrition is to improve patient outcomes, it cannot be claimed to cure, prevent or treat a disease.

5. REGULATORY FRAMEWORKS APPLICABLE TO MEDICAL NUTRITION

In Europe, the two main types of medical nutrition – enteral and parenteral – are regulated by two different sets of legislation. Enteral nutrition takes a special position within the more general food framework (Foods for Special Medical Purposes or FSMP), while parenteral nutrition is part of the pharmaceutical regulatory landscape.

In Europe, in addition to complying with the FSMP legislation, enteral nutrition must also comply with different types of general food legislation.

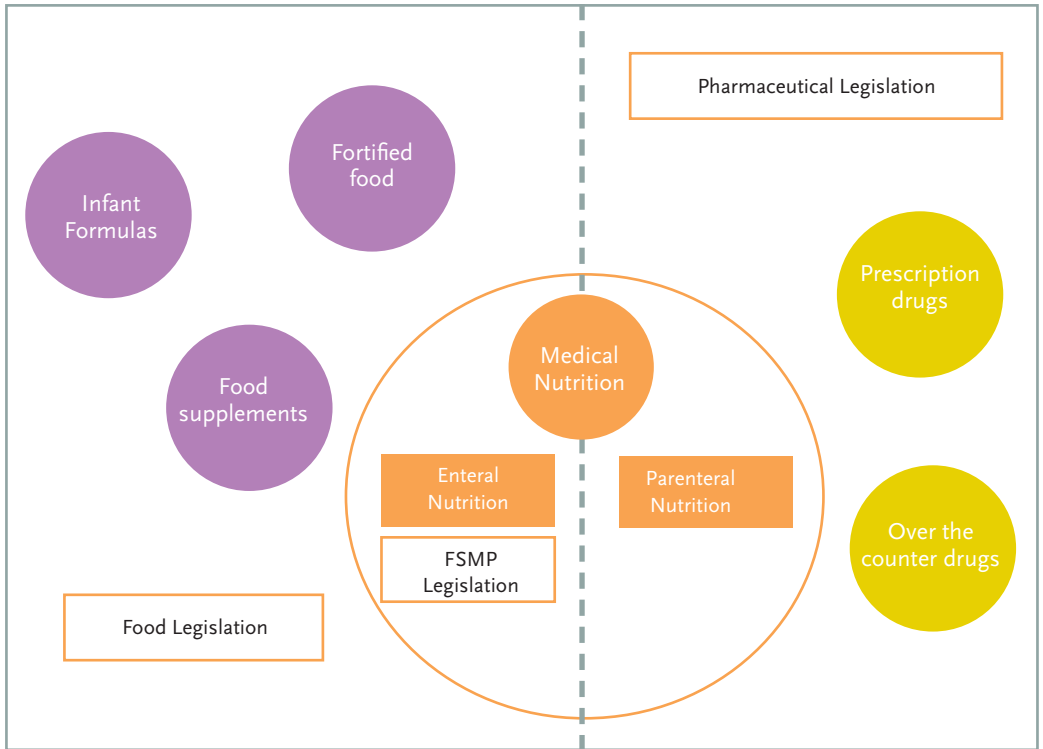


Figure 5 – Regulatory framework applicable to medical nutrition

Currently enteral nutrition is governed by a general dietetic food directive (the PARNUTS Framework Directive), as well as a specific FSMP Directive (Directive 199/21/EC) and a Regulation on the substances that may be used in the manufacture of FSMPs (Regulation 953/2009). Due to market evolution and growth in the development of these products, the European Commission recently decided to review the dietetic food category, which is currently under finalisation.

Enteral nutrition will also, as of December 2014, have to comply with the requirements of the general food law when the Regulation on food information to consumers which sets labelling practices for food products (Regulation 1169/2011) – so-called FIC – will start to apply across the EU.

The uniqueness in terms of research and development, composition and uses of enteral nutrition products explain the differentiated rules applying to this category. Indeed, FIC stipulates that food labels should include a nutrition declaration where appropriate. In the FSMPs case, this nutrition declaration has a number of additional mandatory requirements that have to be on the label compared to normal food. It ensures doctors and other healthcare professionals understand the products and administer them to patients in the proper way.

In contrast, parenteral nutrition is regulated as a pharmaceutical product. Hence, the pharmaceutical drug law defines the rules for testing, documentation and registration by the authorities and the way that products are made available, which is via prescription only.

LOOKING FORWARD

There needs to be greater awareness about the importance of ensuring that all people are able to achieve good nutritional status, even when challenged by certain medical conditions. This is important for the quality of life of individual patients, but also more generally for ageing European societies where balancing budgets become increasingly difficult.

The burden of malnutrition on our societies can be expected to widen year-on-year due to an ageing population and all possible solutions need to be considered. This means re-evaluating the role of nutrition in ensuring a healthy and productive state throughout one's life and ensuring that expert patient groups have a seat at the table when it comes to decision making and information contributions.

For some this will be achieved through careful consideration of what nutrients and foods need to be included in their diet, depending on where they're living, what genetic conditions they might be predisposed to and what age they are. For others that find themselves in compromised health situations, a therapeutic option such as medical nutrition might be needed in order to ensure that they are able to respond well to other medical treatment, feel more comfortable and continue enjoying a decent quality of life. The deployment of medical nutrition in disease management can help to ameliorate nutritional risk, reduce disease symptoms, improve quality of life, and help to assure optimal patient outcomes.

High quality nutrition in general and medical nutrition in particular have been shown to be beneficial to patients and healthcare systems. Sound nutritional principles followed from the earliest beginnings of life through the lifespan are able to help avoid certain nutrition-related chronic conditions which today are posing a huge burden on health systems. It is therefore of vital importance that the general public becomes more aware of the role of nutrition in both health and disease management.

It is only by adopting a holistic approach where everyone, i.e. governments, policy makers, healthcare professionals, patients and carers, understands his

or her role and the importance of good nutritional status that the situation will improve. Breaking silos and creating joined-up approaches across healthcare settings and communities will contribute to reducing the existing knowledge gap around malnutrition and medical nutrition. Furthermore, policy makers setting national health strategies need to ensure that nutrition and specifically tackling malnutrition becomes a key target of health management.

This booklet, developed by and with patient groups has demonstrated that patients and our organisations have a significant part to play in achieving better nutrition. We can foster more collaboration with other stakeholder groups to ensure the appropriate use of medical nutrition is considered more systematically in disease management. This will pave the way towards improvement in nutritional care. Screening for nutritional risk is the first step towards a better inclusion of nutrition in disease management, thus leading to improved patient outcomes. Patients can be instrumental in enhancing understanding about the importance of nutrition in our lives. Working together, increasing awareness and encouraging early detection of malnutrition can drive practice change and achieve better outcomes for patients. Figure 6 helps illustrate how these steps are mutually reinforcing and need to be considered as essential to improving nutritional health.

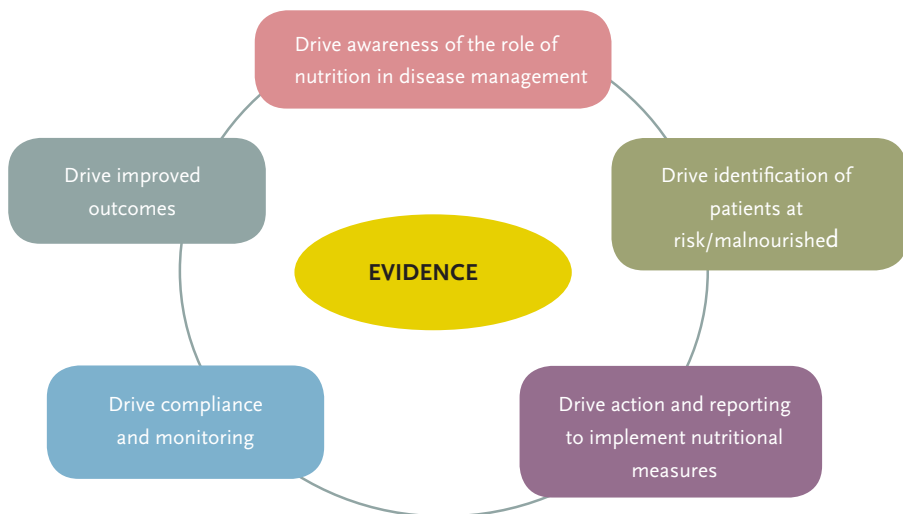


Figure 6 – Steps needed to improve nutritional health

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For many people attaining good nutrition is not a simple question of having good eating habits. Some medical conditions mean that even when a person makes good nutritional and lifestyle choices, achieving good nutritional health remains challenging. In part 2 of this booklet, a number of European Patient Groups explain what impact their diseases have on their nutritional needs.

EUROPEAN PATIENT GROUPS **2**

BRAIN DISORDERS



THE EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS (EFNA) is an umbrella group representing pan-European neurology patient groups.

The disease areas we represent are all ‘brain disorders’. The nutritional needs for each group vary considerably in some cases, but there are also some things in common.

Therefore, rather than focus on the nutritional needs for ‘neurology patients’ in a general sense, we have taken three key nutritional issues – namely ‘alternative feeding’, ‘malnutrition’ and ‘nutritional trigger factors’ for neurological disorders. We have also chosen to focus on each issue in the context of an individual disease area: motor neurone disease, Huntington’s disease and migraine/facial pain.

For information leaflets/booklets on the nutritional aspect of the conditions covered above, please visit the websites of each organisation listed and get in touch! EFNA can also put you in touch with other organisations at an international, European or national level supporting patients affected by other neurological disorders.

For more information: www.efna.net



ALTERNATIVE FEEDING

MOTOR NEURONE DISEASE

Alternative feeding means introducing food and drink to the body in some other way than through the mouth. This usually involves passing liquid nutrition, which has been specially formulated, through a tube into the stomach. There are two frequently used methods:

- Nasogastric feeding, where a narrow tube is passed through the nostrils, down the back of the throat and into the stomach
- Feeding by gastrostomy, where a tube is inserted directly into the stomach through the abdomen.

Nasogastric feeding is designed for short term use, usually less than four weeks, as the tube is visible, may cause nasal discomfort and may need replacing more regularly. For these reasons, gastrostomy is the preferred option for people living with MND who require an alternative feeding method. It is also common in other diseases where swallowing becomes difficult and choking a threat.

WHAT IS MOTOR NEURONE DISEASE?

The motor neurone diseases (MND) are a group of neurological disorders that selectively affect motor neurones, the cells that control voluntary muscle activity including speaking, walking, swallowing, and general movement of the body. They are generally progressive in nature, and cause increasingly debilitating disability and, eventually, death.

GASTROSTOMY IN MOTOR NEURONE DISEASE

There are three types of gastrostomy:

- PEG (percutaneous endoscopic gastrostomy)
- RIG (radiologically inserted gastrostomy)
- PIG (per-oral image guided gastrostomy), which is less common.

The difference is how the tubes are inserted and held in place, but the end result is the same, in that food and fluids enter into the stomach.

What are the benefits?

“By removing so much stress my friendly PEG has greatly improved quality of life for me and my loved ones. Far from being an admission of defeat it is helping me to fight against MND”

Alternative feeding allows you to obtain the nutrition you require and:

- Reduces the risk of chest infections
- Increases fluid intake, preventing dehydration and constipation
- Provides a route for medication
- Decreases the pressure of eating, where chewing and swallowing is difficult
- Increases energy intake
- Helps you to maintain weight
- Improves your feeling of well-being and energy
- Relieves anxiety for all concerned (those supporting you may feel relieved in the knowledge that you are receiving the nutrition and hydration you need).

It is important to note that a gastrostomy will not halt the progression of the disease but it can, like other nutritional interventions in disease management, improve quality of life. It is always your decision as to whether you wish to proceed and you should be given all the information required to make an informed decision. For example:

BRAIN DISORDERS

- Hospitals usually have guidelines and protocols about gastrostomies and you can ask to see these
- This is also a good opportunity to talk about nutrition in the later stages of the disease (without a gastrostomy you are highly likely to experience weight loss if eating and drinking become difficult)
- You may have concerns about how a gastrostomy may prolong life beyond a point where you feel quality of life can exist (it may be beneficial to discuss this with a palliative care specialist).

It is also important to remember that tube feeding does not eliminate oral feeding. Many people with MND continue to take or taste food and fluids by mouth after a gastrostomy has been fitted. You may not even need to use the tube for a while after it has been inserted. Using your tube to deliver nutrition can help reduce stress, if chewing and swallowing have become difficult. You may be able to eat small amounts by mouth for enjoyment, rather than eating and drinking for necessity. Some people choose to continue eating and drinking for pleasure even where there is an increased risk. This is entirely reasonable if you have made an informed decision.

Evidence suggests it is better to consider a feeding tube before considerable weight loss has occurred, and before you experience chest infection due to aspiration (inhalation) of food into the airway. As with many other aspects of MND, the emphasis is on planning ahead in order to avoid crisis management. This is also applicable to other nutritional choices and in other disease areas.

“My resistance to adopting the change to PEG feeding was, I suppose, twofold; I wanted to fight the disease and saw the change as an acceptance of defeat, also I believed that a liquid fed through a tube directly to the stomach couldn't be as beneficial as a healthy diet with plenty of fruit and vegetables, nuts and seeds and supplements. This proved to be wrong on both counts.”

BRAIN DISORDERS

There are three main ways in which a patient is fed through their gastrostomy:

- The liquid feed is fed into the tube in small doses throughout the day by syringe (referred to as the bolus method)
- The liquid feed is dripped into the tube over several hours by an electric pump, either overnight or during the day
- A bag of liquid food is hung from a stand and allowed to drip through a longer tube into the gastrostomy tube, (i.e. by using gravity – this method is rarely used now, but may provide a temporary option if you use an electric pump that needs to be replaced).

Your dietitian will choose the right type and amount of feed for you, based on your needs.

“I was surprised at the ease of the whole process. On awakening after sedation, the tube was in place with no pain and it seemed almost natural rather than invasive. Pouring liquid feed down the tube, flushing with water and cleaning very quickly became part of the daily routine.”

The information on these pages was provided by the Motor Neurone Disease Association UK. For more information: www.mndassociation.org



EUROPEAN HUNTINGTON ASSOCIATION

MALNUTRITION

HUNTINGTON'S DISEASE

When feeding and swallowing become difficult, malnutrition can be a serious issue for a person affected by a neurological (or other) disease. Malnutrition can often go undetected as early symptoms are not always obvious. Once signs begin to appear, malnutrition is usually at an advanced stage and difficult to treat. It is essential that malnutrition is detected early. The example below looks at Huntington's disease but could be applied to other disease areas where malnutrition is a threat. Note: Prevention and treatment of malnutrition is not a cure for Huntington's disease but it can lead to a longer and better quality of life.

WHAT IS HUNTINGTON'S DISEASE?

Huntington's disease (HD) is a hereditary neurological disorder that causes brain cell degeneration leading to deterioration of the physical, cognitive and emotional self. Within the same family, symptoms can vary and may include involuntary movements, speech impairment, difficulties planning and organising tasks and changes in motivation. Symptoms usually appear between the ages of 30 and 45, although they may appear earlier or later.

MALNUTRITION IN HUNTINGTON'S DISEASE

When a patient is diagnosed with Huntington's disease, their health practitioner should agree to measure their body weight once a month.

BRAIN DISORDERS

The risk of malnutrition is present when the patient:

- Loses over 5% body weight in 4 weeks
- Loses over 10% body weight in 6 months

A feeding intervention should be considered when the Body Mass Index score dips below 20. The first step is often working with a dietitian to establish the food intake. A diary can be a useful tool. Family and carers may also be required to help if the patient is suffering from common HD symptoms such as amnesia, involuntary movements (preventing writing), etc. The dietitian can also advise if blood tests would be useful to determine levels of essential vitamins, minerals and other biochemical parameters.

It is recommended to raise the energy intake in patients who are losing weight by a minimum increment of 500 kilocalories (kcal) on each occasion. The dietary needs of a HD patient are generally over twice that of an average person. Eating so many calories daily can seem unattainable and the patient should not be forced to eat extra food if they feel they have reached their limit. The patient should also not be subjected to 8 or 9 large daily meals, repetitive food choices, fear of choking/suffocating, etc.

It is important to balance nutritional needs with quality of life. For example:

Daniel is 21 years old and is suffering from a juvenile form of Huntington's disease. He has lost 7 kg in three months. His dietary history shows that he consumes 2,700 kcal/day. So, on the advice of his dietitian, he increases his intake to 4,000 kcal/day. His weight now stabilises, but he is unable to gain weight. The dietitian proposes the introduction of an additional meal. Daniel points out that this will result in his eating for large parts of the day and this will limit his social contact with friends.

BRAIN DISORDERS

Therefore, it is often necessary to consume foods with a higher energy content – rather than more meals. Full fat foods that are often shunned by a health conscious population are generally more acceptable for the HD patient. High fat and high carbohydrate foods are essential. Tips include adding butter and oils to vegetables, using additional sugar in hot drinks, incorporating creams in soups and desserts, preparing high energy milkshakes, etc.

As advanced HD patients can have problems swallowing food, they can often only ingest food of liquid consistency. However, it is important to note that food which has been ground down, liquidised, etc. can have a lower nutritional value and so larger portions may need to be consumed.

In summary:

- Weigh patients regularly to detect signs of malnutrition early
- Increase calories in increments of 500 kcal and monitor progress
- Keep a diary to accurately monitor food intake
- Listen to the patient's needs and preferences
- Opt for foods with a higher fat and carbohydrate content
- Remember, the consistency of the food can affect nutritional content

This information was adapted from 'Nutrition and Huntington's Disease, A Practical Guide'.

For more information: www.huntington-assoc.com



NUTRITIONAL TRIGGERS

MIGRAINE AND TRIGEMINAL NEURALGIA

This example looks at how certain foods can trigger an illness/attack/disorder in some neurological patients. The example below looks at how the foods we eat and our food consumption patterns can exacerbate our disease. However, it also details ways in which we can manage/modify our diet to bring about an improvement in our illness.

WHAT IS MIGRAINE?

Migraine is a complex neurological condition which is ranked by the World Health Organisation as the 19th leading cause of disability worldwide. It affects between 12% – 15% of the population and yet remains an under-recognised and under-diagnosed illness.

The exact cause of migraine is unknown but symptoms can include nausea and vomiting, a severe, throbbing, one-sided headache, sensitivity to light, noise, and smells, visual disturbances such as zig-zag patterns or flickering lights (known as aura), confusion, slurring of speech, loss of articulation, lack of muscular co-ordination and weakness. Attacks can last from 4 to 72 hours untreated.

WHAT IS TRIGEMINAL NEURALGIA?

Trigeminal Neuralgia is an extremely severe facial pain that tends to come and go unpredictably in sudden shock-like attacks. The pain is normally triggered, for example by light touch, and is described as stabbing, shooting, excruciating or burning. It usually lasts for a few seconds but there can be many bursts of pain in quick succession.

FOOD AS A TRIGGER

Painful attacks can be 'triggered' by a combination of factors which are specific

BRAIN DISORDERS

to the individual. Most commonly these include stress, changes of routine, hormonal changes, an excess or lack of sleep, weather factors, environmental factors such as strong smells or certain types of lighting, and diet. About 20% of migraine attacks are triggered by dietary factors. These can include lack of food, missed or delayed meals, dehydration, and specific types of food.

Foods such as matured cheese or cured meats which are fermented or ripened by bacteria, as well as alcohol (especially red wine), citrus fruits, bananas, nuts, fizzy drinks, caffeine, chocolate, fatty food, and the food additive monosodium glutamate (MSG) are thought to be the most common dietary triggers.

In Trigeminal Neuralgia, many patients avoid certain types of food either because of a mechanical triggering of the pain through eating hard foods such as nuts and apples. Patients can lose significant amounts of weight and become malnourished which also affects their ability to cope with the pain. Patients often resort to eating soft foods only and may choose not to eat with others. All these factors can significantly isolate patients from their normal routine and their social groups.

TIPS FOR NUTRITIONAL CARE

- Keep a diary to establish patterns to your attacks and to identify potential triggers. Remember to examine all potential triggers, not just dietary factors.
- Do not eliminate essential food groups from your diet without first establishing that they are triggers and/or seeking medical advice.
- Eat breakfast. This is considered the most important meal of the day because maintaining blood sugar levels after a period of fasting places the body under stress and can provoke an attack. A slow release cereal or oat-based breakfast is advisable.
- Maintain regular eating patterns.
- Limit caffeine consumption and ensure an adequate fluid intake, especially water.
- Certain vitamins and minerals can help.

The information on these pages was provided by The Migraine Association of Ireland (www.migraine.ie) and Trigeminal Neuralgia Association UK (www.tna.org.uk)

CANCER



EUROPEAN CANCER PATIENT COALITION

Established in 2003, the European Cancer Patient Coalition (ECPC) is the voice of the European cancer patient community, uniquely representing the interests of all cancer patient groups from the major to the rarer cancers. It was established to represent the views of cancer patients in the European healthcare debate and to provide a forum for European cancer patients to exchange information and share best practice experiences.

We derive our mandate to speak with 'one voice' for all cancer patients from our membership and our democratic structure. With its motto 'Nothing about us without us!', ECPC represents over 300 patient organisations in 44 countries, including the 27 EU Member States.

ECPC'S SIX GUIDING STRATEGIC GOALS

1. Making cancer a priority for action on the European health policy agenda.
2. Effecting change in legislative or regulatory policies to help optimise cancer prevention, detection, treatment and care throughout Europe.
3. Ensuring that all cancer patients in the EU have access to timely and appropriate prevention, screening, early intervention, on-going clinical trials and best quality treatment and care.
4. Ensuring that best cancer practice is shared across the EU and gaps within and between Member States are eradicated.
5. Empowering cancer patients to take an active role in shaping European and national policy that impacts on cancer prevention, treatment and care.
6. Fostering co-operation between the cancer patients' organisations within Europe and to develop a common policy.

For more information: www.ecpc-online-org

CANCER



Nederlandse Federatie van
Kankerpatiëntenorganisaties



NUTRITION AND CANCER

Good nutrition is especially important if you have cancer because both the illness and its treatments can change the way you eat. Cancer and cancer treatments can also affect the way your body tolerates certain foods and uses particular nutrients.

The nutrient needs of people with cancer vary from person to person. Your doctor, nurses, and a registered dietitian can help you identify your nutrition goals and plan ways to help you meet them. Eating well while you are being treated for cancer might help.

There are also great differences between the nutritional needs of people with different types of cancer. Some cancers make it more difficult to eat than others.

MALNUTRITION AND CANCER

Many cancer patients have difficulties eating. Therefore they have a certain risk for malnutrition, in particular undernutrition, as a result of a shortage of energy and nutrients. The result is weight loss and a decrease of muscle mass. This can adversely affect resistance to infection as well as physical activity. Therefore someone with cancer is more vulnerable for complications during or after treatment. It can also lead to a slower recovery process.

An important sign of malnutrition is unintentional weight loss. This means that you lose weight spontaneously. Weight loss can lead to a poorer nutritional status and a worsening condition. Fatigue, lack of appetite, aversion to food, taste alteration and decreased muscle strength are signs that can lead to malnutrition.

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Malnutrition has a negative impact on your health. It can severely threaten your quality of life. Also, malnutrition increases the risk of complications during surgery or additional side effects during or after radiation or chemotherapy. When malnutrition is more serious and longer-term, hospitalisation will be needed and the recovery process will be slower. The earlier malnutrition is diagnosed, the earlier treatment can be started with appropriate nutritional intervention.

PATIENT EXPERTS WITH HEAD AND NECK CANCER

Dietitians provide people with advice on the best nutrition, speech therapists know a lot about eating and swallowing of food. Researchers and scientists are constantly looking for the best diet for a long and healthy life and think about solutions for malnutrition and dehydration. But what's most often overlooked is: can patients eat it? Patient experts with head and neck cancer in the Netherlands looked to this issue and they published an information leaflet on this, written from their own perspective.

Immediately after major surgery, head and neck cancer patients usually require liquid food and may need medical nutrition, either enteral (a gastric tube) or parenteral (by intravenous infusion). Usually this is temporary. Sometimes salivary glands do not function properly after radiation or surgery, so the saliva as a means to make food easier to swallow and digest is not there anymore. Sometimes they are not able to open the mouth enough for proper food intake. Most of the time, the people surrounding these patients do not realise quickly enough that food intake - temporarily or even permanently - can only take place in liquid form. In the stage after radiation or surgery, every patient tries to go back to normal eating. But eating and swallowing problems can remain serious for many years. It can then take many hours to eat solid food, which creates social problems when eating with family and friends. Medical nutrition can assist as additional intake of food. This can also be needed when people with these types of cancer go back to work.

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Eating and swallowing problems in head and neck cancer can vary from person to person and also the solutions very often have to be experienced and investigated on an individual basis.

PRODUCTS WHICH ARE EASIER TO EAT AND SWALLOW

Experience shows that food should be smooth and served in small pieces or is easy to cut. The food must also be soft. The use of sauce makes the food easier to swallow. Water should be provided when eating and hot and spicy ingredients should be avoided.

Some examples of dishes, favoured by patient experts are:

- Spreads like jam, sandwich spread
- Fruits, like bananas and mangoes
- Cooked vegetables
- Lasagne, mushrooms and pasta
- Smoothies and milkshakes
- Meat in stew or ragout form

PRODUCTS WHICH IN GENERAL DO NOT MAKE PATIENTS HAPPY

As well as favoured products, there are also those which are not loved by expert patients. So, avoid all spicy food, grains or bones. Never use large pieces, hard and/or dry meats which need a lot of chewing. Some of the less favoured examples are:

- Chips
- Cornflakes
- Crackers
- Foods without sauce
- Nuts
- Crudités
- Sambal, pepper and hot spices

The information for these pages was provided by the NFK, the Dutch Federation of Cancer Patients (www.nfk.nl) and the Stichting Klankbord, the Dutch Patient Organization for people with head and neck cancer (www.stichtingklankbord.nl)

COELIAC DISEASE



ASSOCIATION OF EUROPEAN COELIAC SOCIETIES

Founded in 1988, the Association of European Coeliac Societies (AOECS) is an independent, non-profit organisation. It is the umbrella organisation of European national coeliac societies with 39 enrolled Member societies across Europe.

WHAT IS COELIAC DISEASE?

Coeliac disease affects around 1 in 100 people in Europe, about 5 million people. However, at best less than 1 in 5 of those will be diagnosed while in some countries it will be less than 1 in 10.

The condition is not a simple food intolerance or allergy but is a chronic small intestinal immune-mediated enteropathy precipitated by exposure to dietary gluten in genetically predisposed people. Gluten is found in wheat, barley and rye and some people are also sensitive to oats. When gluten is eaten, the body's immune system is triggered attacking the lining of the small intestine; other parts of the body may also be affected. Coeliac disease may strike at any age.

Symptoms include diarrhoea, anaemia, mouth ulcers and failure to thrive in children. The damage to the gut can also lead to any combination of iron, vitamin B12, calcium or folic acid deficiency.

Left untreated the disease may lead to life-threatening symptoms such as small bowel cancer and osteoporosis.

For more information: www.aoecs.org

COELIAC DISEASE

WHAT IS THE TREATMENT?

The only treatment to date is a strict lifelong gluten-free diet. This can be very difficult to maintain because gluten is found in many staple foods such as breads and pastas. What's more, gluten is widely used in processed foods such as mayonnaise, yogurts and sausages to add bulk and carry flavour making it extremely difficult to be sure foods are gluten-free.

International research illustrates how difficult maintaining a strict gluten-free diet can be; studies show that adherence to the gluten-free diet is poor, ranging from 42 to 91 percent. Keeping to a strict diet impacts on an individual's health and well-being. Research on the quality of life in patients with coeliac disease suggests there may be higher overall rates of depression compared to the general population.

National coeliac societies provide advice and support to people with the condition particularly advising them on safe products to eat. Many societies produce a directory of safe products to eat and guidance on how to read food labels.

There is particular concern for patients where there is no choice in food available and little information about its content. These include hospitals, care homes, schools and nurseries, and workplace canteens.

In some European countries, e.g. Germany and the UK there are reported examples of hospitals being unable to manage the nutritional needs of patients with coeliac disease. The same can happen in care homes for the elderly or meals that are delivered at home for elderly people who are not able to manage buying and cooking their own food.

THE IMPORTANCE OF LABELLING

The AOECs and national societies have campaigned for better labelling on both packaged foods sold in shops and over the internet, and for foods that are served in catering operations to help people select safe foods.

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In 2012 a new European law became mandatory which sets clear standards for the labelling of gluten-free packaged foods. Some countries, including the UK, have applied the standard to the catering sector. It is planned to change the law again in the next two years which will require the same standard in all EU countries in the catering sector. These changes have come about after much lobbying by the coeliac community.

Further changes in labelling law are needed to provide standards around the use of 'may contain' labelling which is being used indiscriminately by some manufacturers. AO ECS will continue to campaign in this area.

THE GLUTEN-FREE DIET AND NUTRITION

There is some debate about the nutritional value of gluten-free substitute foods with suggestions that they may be higher in fats and sugars and lower in nutrients such as iron and calcium. Research by Coeliac UK has identified that fresh breads in particular are higher in fats including saturated fats and there are some concerns around lower protein levels in some products. National societies promote the need for healthier options and nutritional quality equivalent to the products that are replaced.

Due to gut damage, some people with coeliac disease may also experience lactose intolerance at the time of diagnosis but often this is transitory and resolves after some time on the gluten-free diet. In the meantime it can add an extra level of complexity to managing the diet.

In addition, there are genetic commonalities between type 1 (insulin dependent) diabetes and coeliac disease. As a result, a person with coeliac disease is two to five times more likely to have type 1 diabetes than the general population. Again managing two different dietary demands can be very challenging.

The information for these pages was provided by Sarah Sleet, Vice chair and Secretary of the Association of European Coeliac Societies (AO ECS). For more information: sarah.sleet@coeliac.org.uk

DIABETES



IDF EUROPE IS THE EUROPEAN CHAPTER OF THE INTERNATIONAL DIABETES FEDERATION (IDF).

IDF Europe is an umbrella organisation representing both people living with diabetes and healthcare professionals from 66 diabetes organisations in 47 countries across Europe.

IDF Europe is the voice for the growing number of people living with diabetes and those at risk in Europe. Through IDF Europe's activities, they aim to influence policy, increase public awareness and encourage health improvement, promote the exchange of best practice and high-quality information about diabetes throughout the European region.

IDF Europe provides essential expertise and up-to-date evidence on diabetes, support awareness campaigns through a network of partners and stakeholders, and advocate European and international organisations for proper public policies for diabetes.

MISSION

IDF Europe's mission is to advance diabetes care, prevention and a cure worldwide.

For more information: www.idf.org/regions/europe

DIABETES AND NUTRITION

GENERAL INTRODUCTION TO DIABETES

Diabetes mellitus (DM) is a metabolic disorder of multiple aetiology characterised by chronic high blood glucose levels, with disturbances of carbohydrate, fat and protein metabolism. It is due to defects in insulin secretion, insulin action, or both. The effects of diabetes mellitus include long-term damage of several organs, which causes specific complications such as retinopathy with potential blindness, nephropathy that may lead to renal failure, neuropathy with risk of foot ulcers and amputation, and sexual dysfunction. In general, diabetic patients have an increased risk of cardiovascular, peripheral vascular and cerebrovascular disease.

There are different types of diabetes. The most common is type 2 (DM2) which is usually present in adults. This form of DM occurs when insulin is not used effectively by the body. Type 1 diabetes (DM1), formerly called juvenile diabetes, is commonly diagnosed in children. It is an autoimmune disease that permanently destroys pancreatic beta cells. This implies that the body can no longer produce insulin and patients require insulin to manage their diabetes. Gestational diabetes (GDM) is a form of diabetes that specifically occurs during pregnancy. Other forms of diabetes are Latent Autoimmune Diabetes of Adulthood (LADA) and Maturity Onset Diabetes of the Young (MODY).

LINKS BETWEEN DIABETES AND NUTRITION

In the last two decades some dietary factors have been associated with the risk of DM1. In some studies an increase in DM1 risk has been associated with several nutrients and accompanying food additives. In this regard, a positive association with DM1 incidence and daily cow milk intake has been reported in several countries. However, up to now, no clear evidence of a relation between DM1 and a specific food item has emerged from experimental animal or

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human studies. Nevertheless, eating patterns at the population level appear to influence DM1 incidence and it seems that dietary risk factors during pregnancy and early neonatal life can influence the early onset of DM1.

An increased risk of developing DM2 is associated with overweight (BMI over 25kg/m²) and obesity (BMI over 30kg/m²). The risk increases with abdominal obesity. It is known that high intake of fats, especially saturated fats and trans fatty acids, are involved in DM2 risk. On the other hand, non-starch polysaccharides, omega-3 fatty acids, low glycaemic index foods, dietary fibre and breastfeeding may play a protective role. In addition, it is important to note that there is no risk associated with specific individual nutrients. Thus, evidence-based insights emphasise the importance of weight reduction and the intake of normocaloric diets together with an increase in physical activity.

HOW TO LOWER YOUR RISK OF DIABETES?

It is well known from several clinical trials that DM2 can be prevented.

People need to make a few lifestyle changes in order to lower the chances of developing DM2. In addition, the same changes can also lower the risk of developing heart disease and some types of cancers. These changes could be summarised as: 1) control body weight; 2) increase physical activity and 3) better nutrition.

Better nutrition is very important and four dietary changes can have a big impact on the risk of DM2. The changes are:

1. Choose whole grain and whole grain products over highly processed carbohydrates. Whole grains have a low glycaemic index, delaying the increase in blood sugar and consequent insulin release. In addition, whole grains are rich in essential vitamins, minerals and phytochemicals that may help reduce the risk of DM2.

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2. Skip regular soft drinks, cordial, sweetened fruit juices and nectars. These beverages have a high glycaemic load, together with a high energy content. This induces weight gain and an increased risk of DM2. Moreover, it has been shown that sugary drinks contribute to high levels of triglycerides, low levels of high-density lipoprotein (HDL), increased insulin resistance and chronic inflammation, all of which are risk factors for DM2. Studies show that two or more servings per day of these beverages increase the risk of DM2 by more than 30%. Water or tea are good substitutes for sugary drinks.
3. Eliminate “bad fats” from the diet. Saturated fats and trans fats contribute to DM2 development. These fats are present in sweet cakes, biscuits, chocolate, dairy products, meat, margarines, packaged baked goods, fried foods, takeaway foods and any product that lists “partially hydrogenated vegetable oil”. On the other hand, “good fats” (polyunsaturated and monounsaturated fats) are present in liquid vegetable oils (mainly olive oil), nuts and seeds. Practical tips for decreasing fat intake are:
 - 1) remove skin and visible fat from chicken and turkey;
 - 2) bake, roast, broil, grill or boil meats;
 - 3) cook with small amount of oil and always use olive oil;
 - 4) choose low-fat or non-fat dairy products;
 - 5) avoid adding sauces or gravies to food and try to flavouring with herbs and spices instead;
 - 6) replace chips and cookies with whole grain pretzels or low-fat crackers and
 - 7) check food labels.
4. Limit red meat. Evidence is accumulating to show that red meat (beef, pork and lamb), together with processed red meat (bacon, hot dogs and deli meats) increase the risk of DM2. Recent studies have found that eating daily 85-100 g serving of red meat increased the risk of DM2 by 20%. Healthier protein sources such as nuts, low-fat dairy products, poultry, fish or legumes are sensible alternatives.

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5. Moderate alcohol consumption. Studies show that moderate amounts of alcohol (up to a drink a day for women and two drinks a day for men) increase the efficiency of insulin at getting glucose into cells, i.e. improves insulin sensitivity.
6. Make healthier choices and avoid so-called fad diets. These type of diets may help weight loss at first, but their effectiveness at preventing diabetes is not known. In addition, these diets usually exclude particular groups of foods, thus potentially leading to a shortfall in essential nutrients and do not teach healthy nutritional habits.

SOME OTHER TIPS

Sometimes it is very difficult to eat well, mainly because of shortage of time or budget. Here are some general tips for healthier eating:

1. Plan weekly meals and try not to shop when hungry.
2. Use a grocery list when shopping. Choose more fresh vegetables, fruits, whole grain bread and cereals, nuts, fish low fat dairy products and leaner meats.
3. Avoid products with high energy content, but which are poor in vitamins and minerals, such as candies, cookies, chips, sodas, sweets or other snacks.
4. Remember that special “dietetic” or “diabetic” foods are not necessarily healthier and are probably more expensive.
5. Start meals with a salad, broth or vegetable soup.
6. When going to a restaurant ask if meats can be grilled, choose salad or other vegetables as side items, reduce alcohol consumption and try fruit as dessert.

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BEST PRACTICE

Diabetes implies an enormous economic, social and personal cost. Thus prevention is a very important issue. In this regard, one of the most necessary interventions is education. This would include mandatory nutrition education in schools and use of the school canteen as a place to learn healthier habits and enjoy food, ban the advertising of unhealthy foods and subsidise healthy foods at the expense of less appropriate foods.

The information on these page was provided by Sophie Peresson from IDF Europe. For more information: sophie.peresson@idf-europe.org

DIABETES

DIABETES AND A HEALTHY PREGNANCY

The prevalence of type 2 diabetes and gestational diabetes (GDM) in pregnancy is increasing and is often linked to obesity. Current guidance states that women with a BMI >30 kg/m² should limit weight gain in pregnancy to 5–9 kg. There are no recommendations for weight maintenance or weight loss but it is known that poor diets which are low in energy may result in poor pregnancy outcome.

However, overweight women with type 2 diabetes or GDM often reduce their energy intake by following a healthier diet during pregnancy. A low sugar diet alongside a healthy nutrient intake may be a safe way to limit weight gain or encourage sensible weight loss in pregnancy, which may reduce complications and promote significant weight loss in the long term.

POST-PREGNANCY

Once a baby is born, it is a really good idea to breastfeed as it has so many positive benefits for both mother and baby. It is also linked to reduced risk of obesity and diabetes later in life. Breastfeeding is also linked to increased weight loss post-pregnancy. This is especially for women who have GDM and are 60% more at risk of getting type 2 diabetes later in life unless they reduce weight and have regular physical activity.

The information on these page was provided by by Anna Clarke, Research Manager of the Diabetes Ireland Research Alliance.

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HYPERCHOLESTEROLAEMIA



THE INTERNATIONAL FH FOUNDATION

The International FH Foundation focuses specifically on familial hypercholesterolaemia (FH), a genetic disorder characterised by dangerously high cholesterol levels (LDL). People with FH will from birth, unless diagnosed, develop cardiovascular disease without any apparent or outward symptoms. Undiagnosed and untreated, they may well die from a first heart attack in their forties or fifties (men) and their sixties (women). Some who inherit the defective gene from both parents (homozygous - hoFH) are likely, unless recognised by a physician, to die in their teenage years.

Medical opinion for many years has largely been that the incidence rate for FH is 1 in 500 of the population (heterozygous - heFH) and 1 in a million for homozygous. However there is increasing evidence that the incidence rate in the FH population is much higher, indeed about double the frequency¹. Does that mean that 400,000 preventable heart attack deaths worldwide occur each year, not 200,000 and that not 7 million of the world's population has FH but a minimum of 14 million? Probably.

The International FH Foundation believes all partners should wise up and lock on to a whole new way of addressing concern for the danger of leaving undiagnosed FH people to die needlessly in the world today, not only for the sake of new patients but for the sake of their children. Fiscally speaking all governments embracing a new FH awareness policy would reap the rewards of reduced health and societal costs.

FH IS common - it is NOT a rare disease - only its diagnosis IS rare.

For more information: www.fh-foundation.org

¹ Familial Hypercholesterolemia in the Danish General Population: Prevalence, Coronary Artery Disease, and Cholesterol-Lowering Medication. Benn M, Watts GF, Tybjaerg-Hansen A, Nordestgaard BG. J Clin Endocrinol Metab. 2012 Aug 14.

MEDICAL TREATMENT

There is an inevitability in FH healthcare programmes that medical treatment is necessary sooner or later, usually by a combination of statins (drugs used to lower cholesterol levels by inhibiting the enzyme HMG-CoA reductase) and adjunctive medicines. If diagnosis occurs early in life then the right nutrition management is extremely important, partly because an early disciplined regimen is likely to help set a diet for life and partly because early remedial action will lessen the requirement for early medical intervention.

Importantly, lifestyle management of diet is essential as good adherence to nutritional advice will reduce cholesterol levels by up to 20 percent, particularly due to lowering of saturated fat intakes.

NUTRITION

The first step in treatment for those with FH is to change their patterns of diet to reduce the daily total amount of fat eaten to 30 percent of total energy. This can be done by limiting the amount of meat particularly where there is residual fat content, such as in fatty streaks in pork, bacon, lamb and chicken skin; cutting out all lard and butter, full fat milk and cheeses as well as some oils like coconut and palm oils; and eliminating egg yolks, organ meats and other sources of saturated fat from animals.

The earlier a person is diagnosed with FH, and at long last there is a move for healthcare professionals to improve diagnosis in children, the better the outcome. It is becoming clear that early age adherence (up to the age of eight or nine) to good diet regimens will be rewarded with long life retention of those good habits learnt. The later in child or early adult life that diet recommendations are made, the harder it is for people (including FH patients) to adhere to and/or maintain.

GUIDING STEPS

- Eat more fruit and vegetables.
- Eat less fat, particularly less saturated fat, creamy sauces, pastries.
- Replace saturated fat with unsaturated fat.
- Eat more foods containing fibre (oat beta glucan) and choose wholegrain whenever possible.
- Eat more omega 3 rich foods, aiming for 1 or 2 oil-rich fish each week.
- Eat more cardio-protective nuts (25g or 1oz each day).
- Eat less cholesterol-rich food.
- Low fat cheese is fine as are plant sterols and stanols (2 to 2.5g each day).
- Reduce or remove salt intake altogether.
- Limit food and drinks high in sugar or alcohol.

Counselling from a dietitian is often recommended to help people to make these changes in their eating habits.

The information for these pages was provided by Michael Livingston, Director of the International FH Foundation.

For more information: ask@fh-foundation.org

Further resources

UK HEART UK www.heartuk.org.uk
FH Journeys www.fhjourneys.com

INFLAMMATORY BOWEL DISEASE



EUROPEAN FEDERATION OF CROHN'S AND ULCERATIVE COLITIS ASSOCIATIONS (EFCCA)

The European Federation of Crohn's & Ulcerative Colitis Associations (EFCCA) is an umbrella organisation representing 30 national patient associations from 29 European and non-European countries. EFCCA aims to work to improve life for people with inflammatory bowel disease (IBD) and give them a louder voice and higher visibility across Europe. Since 2010 EFCCA has promoted World IBD Day, led by patient organisations representing 36 countries on four continents, officially celebrated on 19 May; [www. Worldibdday.org](http://www.Worldibdday.org)

At www.efcca.org you will find links to the national Crohn's and ulcerative colitis associations in Europe and on other continents.

THE CROHN'S IN CHILDHOOD RESEARCH ASSOCIATION (CICRA), www.cicra.org, is a > 30 year old UK organization which raises funds for paediatric IBD research but also specializes in providing information about children and young people with Crohn's and colitis (IBD) and to their families.

WHAT IS INFLAMMATORY BOWEL DISEASE - IBD?

Crohn's disease and ulcerative colitis are chronic inflammatory, non-infectious conditions involving the digestive system with > 3 m people in Europe; up to 25% are < 18 years old. IBD should not be confused with IBS (irritable bowel syndrome), which, despite similar symptoms, is a separate condition. Ulcerative colitis is restricted to the colon and/or the rectum, whereas Crohn's disease can affect any part of the gastrointestinal tract. Ulcerative colitis is twice as common as Crohn's disease in adults, but not so in children.

INFLAMMATORY BOWEL DISEASE

If the small intestine is also affected as can be the case in Crohn's the inflammation can negatively affect the bodies ability to digest food and absorb nutrients. Some people, especially children, lose weight rapidly as a result of their IBD and this can be dangerous at any age.

SYMPTOMS

Symptoms in both illnesses may include abdominal pain, diarrhoea, vomiting, rectal bleeding and weight loss. Both illnesses may be accompanied by various inflammatory manifestations in e.g. the eyes, mouth, and joints or on the skin. The intensity of the symptoms may vary a lot over time. Patients may experience flare-ups and periods of remission.

DIAGNOSIS

Peak age for diagnosis in both conditions is between 10 and 40, but the disease can occur at any age. The diagnosis is usually based on an endoscopic examination of the bowel and biopsies of pathological lesions. Certain indicators of IBD, such as infection and anaemia, can also be determined in blood tests, but in children the symptoms often mimic others childhood conditions resulting in delayed diagnosis.

TREATMENT

Most adult patients will be treated with anti-inflammatory medication (e.g. 5-ASA, steroids) or immunosuppressives (e.g. azathioprine) but the first line of treatment for children is usually enteral feeding before progressing, if necessary to a drug regime. Sometimes antibiotics or biological therapies (e.g. anti-TNF alfa) may be used. If the illness does not respond to medication, surgery may be necessary. In ulcerative colitis patients, the entire colon may be removed, in which case the illness is "cured"; in Crohn's disease, only the affected parts of the intestine are removed but the disease may reoccur at any part of the digestive tract.

NUTRITION

Nutrition is an important factor in the recovery and maintenance plans for those with inflammatory bowel disease. Some people with IBD may find that certain foods affect their symptoms or have difficulty digesting food.

INFLAMMATORY BOWEL DISEASE

IBD patients may find it helpful to alter their diet slightly, but please do remember everyone is different and advice should be obtained from your dietitian/nutritionist as many patients with Crohn's or colitis find difficulty in tolerating certain foods.

Children and adolescents with IBD, who should still be growing, will probably need extra nutrition to support their growth and development ; especially important during the growth spurt which occurs during puberty, and is often regularly used in the paediatric (gastroenterology) hospitals and health services.

It should be remembered that in the case of Crohn's and colitis (IBD) that the digestive tract (gut lining) will be damaged and the food cannot be absorbed in the same way as those who are well. Nutrients are necessary for energy and to help our bodies develop, to grow and to repair themselves. Healthy eating is important too in IBD with main nutrient groups: carbohydrates, protein, fat, vitamins and minerals all required. As mentioned earlier it is helpful to consult a nutritionist. This should be via your GP or as part of the hospital team.

Dehydration (when your body does not have sufficient water) can be a problem for some patients, including those with a stoma, so it is vital to replace salts and sugars - often an oral rehydration solution is used.

This oral solution is available in pharmacies over the counter, or may be prescribed by your doctor. In some cases those needing regular rehydration while travelling may be able to make their own.

Other diets may help individual people with IBD at some time, such as enteral nutrition, probiotics and prebiotics, low fibre, herbal and other supplements.

The information on these pages was provided by Rod Mitchell, who is a long time carer and IBD patient advocate both in the UK and at the European level. His present connections with inflammatory bowel disease are as Chairman of the Management Board of the IBD Research Foundation (www.ibdresearch.org) and Vice Chairman of CICRA (www.cicra.org)

KIDNEY DISEASE



CEAPIR, THE EUROPEAN KIDNEY PATIENTS' FEDERATION

CEAPIR is the European umbrella organisation for 23 national kidney patients' organisations in Europe. CEAPIR is the voice of the European kidney patients.

The core of the activities is the health and the well-being of chronic kidney disease (CKD) patients and their carers in all stages of the disease. This includes patients in the phase of early detection, those in dialysis treatment (haemodialysis and peritoneal dialysis) and after kidney transplantation. For further information: www.ceapir.org

KIDNEY DISEASE AND DIET

The kidneys are responsible for removing toxins from the body. These are excreted in urine. When the kidneys do not work properly, not enough toxins are removed from the bloodstream, which can lead to illness. By adjusting food and drink intake, it is possible to limit the production of toxins in the body. This will limit physical problems. Additionally, a diet sometimes helps in slowing down the loss of kidney function.

Dietary advice will always be adjusted to your personal circumstances by a dietitian.

Generally, though, it is important to monitor the intake of the following nutrients:

- Protein and energy
- Phosphate
- Sodium
- Potassium
- Water and liquids.

KIDNEY DISEASE

DIET IN THE PREDIALYSIS STAGE

When protein intake is limited, the urea content of the blood does not get very high. This way, it is possible to prevent complaints such as fatigue, headaches and itching.

Moreover, it is important to watch your weight. If you are overweight, you will be advised to (gradually) lose weight. In other cases, however, people are at risk of being underweight, especially when they limit their protein take too much. A dietitian will help you monitor these risks.

Limiting protein intake will help in limiting phosphate intake as well because proteins contain high levels of phosphate. Usually, this is not sufficient to keep phosphate levels in their correct range. If that is the case, you will be prescribed phosphate binders.

If you suffer from chronic kidney damage and high blood pressure, or if you suffer from oedema, a sodium restriction will be prescribed. Usually, it will be sufficient to prepare dinner without added salt and to avoid very salty food. Then you can still eat regular bread, cheese and lunch meats. Alternatively, you could opt for bread without salt, so you can add some salt to your dinner.

When the potassium levels of the blood are too high, the amount of potassium in your food will need to be limited, to avoid heart problems. A potassium restriction encompasses, among other things: eating less fruits, vegetables and tomatoes, regularly replacing potatoes with rice or pastas; drinking tea instead of coffee, and soda instead of fruit juice. Medications are also available to help bind potassium in the body. You should discuss this option with your doctor.

Do drink enough when you suffer from kidney damage, unless your nephrologist advises you otherwise. It is easier for the kidneys to excrete toxins in the urine when there is a lot of urine to produce. (Mineral) water, lemonade made with syrup and tea can be drunk in unlimited quantities, but drinking fruit juice is not recommended. Some sodas contain high

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amounts of potassium; your nephrologist or dietitian will be able to tell you which ones to avoid. Sometimes, a fluid restriction is necessary, for example when you also have high blood pressure, or if you suffer from oedema because of heart problems. A fluid restriction is easier to follow when you also restrict your sodium intake.

DIET FOR HAEMODIALYSIS PATIENTS

When on haemodialysis, you need to increase protein intake because during dialysis the body loses amino acids, the building blocks of protein. Additionally, if you are on dialysis you will be put on a fluid restriction. After starting dialysis, you might notice a decrease in urine production. Persons on dialysis sometimes produce only a few drops of urine per day. In that case, the dialysis machine needs to remove all the fluids you take, both in drinks and food (for example, a water melon contains a lot of liquid). Although every dialysis patient will get personal dietary advice, you are generally allowed to drink about 800 ml per day. The amount of urine you produce can be added to this recommendation.

Malnourishment is a danger in dialysis patients when nausea or a changing sense of taste hampers adequate food intake. The dietitian will regularly check if you are eating enough and will advise you on a well-balanced diet, as well as determine whether or not you might need to take energy supplements (temporarily). A sodium restriction is useful if you have high blood pressure and to make it easier to comply with a fluid restriction, because salty food will make you thirsty. To control the potassium level of your blood in between dialysis treatments, it is often necessary to restrict potassium intake. There are also potassium binders available. To control the phosphate levels, you will be prescribed phosphate binders. In haemodialysis patients, restricting protein intake to limit phosphate intake is not a solution, because you need all the protein you can get.



DIET FOR PERITONEAL DIALYSIS PATIENTS

During peritoneal dialysis, the dialysis solution always absorbs a certain amount of protein. These losses need to be compensated for through your diet. Sometimes, people on peritoneal dialysis are prescribed a fluid restriction. This depends entirely on how much fluid the dialysis solution can remove and on urine production. In peritoneal dialysis patients, phosphate binders are necessary to control blood phosphate levels.

The dialysis solution also contains sugar. This sugar is partially absorbed in the blood stream. To avoid weight gain, one needs to take this absorption into account. Conversely, some people also experience weight loss. Their appetite might decrease because the presence of the dialysis solution in the peritoneal cavity makes you feel full. A dietitian can help you monitor your weight.

DIET AFTER TRANSPLANTATION

If the new kidney works well, you generally will not have any special dietary requirements anymore. Still, there are things to keep an eye on. It might be very hard to switch from a fluid restriction to drinking the massive amounts of liquids that the new kidney needs to keep functioning.

KIDNEY-FRIENDLY FOOD

Do you want to know more about kidney-friendly food? For more information: www.kidneywellbeing.co.uk

The information on these pages was provided by Marjolein Storm of the Dutch Kidney Patient Association (NVN).

For more information: storm@nvn.nl

PRECONCEPTION CARE



PRECONCEPTION CARE

Nutrition is important at the very earliest stages of life – and even earlier, even before a woman becomes pregnant. In the first couple of weeks of pregnancy, when a woman often does not know she is pregnant, most of the organs of the baby are built. Moreover, evidence is accumulating that good nutrition, together with other health interventions, starting prior to conception considerably contributes to healthy longevity of mother and child. This is why nutrition is an essential part in the continuum of healthcare starting before conception.

PREPARING FOR LIFE

The emotional, social and economic burden of maternal and child deaths and disability is high. Preparing for Life is one of the initiatives committed to the reduction of these disasters (United Nations Development Goals 4 & 5). Preparing for Life, a worldwide foundation under Dutch law, is a joint venture of international parent/patient organisations (VSOP, EGAN, IGA), academia, research institutions and service clubs initiated by the parent/patient organisations.

In February 2012 a conference dedicated to this topic was organised at the World Health Organization (WHO) headquarters in Geneva, by WHO, Preparing for Life and the Bill & Melinda Gates Foundation. Agreement was reached on a package of evidence-based pre-conception interventions, some of them applicable to everyone, some of them individually targeted, and that special attention should be given to the position of women, the role of men, and to local/national/regional factors.

For further information about this initiative: www.preparingforlife.net/en

HEALTHY EATING FOR A HEALTHY PREGNANCY

It is generally known that nutrition is an important determinant of health during pregnancy and lactation. However, not generally known is the fact that nutrition and nutritional status prior to fertilisation and the days thereafter, greatly contribute to a good pregnancy outcome and are crucial for maternal and child health, also in the long run.

Healthy eating should be an essential part of the lifestyle when planning a pregnancy. If overweight or obesity is an issue, it is good to start exercising and aim for a BMI between 20-25 before pregnancy as this ensures a healthier pregnancy for both the mother and her baby.

It is advisable to follow a balanced diet based on the following main food groups:

- **Carbohydrates** such as bread, rice, pasta and potatoes
- **Fruit and vegetables** at least two portions a day of each
- **Protein** such as meat, poultry, fish, eggs
- **Dairy products** such as milk, cheese and yoghurt

Energy requirements do not usually increase during the first three months of pregnancy. However, an additional 200-300 kilocalories per day is recommended thereafter, but may not be necessary if physical activity levels have fallen substantially.

In case of a particular disease, specialist advice from a healthcare professional should be sought with regard to nutrition before and during pregnancy.

For food safety advice and reasons for their special importance prior to and during pregnancy, see: <http://www.nhs.uk/conditions/pregnancy-and-baby/pages/healthy-pregnancy-diet.aspx#close>.

PRECONCEPTION CARE

MICRONUTRIENTS

Research has shown the importance of adequate levels of folic acid, iron, iodine and vitamin D prior to and during pregnancy. There are also risks of adverse effects of high intakes of certain vitamins on the development of the baby, in particular the fat-soluble ones such as vitamin A. Liver and shellfish contain high levels of vitamin A, and eating these foods should be avoided.

FOLIC ACID (VITAMIN B₉)

Deficiency in folic acid in the pre-conception period appears to occur even when the intake of other nutrients is considered normal. Because of the serious consequences of this deficiency for the baby-to-be i.e. neural tube defects and other birth defects, supplements are strongly advised. Research indicates that folic acid supplements should start preferably at least four weeks before pregnancy and continue for the first 10 weeks of pregnancy. The dosage should be 0,4 – 0,5 milligram daily.

VITAMIN D

Most vitamin D is produced in the skin under the influence of sunlight. Vitamin D deficiency is regularly found in women living in northern countries with little sunlight, in women with dark skin and women who cover their skin outdoors. As vitamin D deficiency is associated with disorders of bone and tooth formation in the baby-to-be, it is wise for women to have their vitamin D status checked prior to conception.

IRON

Iron deficiency leading to maternal anaemia increases the risk for maternal morbidity and mortality, child mortality, low birth weight, preterm birth and reduced intelligence of the child. Common causes of iron deficiency in women are heavy bleeding during periods, unbalanced diets, and frequent, chronic or recent infections. If there is any doubt about the possibility of iron deficiency, a bloodtest should be performed. Deficiencies should be solved under supervision before pregnancy.

PRECONCEPTION CARE

IODINE

Iodine deficiency increases the risk for spontaneous abortion, stillbirth, mental retardation, congenital hypothyroidism, goitre and infant mortality. It can be prevented by use of iodised salt in food.

MALNUTRITION IN OVER AND UNDERWEIGHT WOMEN AND WOMEN WITH CHRONIC DISEASES

Malnutrition occurs when the diet does not have a proper balance of nutrients. Underweight and stunting can be the consequence of chronic undernourishment (due to shortage of food) since childhood. It can also be caused by diseases such as anorexia nervosa, bowel disease etc. In such causes underweight is practically always combined with micronutrient deficiencies. Women with nutrient deficiencies have an increased risk for complications during pregnancy and delivery such as preterm birth, low birth weight, stillbirth, as well as for diabetes and cardiovascular disease later in the life of the child. Women that are underweight and suffer from chronic diseases should be given information about the health risks for themselves and their babies and offered nutritional risk screening. Furthermore, they should be offered professional medical assistance during pregnancy and childbirth.

In cases of an imbalanced food pattern, whether combined with obesity or not, dietary measures should be taken before pregnancy with professional (para) medical guidance. Tests for detection of diabetes mellitus and nutritional deficiencies should be done as well. Malnutrition, with or without obesity, can lead to a predisposition to diabetes mellitus type 2 and diabetes during pregnancy. Both types of diabetes increase risk of microvascular disease, high blood pressure, bacterial infections, spontaneous abortions, preterm delivery, birth defects, stillbirth, and excessive blood loss during and after delivery.

The information for these pages was provided by Ysbrand Poortman and Martina Ens-Dokkum from the Preparing for Life Initiative (Pfl).

ABOUT EGAN, EPF AND ENHA



ABOUT EGAN - WWW.EGAN.EU

The Patients Network for Medical Research and Health EGAN is an alliance of both National Genetic Alliances and European disease specific patient organisations with a special interest in genetics, genomics and biotechnology. EGAN has started out as the European Alliance of Genetic Support groups (EAGS) in 1992 in Copenhagen. The latest focus areas are nutrition and preconception care.



ABOUT EPF - WWW.EU-PATIENT.EU

The European Patients' Forum (EPF) is the umbrella organisation of pan-European patient organisations active in the field of European public health and health advocacy.

EPF was founded in 2003 to become the collective patients' voice at EU level, manifesting the solidarity, power and unity of the EU patients' movement. EPF currently represent 59 patients groups – which are chronic disease specific patient organisations operating at EU level and national coalitions of patients organisations.



ABOUT ENHA - WWW.EUROPEANNUTRITION.ORG

The European Nutrition for Health Alliance (ENHA) works with key stakeholders to improve nutritional care across Europe by actively promoting implementation of nutrition risk screening and follow up care across Europe. Research of ENHA demonstrates the impact of malnutrition on both individuals and health and social care systems.

ENHA Partners are

- Association International de la Mutualite (AIM mutual health insurers)
- European Federation of the Associations of Dietitians (EFAD)
- European Hospital and Healthcare Federation (HOPE)
- European Nursing Directors Association (ENDA)

- European Society of Clinical Nutrition and Metabolism (ESPEN)
- European Union Geriatric Medicine Society (EUGMS)
- International Association Geriatrics and Gerontology (IAGG)
- International Longevity Centre – UK
- Medical Nutrition International Industry (MNI)
- Pharmaceutical Group of the European Union (PGEU Community Pharmacists)

RECOMMENDATIONS OF THE FIRST INVITATIONAL CONFERENCE FOR EU PATIENT GROUPS ON NUTRITION, HELD ON JULY 4, 2012 IN BRUSSELS.

Following the presentations and discussion delegates identified seventeen key recommendations for further action. These were presented to the group for approval as a part of the actions to follow from the meeting and to ensure that patient groups working together with ENHA could have a focus for future action on nutrition. The recommendations have been classified into categories that may play a role in the EU nutritional agenda.

Nutrition and patient associations

1. Patients and their associations must be seen as key players to drive quality and equity of care.
2. Find a collective agenda and increase the engagement and interaction between patients, industry and other stakeholders.
3. Knowledge on nutrition must be integrated into patient peer support and management.

Nutrition and awareness

4. Dietitians must be a part of a multi-disciplinary health providing team adopting a holistic view on health and it is the responsibility of patients to take the lead in their health.

Nutrition and medical education

5. There is a need to improve medical education so that it includes nutrition.
6. Nutrition education must start for all at an early age.

Nutrition and health

7. Treatment and management of disease as well as identification of need and nutritional care must be considered individually.
8. Nutritional equivalency in substitute products is vital in ensuring good overall nutrition.

9. It is important to keep a holistic view of disease; nutrition is a part of that view and can have a positive impact on patient health.

Nutrition and regulatory requirements

10. Clear labelling of food is fundamental in supporting patients to manage their conditions.
11. Guaranteed access to safe and nutritional food is a right and essential for those who have no choice about what they eat e.g. in institutions.

Nutrition and disease specific information

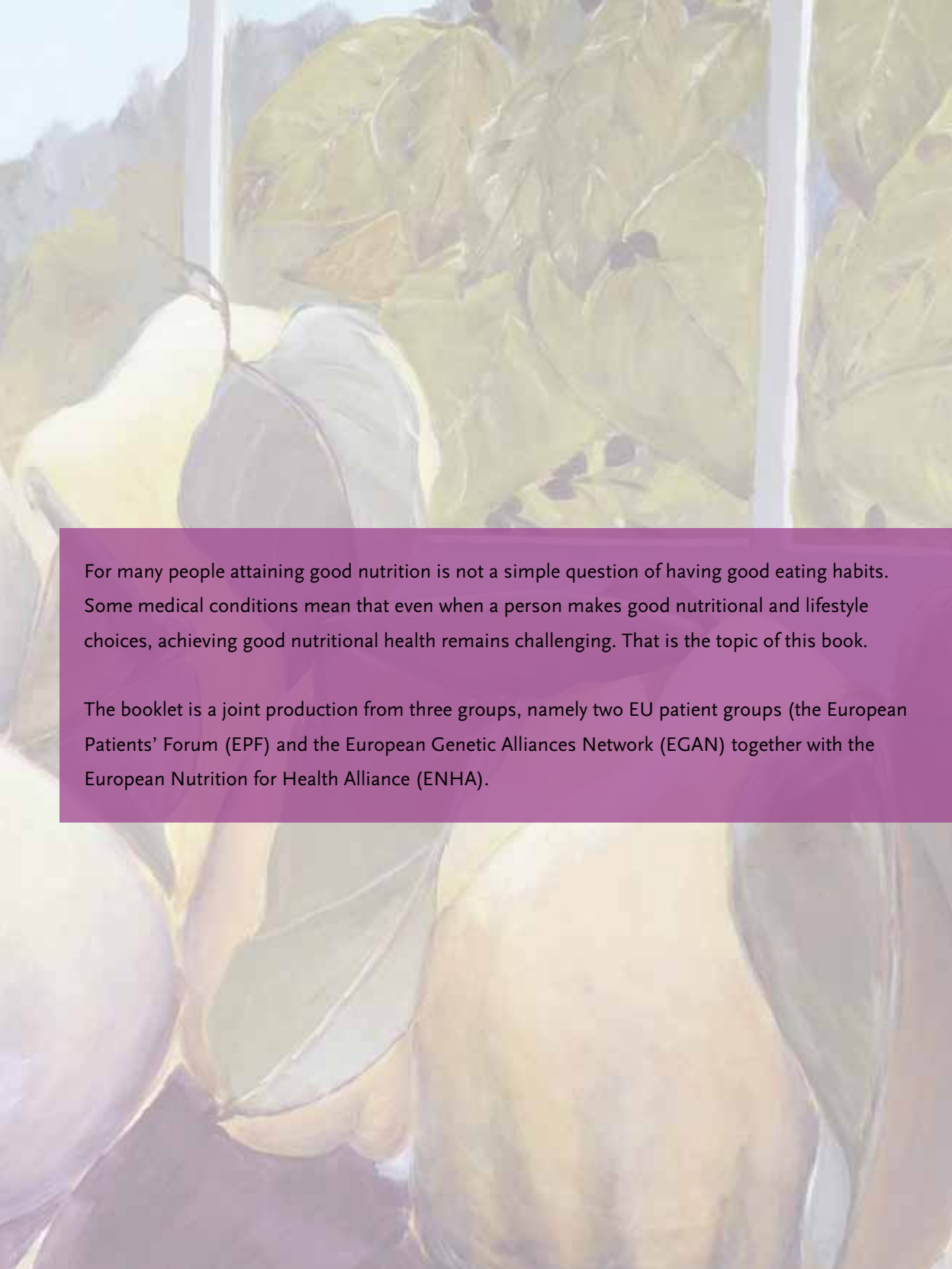
12. It is essential that the importance of dental care in nutrition and its role in ensuring good health, especially in older age is not forgotten.
13. Routine nutritional screening of at risk groups is essential in preventing malnutrition among patients.
14. The area of nutrition in pregnancy must be highlighted as key, influencing health and disease prevention.

Nutrition and research

15. There is a need for further research on the impact of nutrition in retinal disease patients.
16. Vitamin D supplementation should be routine for those over 60. It is a cheap, effective intervention and can prevent deficiency and disease as well as presenting an achievable target.
17. Any further research carried out must be supported by patient groups and driven by their needs.

CONCLUSIONS

The presentation of these recommendations further emphasised not only the breadth of work patient groups undertake, but also the areas in which groups can work together to increase awareness of the importance of nutrition with their members, funders, EU partners and other groups. In conclusion, nutrition is a cross cutting issue that affects all citizens and incorporates a wide number of stakeholders. By engaging with these stakeholders and acting on the recommendations, it is possible to change the way nutrition is viewed, used and understood, by patients, carers, health and social care professionals and the general public.



For many people attaining good nutrition is not a simple question of having good eating habits. Some medical conditions mean that even when a person makes good nutritional and lifestyle choices, achieving good nutritional health remains challenging. That is the topic of this book.

The booklet is a joint production from three groups, namely two EU patient groups (the European Patients' Forum (EPF) and the European Genetic Alliances Network (EGAN) together with the European Nutrition for Health Alliance (ENHA).