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A companion guide for health care professionals

a conversation guide about nutrition for
patients with gastrointestinal cancer

MyFood Program





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Welcome to the MyFood companion brochure

MyFood is part of the **Support Harmonized Advances for better Patient Experiences (SHAPE)** program: an international, multi-stakeholder initiative that aims to transform the lives of patients with gastrointestinal (GI) cancer.

Patients with GI cancer may struggle with eating, cooking, and socializing around food and may experience weight loss, malnutrition, and diminished quality of life. Regular monitoring of patients' nutritional status is vital to allow early intervention where there may be nutritional deficiencies. It is also important to understand the concerns a patient may have around their nutrition and diet – and how to answer them.

This brochure is designed to supplement the MyFood patient brochure, providing:

- Answers to common questions and concerns patients may have about their nutrition and diet
- Practical guidance and resources to help answer these questions

This brochure has been produced with special input from:

- **Dr Alexander Stein**, *oncologist, Germany*
- **Claire Taylor**, *oncology nurse, UK*
- **Lucy Eldridge**, *oncology nutrition and dietetics specialist, UK*
- **Jenni Tamminen-Sirkkiä**, *patient advocate, board member of DiCE and executive director of Colores*
- **Iga Rawicka**, *patient advocate, vice chair and board member of DiCE and VP of EuropaColon Poland*
- **Maria Troina**, *patient advocate, person living without a stomach, Italy*

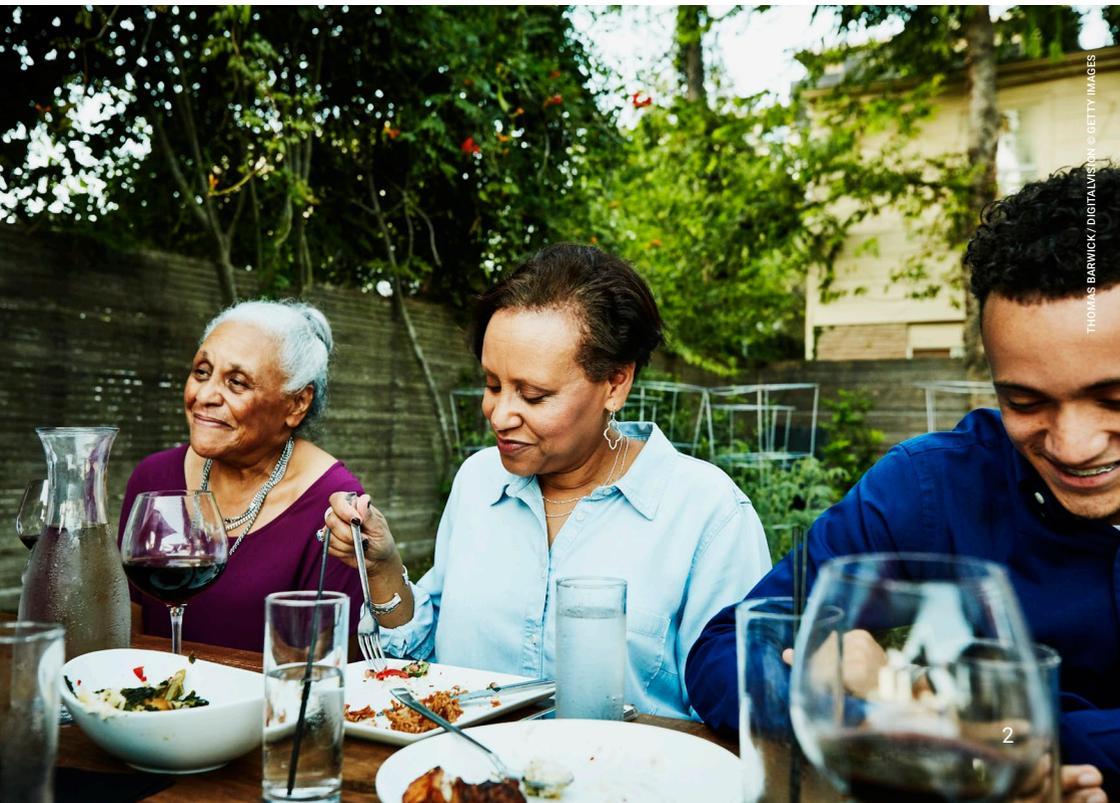
*This brochure has been reviewed by a cancer dietitian, with input from patient representatives, carers, and health care professionals. A glossary of terms can be found at the end of the brochure.

“ Many people who present for their first oncology visit are already nutritionally impaired, some even overtly malnourished.

The potential negative impact of this kind of malnutrition is something we, as health care professionals, must address.

Our patients' nutritional status should be a top priority throughout their care. We must listen to patients' questions and concerns. This brochure provides insights and resources to help answer them. ”

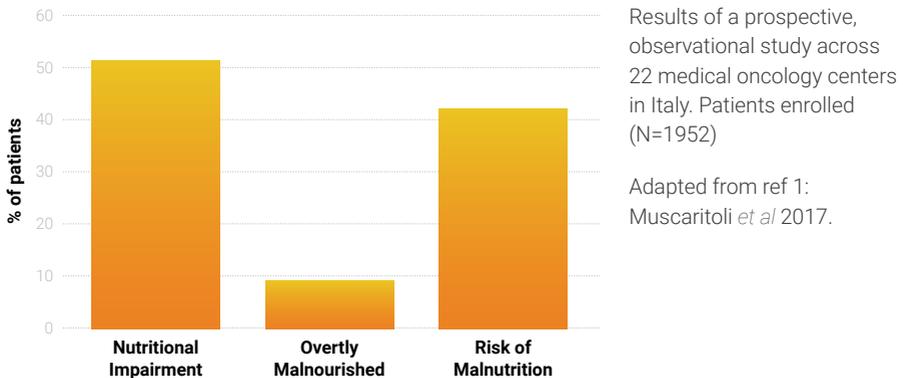
Lucy Eldridge, Head of Nutrition and Dietetics,
The Royal Marsden Hospital, UK



Why use the MyFood brochure with your patients?

Nutritional deficiency affects as many as 50% of cancer patients, negatively impacting quality of life and potentially compromising their treatment outcomes.^{1,2}

Prevalence of malnutrition at first medical oncology visit¹



In addition, at first medical oncology visit, more than 40% of people were experiencing anorexia, and in the previous 6 months, 64% had lost weight (1 kg –10 kg).¹

Malnutrition can have serious consequences for patients:

- Fewer rounds of chemotherapy tolerated
- Lower quality of life
- Longer hospital stays
- Higher rates of complications following surgery¹

We also know that **under nutrition, resulting in malnutrition, has implications for survival**, but **early nutritional intervention plays an important role in improving outcomes**.³

The MyFood patient brochure is designed to support GI cancer patients with issues related to diet and nutrition, helping them to understand:

- The nutritional issues related to GI cancers and the potential impact of dietary changes to improve symptom management, quality of life, and treatment outcomes
- How they can optimize their nutrition and, adapt their diet to help address treatment-related nutritional challenges
- When and where they should seek extra help for their diet and nutritional needs



Eating well
with gastrointestinal cancer

MyFood Program



Welcome to MyFood

MyFood is part of the Support Harmonized Advances for better Patient Experiences (SHAPE) program: an international, multi-stakeholder initiative providing lifestyle support to people with gastrointestinal (GI) cancer.

Is this guide for you?

When you are faced with a GI (also known as digestive) cancer diagnosis, it is really important that you maintain a healthy and balanced diet, making sure you have an adequate intake of nutrients and calories to help keep you strong throughout your treatment and recovery. This can be a real challenge especially when dealing with cancer and treatment. GI cancers include colorectal cancer (CRC), metastatic colorectal cancer (mCRC), pancreatic cancer (PC), and gastric cancer (GC).

Cancer symptoms or side effects of treatment may affect your appetite, and you may not enjoy eating the way you did before. Your weight or bowel movements may change. These effects are common, and there are ways you can overcome these, with the right support.

Along with staying active, being well nourished may improve your quality of life and wellbeing, and may also impact your response to treatment or surgery. You can even find enjoyment from food during your cancer journey.

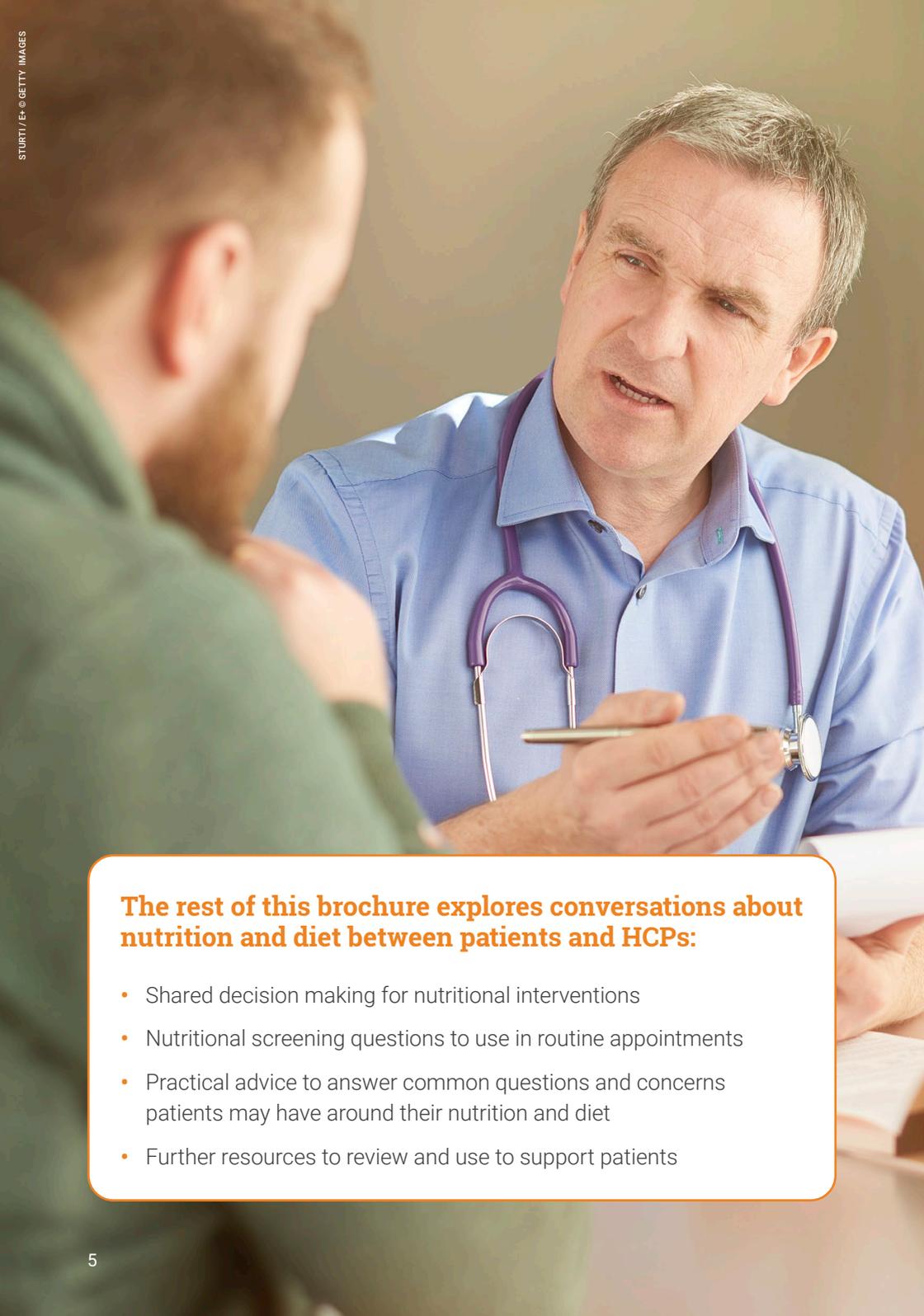
The MyFood brochure is designed to help you adapt the foods you eat depending on your personal situation and to find pleasure from your food, while living with a digestive cancer.*

Developed with special input from:

- **Dr. Alexander Stein**, oncologist, Germany
- **Chloe Taylor**, oncology nurse, UK
- **Lucy Eldridge**, oncology nutrition and dietetics specialist, UK
- **Jenni Tamminen-Sirkka**, patient advocate, board member of DICE and executive director of Coloreal
- **Igor Rawicka**, patient advocate, vice chair and board member of DICE and IP of European Board
- **Maria Truini**, patient advocate, person living without a stomach, Italy

* This brochure has been reviewed by a cancer doctor, with input from patient representatives, carers and health care professionals. A glossary of terms can be found at the end of the brochure.





The rest of this brochure explores conversations about nutrition and diet between patients and HCPs:

- Shared decision making for nutritional interventions
- Nutritional screening questions to use in routine appointments
- Practical advice to answer common questions and concerns patients may have around their nutrition and diet
- Further resources to review and use to support patients

Any decisions on nutritional interventions need to be made jointly, and should be tailored to meet the individual needs of each patient

Initiating the discussion

You can reassure your patients about the necessity of integrating regular nutritional assessment, intervention, and support as part of their cancer care, and inform them about the associated benefits on improving patients' body composition, symptoms, quality of life, and ultimately survival.⁴

Every patient is different and will have different perceptions on their ideal weight and weight loss. They will also have individual circumstances to consider – for example, whether they live alone, or of if they can prepare their own meals.

It's crucial not to apply a 'one size fits all' rule when making nutritional recommendations. The most important thing is to engage in an open dialogue with your patients so that you can decide together what will work best for them and make appropriate recommendations tailored to their individual needs.

You can refer to the MyDialogue brochure for some suggestions on how to initiate a conversation with your patients.

Nutritional screening of your patients

As the nutritional status of an individual is based on many factors, it is critical to take all of these factors into consideration when you conduct each patient's nutritional assessment.⁵

In addition to your measurements to assess **body composition, lab tests** and **clinical assessments** discussing a patient's environmental and social conditions will help to better inform your joint decisions regarding nutritional interventions and diet recommendations. You may want to understand:⁵

- **A patient's economic status:** This may influence their access to certain foods⁵
- **Religious beliefs:** This can potentially limit certain food groups⁵
- **Housing:** If your patient lives alone will they be able to prepare meals for themselves?
- **Individual tastes:** What does your patient like/dislike?

We've provided some examples of nutritional screening questions on the next page that consider body composition, lab tests, and clinical assessments.

Nutritional screening questions to use in routine appointments with your patients^{6*}



The MyMood brochure can be recommended to patients who have been emotionally impacted by their diagnosis

Managing nutritional conversations with GI cancer patients: Answering their questions and concerns

“Is there a diet to help me beat my GI cancer and stop it from returning?”

is undoubtedly one of the first questions people have when it comes to diet, nutrition and cancer. Cancer patients especially, may be willing to do anything to ‘beat’ their cancer so it’s important they receive credible scientific recommendations.

For this, we can turn to the third report published by the World Cancer Research fund on diet, nutrition, physical activity, and cancer.

Encourage patients to practice these behaviors⁷:



Maintain a healthy weight

Advise patients to keep their weight within a healthy range. The evidence for body fatness and cancer risk is increasingly strong. Specifically, there may be adverse effects from gaining weight in adulthood.

Stay physically active

Advise patients to be at least moderately physically active as a part of everyday life, following or exceeding national guidelines, and to limit sedentary habits. There is strong evidence for the protective effect of physical activity.

Eat a diet rich in wholegrains, vegetables, fruit, and beans

Advise patients to eat a diet high in plant-based foods, with at least 30 g of fiber/five portions of non-starchy veg and fruit per day. Evidence suggests a protective effect of such a diet is likely.

Reassure patients

When giving dietary advice, remember to reassure patients that cancer development is complex and multifactorial, and that their cancer is not ‘their fault’ or caused solely by their diet.

The MyFood patient brochure also touches upon these recommendations.

While focused on dietary interventions for cancer prevention, this evidence-based report encourages people who have been diagnosed with and/or survived cancer to follow the same recommendations as much as possible.⁷

Encourage patients to limit consumption of:⁷



'Fast foods' and other processed foods

Advise patients to limit processed foods that are high in fat, starches, or sugar – ie, fast foods, pre-prepared meals, bakery goods, or confectionery. There is evidence that these foods promote obesity.

Red or processed meat

Advise patients to limit red meat to three portions a week (350 g – 500 g cooked), and to eat very little, if any, processed meat. There is strong evidence linking red and processed meat to colorectal cancer risk.

Alcohol

Advise patients that it is best not to drink alcohol for cancer prevention. Strong evidence links alcohol with an increased risk of several cancers, even with low levels of consumption.

Sugar-sweetened drinks

Advise patients to drink mostly water and unsweetened drinks, limiting sugar-sweetened drinks. There is strong evidence that sweetened drinks lead to weight gain and obesity in children and adults.

Advise against supplements for cancer prevention

Advise that dietary supplements are not recommended for cancer prevention; patients should aim to meet nutritional needs through diet. Trials with high-dose supplements have not shown a consistent protective effect. However for some GI cancer patients undergoing treatment there will be a need to take supplements recommended by you.

Managing nutritional conversations with GI cancer patients: Answering their questions and concerns

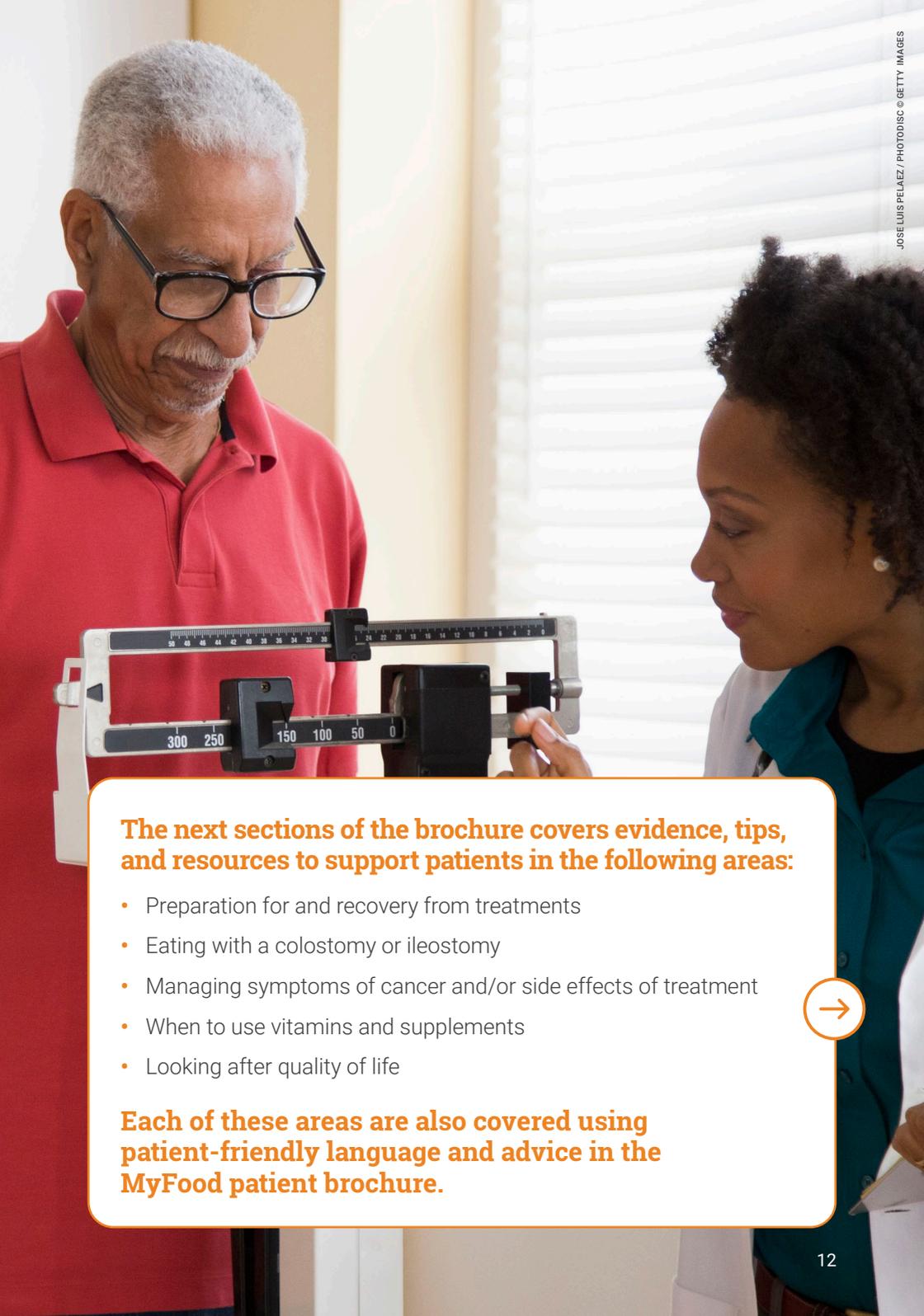
Cancer symptoms, treatments, and related procedures often make patients feel very unwell. For some, diet and nutrition may be the last thing they want to think about; while others will want to know exactly what they can do to keep as well as possible.

“How can diet and nutrition improve my GI cancer treatment experience?”

Is another important question your patients may frequently ask. Some patients want to be as informed as possible so that they can be empowered to make positive nutritional choices that may improve their cancer journey.

Health care professionals play an important role in talking about nutrition and diet with patients, as well as providing information about the most appropriate nutrients and foods for them. Resources like the MyFood brochure can help to support these discussions.

We should regularly review our patients’ nutritional needs during and after treatment, ensuring that they maintain a healthy weight. Conduct food and nutrition-based health assessments with patients at first contact and regularly thereafter, including weight and BMI measurement, serum albumin (especially before chemotherapy/surgery)⁸ and VAS score for appetite. Where relevant, we should also indicate where a nutrition or dietetics professional should become involved in care.

A healthcare professional, a woman with dark curly hair wearing a teal lab coat, is measuring the blood pressure of an elderly man with white hair and glasses wearing a red polo shirt. They are standing in front of a window with white blinds. The man is looking down at the blood pressure cuff on his arm. The woman is looking at the man's arm and the device.

The next sections of the brochure covers evidence, tips, and resources to support patients in the following areas:

- Preparation for and recovery from treatments
- Eating with a colostomy or ileostomy
- Managing symptoms of cancer and/or side effects of treatment
- When to use vitamins and supplements
- Looking after quality of life

Each of these areas are also covered using patient-friendly language and advice in the MyFood patient brochure.

Help patients to adapt their diet and understand what to expect before and after their treatment: Chemotherapy

Knowing what to expect before treatment is initiated can help patients to feel more in control and prepared for any potential side effects they may experience following treatment

Eating problems resulting from side effects following chemotherapy include:⁹

- Appetite loss
- Changes to sense of taste
- Constipation
- Diarrhea
- Nausea
- Sore mouth
- Sore throat
- Vomiting
- Weight gain
- Weight loss

Understanding your patient's lifestyle can help you to make appropriate recommendations

For example, if they live alone, they may want to stock their cupboards and freezer before their surgery or cook in advance and freeze foods.

Perhaps they can ask family and friends to support with cooking and shopping regardless of their living situation

Economic factors can also influence what they can and can't afford to buy

Before chemotherapy

The main advice you can offer your patients is to try to avoid losing weight by maintaining a nutritious and well-balanced diet. This will help patients to:

- Better tolerate their treatment
- Prevent nutritional deficiencies
- Reduce the risk of infection
- Recover from their treatment⁹

After chemotherapy

Advise patients to:

- Eat many different kinds of foods
- Include plenty of fruits and vegetables in their diet. These can be raw, cooked, or even juiced
- Eat wholegrains, whole wheat bread, oats, brown rice
- Eat small portions of lean meat and poultry without the skin and limit red meat intake
- Limit fat, sugar, salt, smoked or processed meats, and alcohol
- Alcohol should be avoided where possible or limited to 1 drink per day for women and 2 drinks for men⁹
- Inform you or another HCP as soon as possible if they find eating difficult or lose weight unintentionally

The MyFood patient brochure details dietary modifications to address some of the most common side effects that cause eating problems.

There is some evidence in small populations that short periods of fasting before, during and after chemotherapy is safe and can reduce chemotherapy-induced toxicities, improve the tolerance of chemotherapy and enhance certain QoL and illness perception domains.^{10,11,12} However, to date, fasting has only been tested in patients without malnutrition/cachexia or other comorbidities, such as diabetes, so this message should only be communicated to those appropriate.¹⁰ Close monitoring by a nutritionist would be recommended to prevent unacceptable weight loss.¹⁰

Help patients to adapt their diet and understand what to expect before and after their treatment: Surgery

Preoperative immune-enhancing nutrition in GI surgery can significantly reduce post-operative complications compared with standard nutrition¹³

Before Surgery

Evidence indicates that malnutrition is a modifiable risk factor for surgery, with nutritional deficiencies and repletion both impacting recovery.¹³ Advise patients about the importance of prehabilitation and advise them to maintain a healthy-well-balanced diet prior to surgery. If they are weak or underweight they may require a high-protein, high-calorie diet presurgery.

A few other simple steps they can take as part of their prehabilitation include:



Reduce or stop alcohol intake



Reduce/stop smoking



Increase activity levels



Avoid junk food, fried foods, and sugar

After Surgery

Advise patients to:

- Eat small, frequent meals with nourishing drinks in between, which may be more manageable than larger meals
- Eat meals and drinks that are high in calories and protein to meet daily requirements
- Fortify drinks, snacks and meals to make them more nutritious, i.e. by adding cream, butter, cheese, etc.¹⁴

Let your patients know that eating problems are likely to follow after surgery and it may be some time before eating returns to normal

Reassure your patients that it is very common to have eating problems after surgery. These may include:

- Early satiety
- Diarrhea
- Dumping syndrome
- Weight loss¹⁵

If your patients are struggling to achieve an adequate nutritional intake during their recovery phase, suggest meals and drinks that are high in calories and protein to ensure that they still meet their daily nutritional requirements.

The MyFood patient brochure provides some ideas on how to adapt a diet after surgery/eating problems that arise from surgery.

Further resources to share with patients:

Get Set 4 Surgery materials¹⁶ – simple prehabilitation guidance for patients.

Eating with a colostomy or ileostomy

After a colostomy or ileostomy patients should be advised to maintain a well-balanced diet to promote healing and to regain any weight lost before surgery.

Remind your patients they can enjoy eating a varied diet, with adequate fluid intake, after a colostomy procedure.¹⁷

It is difficult to provide absolute advice, since people react to different foods in different ways; although it is expected that most people with a colostomy will be able to eat a healthy, balanced diet, including all foods and drinks.¹⁷

You may want to share the following simple suggestions with your patients:¹⁷

- Aim to eat a varied, balanced diet of foods low in fat and moderate in fiber
- Try all foods and only avoid those that consistently cause unacceptable symptoms – some patients experience diarrhea or constipation, which may require dietary adaptation or other intervention (ie, laxatives), but otherwise colostomates can eat a balanced, healthy diet
- It may take some months for the stoma to settle, during which time they may experience symptoms like odor or gas
- To ensure adequate fluid intake to avoid dehydration
- To develop a regular pattern of eating for acceptable colostomy function.
- Gradually reintroduce fiber into the diet

Further resources to share with patient:

Dietary advice for people with a colostomy¹⁷ – St Mark's Hospital: a detailed guide to eating with a colostomy aimed at patients.

Remind your patients of the importance of maintaining a balanced, varied diet after an ileostomy.¹⁸

In the first few weeks, the ileostomy output will be quite liquid. Advise your patients to avoid foods that contain fiber in large quantities and to gradually re-introduce these in small quantities – well chewed – after 6 to 8 weeks. At this stage, encourage your patient to try more fruits and vegetables, which they may tolerate better if they take off the skin, remove the seeds or have them cooked so they are softer.¹⁸

Patients with high output ileostomies need to be carefully managed. They may need to be prescribed an oral rehydration solution to help prevent dehydration.¹⁸

You may want to share the following simple suggestions with your patients:¹⁸

- Aim to take a varied, well balanced diet
- Ensure an adequate fluid and salt intake to avoid dehydration
- To develop a regular pattern of eating for acceptable ileostomy function
- Try all foods and only avoid those that consistently cause unacceptable symptoms

Further resources to share with patient:

Healthy eating for people with an ileostomy¹⁸ – St Mark's Hospital: a detailed guide to eating with a ileostomy aimed at patients.

Managing symptoms of cancer and/or side effects of treatment

Certain dietary adaptations may help patients to manage cancer symptoms or side effects of treatment, some of which are particularly common in patients with GI cancers.

Here are some suggestions you can share with your patients if they are experiencing any of these common eating problems:



Diminished appetite

- Eat small, frequent portions with as much nourishment as possible
- Eat foods that release energy over time, like wholegrains
- Drink peppermint or ginger tea for relief from nausea
- Use food flavoring, contrasting temperatures, and different textures

Two-thirds of patients report taste disorders after chemotherapy, so there may be benefit to intensified nutritional counseling with taste and smell training to improve taste perception.¹⁹



Diarrhea/constipation

- Eat little and often
- Avoid spicy/fatty foods, caffeine, alcohol, nuts, and seeds
- Replace lost fluids by sipping water, sugar-free drinks, clear soups and broths
- For constipation, eat a high-fiber diet; wholegrains, fruit and vegetables, oats, seeds and nuts, with adequate fluid intake for constipation



Gas and bloating

- Avoid foods such as beans and pulses, broccoli, cabbage, sprouts, onions, fizzy drinks, and some artificial sweeteners
- Eat little and often, chewing foods well and sipping slowly
- Take time when eating to avoid swallowing too much air



Acid reflux

- Over-the-counter medications, including proton pump inhibitors or antacids
- Avoid eating large meals, lying down right after a meal, smoking, or wearing tight clothing
- Avoid alcohol, fizzy drinks, coffee or tea



Changing food preferences

- Cook when feeling good/well
- Eat favorite foods on the days they feel well
- Enjoy a treat once in a while and don't feel guilty

Early nutritional intervention can help to improve outcomes for patients with GI cancer,³ so they should be encouraged to contact an HCP as soon as they experience any eating complications.

Further resources to share with patients:

The MyFood patient brochure provides simple suggestions that you may want to share with your patients.

World Cancer Research Fund: Eating Well With Cancer²⁰ – a general guide to eating well with cancer, although not suitable for people who are eating very little, have lost a lot of weight unintentionally or receiving palliative care.

How to address patient concerns about when to use vitamins and supplements

It is important to remind patients of the primary aim to meet nutritional needs through diet, where possible, and that any supplements should be taken under the supervision of a health care professional.²¹

It is also important to highlight that there is no reliable evidence that dietary supplements can help to prevent, cure or control cancer.²¹ Regarding probiotics, these should also be used with caution during chemotherapy when the immune system may be weakened, since they contain live bacteria.²²

For patients with certain cancers, there may be additional benefit to some forms of supplementation:

- **Pancreatic enzymes** may be needed if there is a blockage in the pancreatic duct or removal of part of the pancreas – pancreatic enzyme supplements contain lipase, amylase and protease that help with the digestion of fat, carbohydrates, and proteins. **Insulin** may also be needed to regulate blood sugar. **Long term vitamin B12** given subcutaneously may also be required. Research into the benefits of vitamin D supplementation in pancreatic is ongoing but promising.²³
- For patients who have received stomach surgery, **extra calcium, vitamin D and iron** (normally absorbed in the stomach) may be recommended, as well as **vitamin B12 injections**.²⁴

Further resources to share with patients:

Vitamins and diet supplements²¹ – general information and guidance around dietary supplementation for patients with cancer.



Looking after patients' quality of life

The impact of poor nutrition goes beyond treatment outcomes, also impacting patients' quality of life and wellbeing.

How well patients do after chemotherapy has been shown to be connected to their social interaction with other patients during treatment; patients were more likely to survive for 5 years or more after chemotherapy if they interacted with other patients who also survived 5 years or more (during their chemotherapy).²⁵ Peer support during chemotherapy is valuable as it empowers patients to share tips and advice which can help to manage lifestyle changes.

If patients live alone or don't have a wide social network, they can still find enjoyment and pleasure in eating. Remind patients to cook when they're feeling good to keep that pleasure of cooking alive and that it's also okay to treat themselves to their favorite foods on the days they feel like eating.

Simple suggestions to support your patients may include:

Tips for eating out



Check menus and plan ahead when they eat out or with friends



Check the location of toilet facilities as soon as they arrive at a restaurant



Highlighting the importance of food safety when eating out, particularly for patients receiving chemotherapy

Tips for eating at home



Choose foods that look and smell good



Use marinades to improve the taste of meat and fish



Make foods sweeter if they are salty, bitter, or acidic, and add extra flavor to foods with herbs and sauces

Recommend the MyFood patient brochure to your patients. It provides some great tips for succeeding when eating alone or in a social situation.



Resources



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The SHAPE Steering Committee:

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- Claire Taylor, St Mark's Hospital, UK (oncology nurse)
- Klaus Meier, HKK Soltau, Germany (oncology specialist hospital pharmacist)
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Thank you to our partner in patient perspectives and insight – Digestive Cancers Europe (DICE) – and its members for their collaboration.

The MyFood brochure is part of the Support Harmonized Advances for better Patient Experience (SHAPE) initiative that is funded by an unrestricted grant from Servier.

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