



European Cancer
Patient Coalition

*Living well
during*

**CANCER
TREATMENT**

Patients' Stories



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The European Cancer Patient Coalition

ECPC Secretariat Rue Montoyer 40
 Tel: + 32 (0) 2 342 01 14 1000 Bruxelles
 Email: info@ecpc.org Belgium
www.ecpc.org

This is an Annex to our [Nutrition Booklet Living well during cancer treatment](#) published in 2018. For comments and /or inquiries please email: info@ecpc.org

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Contributors

Editors

Antonella Cardone, Director of ECPC

Paulina Gono, Senior Partnerships and Communications Manager

Aina Laura Errando Calleja, Partnerships and Communications Assistant

Patient testimonials

Chris Elkington, Head and Neck Cancer survivor

Menia Koukougiani, Founder of NGO KARKINAKI, Awareness for childhood and adolescent cancer and Board Member of the Pan-European Network for Care of Survivors after childhood and adolescence care (Pancare)

Jonathan Clark, Mantle Cell Lymphoma (in complete remission)

Petra Svobodová, Breast Cancer survivor

Andi Carlan, Colorectal Cancer survivor

The **Medical Nutrition International Industry** congratulates the ECPC for this collection of patients' stories on cancer and nutrition. One in three cancer patients are malnourished. Malnutrition leads to muscle loss, lower quality of life, reduced tolerance to chemotherapy, higher risk of complications infections and is associated with increased mortality. This collection of stories is a fantastic tool to inform patients and healthcare providers of the importance of detecting malnutrition at diagnosis and supporting patients with nutritional interventions early on during cancer treatment.



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INTRODUCTION

To capture patient's views, experience and perceptions towards nutrition and nutrition care throughout their cancer survival journeys is of vital importance. Patient voices are also crucial regarding informed service planning and for the provision of effective health care. Many hospitals/oncology centres are now increasingly aware of this and there are more and more opportunities for patients to participate and engage in their care.

While issues around the right nutrition and food choices seem like a high priority in many cancer patient's agendas, it is also known that throughout Europe, there is still a lack of uniform access to specialized nutrition care or to oncology dietetic services. A recent survey in Ireland, has shown that, for 89% of respondents, issues related to Nutrition and Nutrition Care were rated as 'very or extremely important', but less than half of the participants (39%) had accessed specialized oncology nutrition care (provided by a registered –dietitian/nutritionist). Likewise, 58% reported that their doctor or nurse only 'sometimes', 'rarely' or 'never' enquired about their dietary issues. Furthermore, 57% of those who did not get to see a specialist, mentioned that they felt the need for more support with diet. For the few that had access to specialized nutrition, 74% rated this advice as 'very or extremely helpful'.

This survey does seem to provide support that Nutrition and Nutrition Care do matter to cancer patients.

And there are many sound reasons for these patients' voices to be listened to.

Food embeds every dimension of one's life and current evidence shows that healthy eating and, a timely and adequate, nutrition support contributes to better oncology treatment - related outcomes and to an overall improvement in quality of life. In this context, it is also important that the patients have access to individualised nutrition care, that is evidence-based and tailored to meet their needs.

For more information on how to access specialized nutrition care in your country, please visit:

<http://www.efad.org/en-us/about-efad/membership/full-members/>

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THE EXPERT'S
VOICE!

Inside this frame you will find valuable information provided by experts in the field. The European Federation of the Associations of Dietitians (EFAD) has complemented our patient stories with relevant and valuable data that can help cancer patients and cancer survivors to improve their nutrition habits and quality of life.

★
Patients' Stories

CHRIS

 United Kingdom

Having had no health problems throughout my previous 58 years, it came as a major shock to be diagnosed with a type of head and neck cancer called chondro sarcoma, which is a type of bone cancer. The tumour was centrally positioned in my jaw around 2.5 centimetres below my bottom lip.

Due to a late diagnosis, the only option was to remove the jaw in its entirety and the operation took almost twelve hours. I had been well prepared by my surgeon at a local hospital, who had explained, in great detail, the possibilities of an inability to eat or speak for many months, if ever. Nevertheless, there was no option other than to go ahead with the operation and deal with the after effects as they arrived.

'My wife liquidised and mashed a variety of foods with a close eye on the nutritional value'

I had a few weeks prior to the surgery to get as fit as possible to make sure I survived the operation. During this period, my wife and I prepared ourselves for alternative ways of communicating and discussed eating options.

After surgery, I was fed through a tube through my nose until such time as I was able to take sloppy foods. Despite this, I lost weight and muscle mass whilst in hospital. Living in a rural location over 150 km from the hospital, I had to rely on my local doctor and district nurses for day to day advice and my wife's imaginative cooking skills.

I was prescribed vitamin drinks; and my wife liquidised and mashed a variety of foods with a close eye on the nutritional value and aesthetic appearance to encourage me to ingest food. I enjoyed vegetables, fruit and starches such as potatoes and rice, all prepared for easy swallowing. I developed a system of using my tongue as a lower jaw, being able to crush food against my upper teeth.

'The correct quantity, quality and balance of food had been imperative in my rehabilitation'

Fourteen months after my operation, I was supplied with a bridge containing eleven teeth fixed to my new jaw. This created a new chapter, I now had the ability to chew food properly and to bite. Whilst it took a short period of time to get used to my new teeth, my options had now expanded to the extent that I soon became able to eat almost anything. Whilst I have no feeling below my mouth, which occasionally results in spillage of food or dribbling from the corners of my mouth, I have no hesitation in eating in public. I keep a small mirror with me at all times to ensure there are no embarrassing events.

Throughout the whole episode, the correct quantity, quality and balance of food had been imperative in my rehabilitation.



Chris was diagnosed with a type of Head and Neck Cancer called chondro sarcoma, a type of bone cancer.

WHAT DOES THE EXPERT THINK?

"An ounce of prevention..." does seem to have great impact when patients are undergoing extensive treatments, especially surgical interventions. It is important to find out next to your clinical team, how and what, one might do to better prepare for the treatment challenges ahead. Emergent evidence has been showing that the adoption of a healthy lifestyle (encouraging balanced food choices, and privileging fresh, seasonal plant-based produces, alongside adequate physical activity) may facilitate an improvement in clinical outcomes and quality of life. This story asserts the importance of nutrition and of a healthy varied diet, following treatments during the rehabilitation.

From our booklet 'Living well during cancer treatment' ...

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

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

Read [the booklet](#) to learn more.



Chris, Head and Neck Cancer survivor.

MENIA

 Greece

Nutrition is an important factor for the health of all children, but it is especially important for children under cancer treatment. And what do children with cancer need? They need nutrients.

My name is Menia Koukougiani, Founder and Manager of NGO KARKINAKI, Awareness for Childhood and Adolescent Cancer and I am also Board Member of the Pan-European Network for Care of Survivors after childhood and adolescent cancer (Pancare).

'I was very worried about her daily nutrition as I wasn't given a special diet for a little kid'

My kid was 3 years old when she was diagnosed with cancer. Because of her treatment she couldn't follow the nutrition programme for a 3-year-old healthy child. She couldn't even bare the smell of milk. She never drank milk from that age! I was very worried about her daily nutrition, as I wasn't given a special daily diet for a little kid, only some general instructions such as "avoid sugar and salt".

She was under chemotherapy, she had long periods of time that she didn't want to eat anything, she had long periods that she wanted to eat everything!

Menia Koukougiani,
founder of NGO
KARKINAKI,
Awareness for childhood
and adolescent cancer.



Children with cancer need protein, carbohydrates, fat, water, vitamins and minerals.

Childhood cancer survivor rates are increasing as a result of advances in treatment and supportive care. This positive outcome is tempered by the recognition of a high burden of chronic health conditions. They face increased risks of developing secondary cancers and other diseases such as cardiovascular disease, osteoporosis and diabetes.

Unfortunately, parents/caregivers are not familiar with healthy eating habits and exercise guidelines for childhood cancer survivors, neither during the treatment nor after it, despite their essential role in developing effective interventions to improve survivors' health and well-being.

I didn't know if I could give my kid fresh fruits, fresh juices, vegetables. Nurses informed me that I should sterilize the fresh fruits, the fresh juices were not allowed, I had to forget strawberries and grapes... I really needed a specialized diary plan for my kid.

'We need improvements in educating and encouraging parents and survivors to adapt healthier habits'

The most important challenge was that I had to find out by myself the right nutrition guidelines for my kid, not only when she was hospitalized but at any stage of her physical development. I had to consider her body mass and her height. At the same time, she was just a kid, a kid that couldn't walk, run, play with other kids...

Nutrition is the key in all stages of treatment, from another aspect too: the psychological aspect of any patient under cancer treatment. Nutrition operates as "comfort food", as a way to socialize, as a way to be with each other. But the most important challenge for me, as a parent, is to teach my kid to follow healthy eating habits for the rest of her life.

We need improvements in educating and encouraging parents and survivors to adapt healthier habits and lifestyle actions to prevent obesity and morbidity.

Healthier eating habits and physical activity contribute to an efficient management of hypertension and dyslipidemia, while educational programs should be inserted to the therapeutic protocol of cancer. Medical rehabilitation programmes should include physical activity and empower little patients to exercise and adapt healthier nutrition habits in their everyday program.

THE EXPERT SAYS...

This report highlights the lack of support and clear health education messages adapted to each step of the cancer and survivorship journey. Nutrition and health education should undoubtedly belong in a proactive care model. But, more often, than not, cancer survivors have to procure and gather relevant information on their own. For long, it has been known that certain risk factors can overlap, namely being common in both cancer and other diseases, for example, cardiovascular disease (CVD). This, in conjunction with a certain degree of long-term toxicity associated with several cancer treatments, might significantly increase the risk of cancer survivors developing CVD and other chronic diseases. It is important to get to know and understand what type of healthcare services are available to support you. Robust and evidence-based information can help with the reduction of these common risk factors, mitigate treatment-related long-term complications and promote lifestyle interventions for overall health in cancer survivors.

JONATHAN

United Kingdom & the Netherlands

My name is Jonathan Clark. I was diagnosed with Mantle Cell Lymphoma in 2014.

I had chemotherapy and an autologous stem cell transplant. Unfortunately, my cancer came back in 2017 and I became severely ill very quickly. I was lucky to be able to join a clinical trial for CAR-T cell therapy in 2018 and I have been in complete metabolic remission ever since. Amazing.

I find that living within cancer and cancer treatment is like a rollercoaster with many ups and downs. It is draining both physically and mentally. Nutrition too was a story of good days and bad days. I struggled to cope with the nausea and the weird taste-altering effects of chemotherapy, but rejoiced when my coffee stopped tasting like mud.

'I find that living within cancer and cancer treatment is like a rollercoaster with many ups and downs'

The nightmare of losing my appetite yet knowing that I had to eat to stay strong. The euphoria at cooking myself an omelette for the first time since treatment.

When I was recovering from the stem cell transplant I became obsessed with eating enough. I had lost a lot of weight during the treatment and I knew I had to build myself up again. I was struggling with a nasty e-coli infection so keeping food down was a challenge.

I was in a real mess, convinced my inability to eat would jeopardise my recovery. Until one day when a wonderful doctor realised what was going on and simply told me to

'I had lost a lot of weight during the treatment and I knew I had to build myself up again'



Jonathan Clark was diagnosed with Mantle Cell Lymphoma in 2014.

stop worrying! I should just eat what I could (every little helps!) and if necessary they would set up tube feeding.

Simple perhaps obvious, advice but life changing for me at that moment.

Riding the cancer rollercoaster, it is all too easy to forget that food is more than just nutrition, at least it is for me. I am a huge foodie - I love to cook and to eat in great restaurants.

Food lifts my mood, brings a smile to my face. If I had a wish it would be that there is a kitchen on every cancer ward in hospitals where patients can (learn to) cook. I think of it a physiotherapy for the soul.

'If I had a wish it would be that there is a kitchen on every cancer ward in hospitals where patients can cook. I think of it a physiotherapy for the soul.'

EXPERT'S ADVICE...

Cooking skills and the confidence on how to use them, have always been a great asset to have, as it may help to maintain a healthy diet. Home cooked meals tend to be healthier because whoever is cooking can tailor the recipe to their needs and has control on quantities and which ingredients are included. An overreliance on pre-cooked highly processed meals has been related to an increase risk of developing excess body weight and chronic diseases.

PETRA

Czech Republic

I was satisfied with my life, I had a good job, and I had just found a new boyfriend. But then all of a sudden breast cancer entered my life. I fell ill at the age of 29. I felt a small lump in my breast, so I went to my gynaecologist, and he sent me to the senology department to be examined. About a week after the biopsy, the results came back showing that I had an invasive ductal breast carcinoma.

At first I just thought it was the end, and that there was no way I could cope. But then I started to see things more clearly and realised that I had to pull myself together and not just sit there weeping in the corner.

The first thing I had to face was an operation to remove the nidus of the cancer along with several of the closest lymph nodes in the armpit area. About one month after the operation, I started my first chemotherapy session, of which I had a total of sixteen.

'I had totally lost my appetite, the smell of food made me nauseous'

The chemotherapy was probably the toughest time for me. I searched for information about how to help the body regenerate properly after each session, and mainly what to eat and not to eat. But I was just confused by it all, because some people suggested one thing, and others rebutted it. In hospital I heard several conversations between patients on this topic. Sugar is bad. Sugar is OK, but you shouldn't eat meat. I could continue. I discussed the whole matter of nutrition with my treating doctor, and he recommended that during chemotherapy I shouldn't over think it and, as long as there are no problems, that I should eat everything I fancy.



Petra was diagnosed with breast cancer at the age of 29.

After about the third chemotherapy session, my ideas and questions about what to eat or not to eat transformed into a need to simply eat something. I had totally lost my appetite, just the smell of food made me nauseous, and I was losing strength. At that time I didn't discuss it much with the doctor, because I knew that it happens with this kind of treatment. My partner started to cook different types of food, and we tried to find out if some smells wouldn't matter so much and I would be able to eat at least something.

'My partner developed a passion for cooking, I entered him for the competition'

WHERE TO
LOOK FOR
INFORMATION?

Fake news and misinformation surrounding nutrition and food choices are not new. Miracle ingredients, fad diets, super-foods and celebrity opinions on what and how to eat, may put cancer patients and survivors at a greater risk of malnutrition. Although many of these claims have no sound scientific grounding or are extrapolated from experimental conditions, they do seem to spread very quickly amongst the public. Worryingly, there is no telling how these might influence clinical outcomes. On the other hand, it is now unquestionable, that malnutrition does have a negative effect both in the potential treatment's benefits and on patient's quality of life. Avoid these unnecessary risks, and always consult with your clinical team before deciding to try other approaches.



Petra with her partner, winner of a well-known cooking competition.

It gradually started to work, and after some weeks I could regularly eat the fine-tuned food that he cooked for me, and I successfully completed the chemotherapy series. My partner kept on cooking and started to spend a lot of time in the kitchen, where he developed a passion for cooking. So I couldn't resist the temptation to enter him for the competition of a well-known cooking competition, which in the end he quite deservedly won. I know this was a dream come true for him, and I think that in this case the old saying "It's an ill wind that blows no good" really does make sense.

ANDI

 Romania

My name is Andi Carlan and I am a colorectal cancer survivor. The first thing I found out when starting the chemotherapy was that there is no specific diet for people suffering from cancer.

A healthy diet, recommended for any ill or healthy human being is a mixed one, with lots of fruits, vegetables, as natural as possible, with milk and cheese, with fish, white and red meat, etc. It should also include a small amount of carbs and sugars as well as little to no alcohol.

Everyone knows that the tumour cells are fed with oxygen and glucose but so are your brain and hearth. If one completely takes sugars out of their diet, both the hearth and brain will suffer, while the malign cells will find a way to synthesize glucose from other sources.

'The first thing I found out when starting the chemotherapy was that there is no specific diet for people suffering from cancer'

The problem I faced in Romania – where I come from – is that there is no nutritionist with oncological competencies. Oncologists are giving brief advice regarding nutrition and so are the regular dieticians. Most professionals here seem to be scared about giving a cancer patient a straightforward diet. Therefore, immediately after my surgery I underwent in June 2019, the medical recommendation was 'no sugar' and later 'no red meat'.

Once I had already started the chemotherapy, back in July 2019, I was recommended to follow a normal diet that included red meat in order to help the body resist chemotherapy. In fact, during my treatment I received mixed recommendations from various experts: no meat/little meat, no alcohol/little alcohol, no sugar/little sugar, no milk & diaries/normal amounts of milk & diaries, vegan/not vegan and so on.



Andi Carlan, Colorectal Cancer survivor.

In the end, the only recommendations I followed and still do are: no preservatives, no junk food no semi-prepared food (nothing with a plastic foil on top – hummus, eggplant salad etc.), no processed meat (salami, sausages etc.) and little to no processed food. I trusted my oncologist and my voluntary cancer patient navigator whose nutrition recommendations made the most sense to me.

I honestly have not found any useful information in patient groups because everything was chaotic. Everyone had their own philosophy and beliefs, and they were constantly arguing about other people's choices. However, that is the same experience I encountered when speaking about diet with other cancer survivors. For example, some of them went full-vegan and others ate normally. This fact made it even harder for me to make up my mind.

After I finished chemotherapy, I tried to keep a healthy and balanced diet as much as possible but without completely changing my lifestyle. Right now, I have a regular, balanced diet, with fruits, vegetables, diaries, meat (mostly white but red too, in smaller amounts), carbs, low intake of sugars, sometimes sweeteners, coffee and occasionally one glass of red wine (no beer, no strong alcohol like vodka or whisky). For me the nutrition and cancer remains a confusing topic, also now when I am cured, it makes me doubt almost everything I eat.

THE EXPERT ADDS THAT...

Unfortunately, the availability of specialized oncology nutrition services provision still varies greatly in Europe. As a simple rule... regarding any food or nutrition information one might encounter, if it sounds too good to be true!- maybe side with caution. Prudent, balanced and varied food choices are always the best option. Thinking of ways to increase the amount of fresh, seasonal and colourful plant-based foods in every meal, is a great place to start and will do just that!

For advice on diet before, during and after cancer visit the website of the [Irish Nutrition and Dietetic Institute](#) or the [Irish Cancer Nutrition website](#). You can also contact [your local dietetic association](#).

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This Document provides general information regarding nutrition and cancer. It is not intended to offer medical advice or replace advice given by your healthcare team. It is important to address all medical questions and concerns about your care with your healthcare team.

