



IT'S YOUR CONSULTATION!

**How to communicate
effectively with healthcare
professionals?**

ECL Patient
Guide 2019

ECL  **PATIENT
SUPPORT
WORKING GROUP**



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ABOUT THE ECL PATIENT SUPPORT WORKING GROUP

Since 2007, the ECL Patient Support Working Group (PSWG) connects cancer care experts who share knowledge and work together on developing best practice guides and informational materials to raise awareness and improve the quality of cancer care in Europe. The PSWG focuses on a wide range of matters, including access to insurance and financial services, return to work, caregiver support, sexuality and relationships issues, cancer rehabilitation and palliative care. PSWG members strive to make the patient voice heard in national and European decision-making.

AUTHORS OF THIS GUIDE:

Alrik Meesen, Policy Officer – Quality of Life Department, Dutch Cancer Society
Hans Neefs, Expert on Cancer Care and Treatment, Stand Up to Cancer Flanders
Monick Leal, Psychologist, Portuguese League Against Cancer
Maria Ioannidou, Director, Cyprus Anti-Cancer Society
Sigrún Lillie Magnúsdóttir, Manager of Counselling and Support Centre, Icelandic Cancer Society
Imre Gaál, Vice President, Hungarian League Against Cancer
Dervilia Kernaghan, Head of Patient Care Services, Cancer Focus Northern Ireland

THE GUIDE WAS REVIEWED BY THE FOLLOWING ORGANISATIONS:

European Cancer Patients Coalition (ECPC)
European Oncology Nursing Society (EONS)
European Patients' Forum (EPF)
European Society of Radiology and Oncology (ESTRO)
League Against Cancer Slovakia
Swiss Cancer League

COORDINATED BY:

Anna Prokůpková, Association of European Cancer Leagues (ECL)

EDITED BY:

Anna Prokůpková, Association of European Cancer Leagues (ECL)
Ginevra Papi, Association of European Cancer Leagues (ECL)

DESIGNED BY:

Porter Novelli

Disclaimer: Opinions and recommendations expressed in this guide represent the views of the ECL Patient Support Working Group (PSWG) as a whole, and do not necessarily reflect opinions of individual PSWG members and/or their respective organisations. Recommendations are based on best practices identified and agreed by the PSWG, and should be read within the context of the organisation of care of respective European countries.

ENDORSEMENTS



In the age of ever-increasing time pressure on healthcare workforce, smooth communication between patients, nurses and clinicians is crucial to safeguard trust and deliver high standards of cancer care. EONS works vigorously to ensure nurses contribute to the humanisation of patient care. We are happy to work together with ECL to ensure both professionals and patients are playing an active role in improving the relationship between the two.

Rebecca Verity, Chair of Education Working Group, European Oncology Nursing Society (EONS)



Shared decision-making is a cornerstone of patient empowerment. The relationship between patient and professional is delicate and should be based on mutual respect, openness and honesty when it comes to, for example, weighing the pros and cons of different treatment options. The ECL guide is a great tool to empower patients, but also professionals, to have more meaningful conversations.

Kaisa Immonen, Director of Policy, European Patients' Forum (EPF)



At ECPC we place the patient at the centre of the healthcare system and aim to empower them in their journey through the complexities of their cancer diagnosis and treatment. This guide upholds those values through providing high quality information and advice, and ensuring that concerns are addressed, with the patient's needs at the forefront. We gladly welcome this and are eager to see steps being taken to enhance an effective communication system for both patients and healthcare professionals.

Antonella Cardone, Director, European Cancer Patient Coalition (ECPC)

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1. INTRODUCTION

The patient-clinician relationship is the keystone of cancer care. However, interactions between patients and healthcare professionals (hereafter HCPs) can sometimes be challenging. So, how can HCPs provide high quality information to their patients within the often rigid time frames? And, how can patients make sure their concerns are communicated effectively and properly addressed during medical consultations?

In January 2018, the Association of European Cancer Leagues (ECL) surveyed its members about common challenges and possible solutions for improving communication between HCPs and patients. 19 European cancer societies answered the survey and the results served as a basis for creating this guide. Cancer societies found that patients across Europe often do not know what to expect, what kind of information they should receive or how to prepare for medical consultations. The survey also found discrepancies between existing national and local guidelines in different countries across Europe. Consequently, 95% of respondents called for the development of a European guide that would help patients improve communication with the wide range of HCPs (including oncologists, nurses, radiation therapists, supportive and palliative care specialists) involved in cancer diagnosis, treatment and care.

Throughout Europe, regardless of whether the patient was in a lower- or higher-income country, cancer leagues identified similar challenges, including:

- › patients feeling their views were disregarded or not taken seriously;
- › patients displaying anxiety and feeling nervous during consultations;
- › patients not having enough time to thoroughly discuss their situation with HCPs; and
- › patients lacking clear, consistent information and advice throughout their care pathways.

To address the issues stated above, the following solutions were suggested by survey respondents:

- › bringing a pre-drafted list of questions to the consultation;
- › taking a family member and/or a friend to the consultation; and
- › creating patient-friendly, decision aids (both print and multimedia materials) that present focused information about cancer, treatment options and their outcomes.

HOW TO USE THIS GUIDE?

While the leagues also discussed how healthcare professionals can enact patient-centered communication by engaging in active listening, expressing empathy and exploring the patient's feelings, ideas and concerns about treatment options, this guide focuses on how patients themselves can ensure to receive sufficient and clear information from HCPs.

Successful treatment and care is a two way process where the attitude of both the patient and the HCP plays an important role. This guide is primarily aimed at patients. However, it can also be useful for patient organisations, cancer leagues and healthcare professionals. It explores the key communication challenges between HCPs and patients, and describes the essential information patients should always receive.

This guide offers insights on what to expect and what to ask within the limited time spent with their HCPs. It also outlines the roles of different oncology professionals and offers suggestions and sample questions that patients can use during medical consultations.

Due to cultural differences and varying practices across European healthcare services, users of this guide are welcomed to adapt it to their local contexts.¹

¹ This guide is created in respect to the patients' right to information, as defined in the national legislation of European countries.

2. HOW CAN PATIENTS GET THE MOST OUT OF THEIR MEDICAL CONSULTATIONS?

Although brief, consultations are an essential part of providing care to cancer patients. Consultations help patients understand the nature and the complex management of their illness.

Effective communication during consultations form the foundation for a positive patient-clinician relationship, leading to greater patient satisfaction. In the patient's eyes, in fact, the ability to communicate well forms a major component of a provider's clinical competence. For HCPs, the ability to communicate effectively can contribute significantly to improved patient compliance and outcomes and aid trust building.

Good communication between the two parties is integral to delivering high-quality care. However, some patients may hesitate to ask questions or not ask the right questions because they have no way of knowing what to ask.

Below, we explore the most common issues patients regularly face during consultations. For each issue, the guide presents possible solutions together with a quote from a patient or a caregiver related to the specific situation. All quotes have been extrapolated and translated from the results of a campaign held by Stand Up to Cancer Flanders.²

2 Neefs, H. et al. 'Slechtnieuwsgesprekken: aanbevelingen voor een betere communicatie met de kankerpatiënt en zijn naasten' [Delivering bad news: recommendations for a better communication with the cancer patient and his informal caregivers]. Vlaamse Liga tegen Kanker, 2014. (see https://www.komoptegenkanker.be/sites/default/files/media/2018-10/slechtnieuwsgesprekken_def_2.pdf)

TIME CONSTRAINTS

HCPs experience significant time pressure during their consultations, which can have a negative impact on the quality of their communication with patients. Through their non-verbal language (e.g., looking at the watch, skipping questions, standing instead of sitting, leaving the office door open), HCPs may unintentionally make patients uncomfortable, hesitant to ask questions and unable to properly express your feelings. When questions remain unanswered, delays occur and additional time will have to be spent in future appointments. As a patient, you have the right to be heard and express your feelings and concerns. Therefore, asking for an additional consultation or an appointment with a specialist is the best approach.



"10 minutes after my mother had heard the bad news of a cancer diagnosis, we were already standing outside the doctor's office. We did not even have the chance to let it sink in. We stood there in an overcrowded waiting room, without even a chair to sit on."



"My wife got bad news from her doctor. When the consultation ended, the doctor suggested that she stuck around in the waiting room until he had seen the next patient. Then, he would answer any additional questions that came up after the consultation. In this way, she got time to recover from the bad news and think about the questions she still had in her mind."

PRIVACY ISSUES

Much of the communication between HCPs and patients is personal. HCPs should ensure that the privacy of patients is respected at all times during consultations. In some cases, HCPs discuss their patients' sensitive issues in corridors, waiting rooms, hallways and other open spaces. This practice, which often occurs due to tiredness, stress and lack of time or awareness, may hinder you from asking questions and expressing your concerns and needs. If this happens, you should remind your HCPs about your need of, and right to, privacy and dignity by asking for a private conversation in an office or an empty room.



"Once, we were in the oncologist's office, he left the door open. All the patients in the waiting room could hear every word he said."



"When my phone rings, I end the call before my patient's eyes. In this way, I give him/her the message that s/he is the only person that matters in that moment."

UNCLEAR AND CONFLICTING INFORMATION

As a patient, you have the right to receive clear verbal and written information about your health condition, including diagnosis, available treatments, their side effects and available supportive services.

However, patients often feel that the use of medical jargon and the quick delivery of information makes it difficult for them and their carers to grasp and process adequately. HCPs may also experience difficulties in breaking bad news and creating the appropriate balance between hope and truthfulness. For this reason, it is important that you have the confidence to interrupt the HCPs and ask them to clarify or repeat what they have just said so that you can process the information at your own pace.

HCPs can provide you with more details about the different types of treatments and help you decide the most appropriate option for your situation. You should take the time you need to understand and absorb your situation as well as carefully weigh the benefits of each treatment option against the possible risks and side effects. Considering your values, lifestyle and personal priorities whilst making decisions, will increase your chance of being satisfied with the choice you make. Even if you are more comfortable asking your doctor to decide on your treatment, the information and knowledge you have acquired will empower you. Conversely, if you disagree with your doctor's recommended treatment plan, you should be the one making the final decision. Ultimately, your treatment is your decision.



"My doctor never mentioned the word 'cancer' throughout the consultations till I asked him what he meant by 'lump'. He only said: 'uumhh, yes', so I asked him straightforwardly: Are you telling me that I have cancer? He then said that it was probably skin cancer..."



"The doctor showed me the scans to better explain the problem. He carefully explained that it could be a malignant tumour, but that it was not certain yet. The doctor took the time to discuss all aspects, next steps as well as possible treatment options - if it turned out to be malignant."

EMPATHIC ATTITUDE

In addition to respecting patients' rights, HCPs should also demonstrate empathy, compassion, caring, and concern. These characteristics are essential to aid relationship and trust building and understand your needs. HCPs should put themselves in your shoes, use appropriate non-verbal language when communicating bad news, taking your concerns and questions seriously, and taking enough time to discuss options and solutions together. An empathic attitude is also necessary to facilitate your inclusion in shared decision-making with regards to treatment options and disease management. It is your right to ask for a second opinion or a consultation with a different HCPs, especially when your HCPs do not inspire you confidence or have not managed to establish a condition of rapport with you.



“The doctor said: ‘yes, you have cancer and it doesn’t look good. If it is a lymphoma, you have a 70% chance of survival. If it is a carcinoma, 50%’. I got really upset and said to the doctor that I did not feel well. He simply replied that my reaction was normal and he left the room. The only thing I remember is that I was lying in my room for a long time and nobody came to look after me.”



“The doctor entered the room and took a seat close to my friend. He was very calm and asked if my friend was in a lot of pain. Then, he communicated the diagnosis, described the treatment and advised us not to search for information on the Internet. The doctor was very empathetic and nice. He answered all our questions and realised that it was a lot of information we had to deal with.”

PATIENTS’ EMOTIONS

While emotions can be powerful motivators, they also impact negatively on your ability to think clearly. Patients frequently experience difficulties in coping with their diagnosis, digesting information and expressing their needs when overcome by emotions. You might be very nervous when entering the doctor’s office (e.g., due to a fear of relapse), feel embarrassed to address some issues (e.g., sexual problems after cancer therapy) or affected by pain. Moreover, due to your state of mind, HCPs might withhold important information from you to not further upset you. That is why, you should take a second person with you to consultations for emotional support and to help you communicating your wishes or making decisions.

If you are still trying to process your diagnosis, it is okay to wait before booking a consultation and exploring your treatment options. Remember that taking a bit of time to adjust to this life-changing event and re-evaluate priorities and life goals is unlikely going to alter the outcome of your treatment.

HCPs should be attentive to your emotions and communications' needs. They should check whether you need any additional support to understand the given information, including written and visual information aids.



“At the consultation, we finally managed to open up about our sexual problems and related feelings of frustration and shame. The doctors explained that what we were experiencing was a frequent issue among cancer patients and that it made them uneasy to mention this issue to their patients. I felt both relieved and angry – if the doctors had mentioned sexual side effects earlier, we would not have wasted so much time been so worried and frustrated.”



“When you talk to the patient, it is important to articulate what you see when he gets emotional. You can for example say you have the impression that the patient looks very angry and then he will admit you are right. This is the way to address emotions during a consultation.”

Patients are increasingly included in shared decision-making and disease management. For this reason, it is essential that you prepare well in advance of your consultations. So, what can you do to overcome the key challenges outlined above?

ASK TO HAVE YOUR CONSULTATION WITH THE HCP IN A PRIVATE ROOM.

You have the right to expect your privacy and dignity to be respected when receiving health care and to expect HCPs to respect confidentiality by having your private consultation in empty, enclosed spaces.

PREPARE AND WRITE DOWN A LIST OF QUESTIONS TO BE ASKED DURING YOUR CONSULTATION.

In order to be as prepared for your consultation as possible, we advise you to draw up a list of questions you definitely want to have answered. Write them down and take the list with you to the consultation. During the consultation, make sure to go through the questions you deem to be the most important first and to get satisfactory answers to all of them. At the end of this guide, you will find sample questions you can start with.



“What I really appreciated was that the doctor gave me a new appointment two days after I got bad news. This second appointment was very important to me – I could think about what was said and prepare my questions in advance. I felt that she considered my problem important enough to spend extra time on it.”

RECORD YOUR CONSULTATION WITH THE HCP.

Ask the doctor if you can record the conversation on your smartphone. This way you can go over key issues and playback critical information without missing anything. You should play the recording back at a later time and discuss it with your loved ones and the person who accompanied you to the appointment. Many expert physicians have endorsed the idea of recording the discussion at appointments, so do not be afraid to ask.

DO NOT HESITATE TO ASK QUESTIONS IF YOU DO NOT UNDERSTAND WHAT YOUR DOCTOR IS SAYING.

Ask your doctor to repeat what they say and to give further explanations, if needed.

BRING A RELATIVE, FRIEND, PARTNER, CARER OR ADVOCATE TO THE CONSULTATION.

A consultation can be emotionally very hard for you to process. The quantity of information is often overwhelming. When you do ask questions, the answers can be delivered so quickly that you do not remember everything the HCP said. To address this problem, you should bring a family member or a friend with you, so they can ask questions you did not think of or are afraid to ask. With two people, it is also easier to remember all the information you get from the HCP.



“My partner was called to discuss the results of the biopsy. My surgeon had already told me that I had cancer. Together with my partner, I again heard the diagnosis but when we arrived home, I barely knew which cancer I had not to mention the more specific details that were told. At that point, I realised what patients mean when they say that the world stops turning when you get bad news and you don’t take in any information given to you.”

COLLECT INFORMATION LEAFLETS AND FACTSHEETS AT THE HOSPITAL AND SEARCH FOR ADDITIONAL INFORMATION ON PROPOSED SOURCES ONLINE

Hospitals and care centres regularly stock and offer leaflets with reliable information to patients which they can take home and refer to when they are uncertain about specific aspects which were discussed during the consultation.

A lot of information is available online, but reliable information can be difficult to find. Information on the Internet may be too general or not relevant to your specific situation. Although websites, forums and online magazines can serve as useful sources of information, you should always be aware of the risk of coming across misguided and misleading, yet compelling, information which is not based on strong, science-based facts. You should ask your HCP which sources of information are most appropriate for your case, look for information on websites of trustworthy organisations and check the sources of the articles you read.

ASK FOR A SECOND OPINION IF YOU FEEL UNCOMFORTABLE WITH THE DIAGNOSIS OR PROPOSED TREATMENT PLAN

Many patients are reluctant to seek a second opinion, as they do not want to come across as difficult and distrustful or because they feel a sense of urgency to get into treatment as soon as possible. Studies have shown that a high proportion of patients and caregivers are concerned that asking their doctor about a second opinion will create an uncomfortable relationship with that doctor, which may negatively affect their medical care.

Other patients may be confused by the complexity of the healthcare system, and are too overwhelmed by their diagnosis, too intimidated, or just not aware of their right to ask for a second opinion.

Doctors are usually happy to help patients arrange a second opinion and some may even recommend it to you. You should definitely think about getting a second opinion and discussing it with the doctor who diagnosed you. A second opinion provides you and your HCPs with either confirmation of their diagnosis and treatment, more details about their diagnosis and treatment options or recommendations for alternative diagnoses and treatment plans. Your doctor may have suggestions or referrals for a second opinion.

If your doctor does not have recommendations, you should seek for a second opinion at a different medical institution. If your doctor responds negatively to the idea of a second opinion, you may want to reconsider whether this is the doctor with whom you want to work throughout your disease pathway.

Here is a list of situations where a second opinion may be particularly important:

- › You have a rare, unusual, terminal or incurable cancer;
- › You have multiple chronic conditions and needs;
- › You feel uncomfortable with your doctor, the diagnosis or you need confirmation;
- › Your health insurance requires it;
- › You want the medical opinion of a specialist for your type of cancer;
- › The treatment offered have side effects or risks that you find unacceptable;
- › The treatment options will result in unacceptable or unreasonable demands on your life and your family;
- › Your doctor's treatment goals are different from your own;
- › You are interested in clinical trials or alternative therapies;
- › Your cancer is not responding to your current treatment.

3. HOW CAN PATIENTS MAKE USE AND COLLABORATE EFFECTIVELY WITH HCPS?

An essential component of high quality cancer care is good teamwork. Many different types of doctors (e.g., medical oncologists, radiation oncologists, surgeons, hematologists, specialists treating specific organs) and other healthcare professionals (e.g., nurses, psychologists, social workers, general practitioners) might be involved in your treatment. For patients, it can be confusing to talk separately to different types of HCPs with different professional expertise and backgrounds, or to know which issues should be discussed with whom.

Some HCPs may be too focused on their own opinions and specific expertise at the expense of looking at the bigger picture. In addition, their communication with other team members about your case may be infrequent and incomplete. Therefore, we advise you to raise specific issues and questions with the relevant HCP. If you are unsure about who is the best person to answer particular questions, ask any of your HCPs to direct you towards an appropriate colleague.

MEDICAL TREATMENT



CANCER SPECIALIST

A cancer specialist is a medical doctor who is specialised in diagnosing and treating a specific type of cancer. Cancer specialists focus on diagnosis and treatment of a particular organ or body system, a specific patient population, or a particular procedure and include medical oncologists, radiotherapists, surgeons, hematologists, urologists, gynaecologists and gastroenterologists.

A cancer specialist is also a care coordinator who works as part of a wider team of medical, nursing, psychosocial and other healthcare professionals, dedicated to the care and well-being of patients. They not only prescribe chemotherapy, radiotherapy or other treatments to control tumours but are also committed to a holistic approach to cancer care, helping patients with cancer to live as long and as comfortably as possible.

Giving clear information about your diagnosis and advice about the treatment options is certainly a large part of the role of a cancer specialist. The role of a cancer specialist also includes explaining the side effects of cancer treatments, paying attention to your quality of life and recognising possible psychosocial issues you may experience.

A cancer specialist can be a powerful source of knowledge, guidance and personal support for you and your family, and can help guide you in decision-making about potential treatment options. They should provide full information on diagnosis, different treatment options, and explore your goals, wishes and expectations in order to make shared decisions on your treatment and care. Do not hesitate to ask them any questions about your diagnosis, treatment and side-effects.



Oncology nurses have specific expertise in the management of side effects and complications of cancer treatments. They can be a wonderful source of support, guidance and information along your disease pathway, from the diagnosis to the end of treatment and even after treatment ('survivorship care'). Working alongside cancer specialists, they repeat and give practical, tailored information and support you to make informed decisions about your treatment and care. They also assess symptoms and side-effects during your treatment plan and are responsive to your physical and psychosocial needs.

Nurses often act as your point of reference. In addition, they can help you address all kinds of physical, psychosocial and spiritual issues, as well as provide referrals to other medical and psychosocial care specialists. In some cases, nurses also perform care coordination tasks by following up on your needs and results from the additional care they referred you to, and discussing its effectiveness with you. However, this may depend on the practice in your country and the institution you are treated at.³



General practitioners (GPs) hold your health records and know your full medical and disease history. Despite cancer treatment often being administered in a hospital setting, GPs can play an important role in your home care. Outside the hospital, GPs are key in providing you and your family with more information about cancer diagnosis and treatment, including the impact of treatment options on your quality of life, and supporting you in making decisions which best align with your wishes and goals.

GPs may keep an eye on your health and quality of life at home by visiting you throughout your cancer journey and contact the hospital care team if issues arise. You may also discuss other concerns with your GP, such as your psychosocial issues, home support and referral to other specialists.

³ Depending on the country of origin, these tasks exist under different names, such as: project nurse, breast nurse (for breast cancer patients), oncocoach, (onco)nurse specialist, cancer nurse, specialist nurse etc.



Palliative care specialists are doctors and nurses with special expertise in managing physical and psychosocial support for patients when a curative treatment is no longer an option. Palliative care is not only about supporting terminally-ill patients and their caregivers in the last months of life, but also about enhancing patients' quality of life after the diagnosis. You can receive palliative care at any stage of your illness. Some patients receive palliative care for years.

Palliative care specialists have an extensive knowledge of symptoms management, side-effects of treatments; health and fitness promotion as well as emotional support. They help you understand your concerns, set goals and develop advanced care planning with your family. A palliative care plan should be introduced as early as possible after the diagnosis when complete remission is not an option.

PSYCHOSOCIAL SUPPORT

Getting diagnosed with cancer can be one of the most frightening and stressful experiences you have ever faced. Dealing with the wide range of emotions sparked by your diagnosis and finding appropriate coping skills are just as important as the medical attention and treatment you will undergo. During the diagnosis, treatment and after treatment, some changes will occur in your routine, responsibilities and roles. These changes can lead to feelings of fear, sadness, helplessness, hopelessness, guilt, anxiety and depression. Supportive care services, psychosocial interventions and practical assistance can help you cope and deal with your emotions. Psychologists, social workers and other healthcare professionals form part of the multidisciplinary team that aim to provide holistic care and improve your quality of life as well as that of your loved ones.



Psychological distress is quite common after a cancer diagnosis and a psychologist's role is to help you deal with the range of emotions that you may experience. You can expect to experience shock, apathy and denial after getting diagnosed, anxiety regarding the treatment and outcome, feelings of loneliness and vulnerability associated with a strong sense of loss, fear of recurrence, etc. You may also experience depression, post-traumatic stress, sexual side-effects, and loss of control. Psychologists can help you work through whichever issues are most relevant to you, at all stages of your illness, and discuss ways or techniques to help you cope with these emotions and the challenges you may face.

Your family members and caregivers, who are also susceptible to stress and distress, will also benefit from psychological support and counselling. A psychologist will be able to assist them to understand the issues you are facing, to express their feelings and concerns, and to help them find ways to cope with distress. Encouraging your loved ones to seek help and support, will not only benefit them but will have a positive impact on your wellbeing as well. In some cases, a specialised psychosocial support may be appropriate. For instance, you as well as your partner can seek advice on sexuality and relationship issues by consulting a sexual therapist.



SOCIAL WORKER

A social worker is the HCP you may be referred to in order to help you manage the psychosocial, financial and practical issues resulting from your illness. By gaining an understanding of the circumstances, concerns and needs you and your family face, the social worker can help you decide on the best course of action to organise your day-to-day life and tasks. Social workers act as the link between you, your loved ones and your team of HCPs.

Social workers can organise individual counselling sessions or arrange family meetings to discuss various concerns and ways forward. They can help relay information given by HCPs to your loved ones, discuss options and steps needed to properly address your everyday needs.

Social workers also lead patient support groups that you might want to participate in, arrange services that are needed (e.g., transportation, medical equipment for home use), refer you to facilities, resources and other relevant organisations in your community, as well as identify financial assistance programmes you can apply for. Social workers can provide extra support if you live alone or have dependants.



REHABILITATION THERAPIST

Some patients experience a number of symptoms and side effects as a result of their illness or treatment plan. Rehabilitation therapy aims to help you alleviate symptoms and improve your physical abilities and psychosocial well-being. Your team of HCPs can recommend the rehabilitation programme that best suits your needs, and help you achieve the highest level of functioning and independence.

Rehabilitation can enable you to carry out daily tasks. HCPs may recommend physical therapy to help you gain physical strength, attain better mobility, improve endurance, and coordination, as well as help you manage pain and fatigue. Apart from sessions with your rehabilitation therapist, you may be given an exercise plan for you to do at home.

If you experience a reduction in your physical strength or manual dexterity, occupational therapy may be recommended to you. Occupational therapy enables patients to perform everyday activities, such as bathing, cleaning, dressing, writing, and return to work. An occupational therapist can also recommend assistive equipment and special massages, exercises and garments, that will help ease your specific condition.

Rehabilitation may also involve recreational therapy to improve social and emotional well-being through arts and crafts, music, dance, games and other group activities.

Rehabilitation programmes are often offered by national and regional cancer societies. Please see the ECL rehabilitation atlas to learn more about about programmes available in your country.



PATIENT ORGANISATIONS

Patient organisations help patients throughout their disease pathway, from diagnosis to survivorship. Patient organisations can provide you with useful and reliable information about cancer (e.g., types of cancer, symptoms, treatments and side effects) and support (e.g., supportive care services and peer support groups) available in your community.

Many patient organisations employ a multidisciplinary team of HCPs and provide holistic care to both patients at the hospital and the community. Their services may include medical and nursing care, physical therapy, psychosocial support, on-call service for home visits, helplines, access to medical equipment and transportation assistance.

Patient organisations often specialise in particular types of cancer and can provide specific information regarding the disease, treatment options, clinical trials, and links to support groups that you can connect with.



VOLUNTEER AND PEER SUPPORT⁴

Volunteers are an invaluable source of help to you and your family. In hospital settings, volunteers can support cancer patients by:

- › Providing psycho-emotional support, comfort and hope
- › Welcoming patients and their families to hospital units and providing information and guidance
- › Providing support during hospitalisation
- › Promoting leisure/occupational activities for patients

Peer support volunteers have had cancer themselves and can perfectly understand what you are going through at the moment. Some, might have professional healthcare training, but prefers to support patients in volunteer capacity.⁵ Others provide help at home and outside the hospital.

4. WHAT ARE THE ESSENTIAL INFORMATION PATIENTS SHOULD RECEIVE?

Throughout the disease pathway, you will have different information needs and doubts. Maintaining an open and honest communication with your HCPs and seeking information about your condition is an important part of your overall care. Research has shown that patients who have a good relationship with their doctors tend to be more satisfied with the treatment and care they receive. Nevertheless, starting the conversation can be difficult.

Below we outline various stages in your cancer journey and suggest practical questions which you might want to ask during consultations with your team of HCPs.

4 Some European countries do not offer volunteer services as a part of their patient support activities in hospitals. However, the ECL Patient Support Working Group believes that the role of volunteers in high quality cancer care is crucial.

5 Please note that volunteers with professional healthcare training have different roles and liability than hospital staff.



PROGNOSIS

One of the first things patients wonder about after receiving a cancer diagnosis is whether their disease can be successfully treated. Many patients hesitate to ask about their prognosis, while others prefer not to know about it. Similarly, some doctors avoid discussing prognosis whilst others mention it at the first appointment. If you would rather not know about it, make sure to let your HCPs know as soon as possible.

When asking about your prognosis, remember that doctors will give you some estimates based on available scientific evidence and their experience. Doctors' predictions are unlikely to be 100% accurate, as too many factors will influence survival rate. These include:

- › the type of cancer and where it is in your body;
- › the stage of the cancer (defining the anatomical extent of disease);
- › if it has spread to other parts of your body (metastases);
- › the cancer grade (referring to how abnormal the cancer cells look under a microscope);
- › certain traits of cancer cells;
- › your age;
- › how healthy you were before cancer; and
- › how you respond to treatment.



TREATMENT OPTIONS

It is the oncologist's role to help you decide on the most appropriate treatment plan by explaining treatment options available to you and their related benefits and risks. Cancer treatments affect your physical, social, psychological well-being. Thus, it is crucial that your choice is not rushed and that you take some time to think about different options and consider your goals and needs. Once you take a decision, you will need to consent to the treatment plan by giving verbal consent and/or signing a written agreement.



SECOND OPINION

It is your right to ask for a second opinion. Ask your oncologist, family doctor or surgeon, to recommend you a specialist who is an expert in your specific condition. You should also ask your oncologist to draft a summary letter describing your specific situation and their recommended treatment plan. Remember to bring the summary letter and any test results to the second opinion appointment.



LENGTH OF TREATMENT

The length of cancer treatment is determined by a variety of factors. The type and stage of your cancer, the types of treatments given, the expected side-effects (toxicities) of the medicines and the amount of time necessary to recover from them all have an impact on treatment timings. Many treatment plans have been established through clinical trials. You should be informed about the duration, frequency and number of cycles (chemotherapy) or sessions (radiotherapy).



SIDE-EFFECTS

You should ask your oncologist about the type, intensity and time-span of the side-effects you are likely to suffer from. Asking if side-effects can be prevented and if any of them are dangerous or life-threatening is equally important.

If side-effects occur during or after treatment and have a negative impact on your quality of life, do not hesitate to discuss them with your team of HCPs. This is not always easy, especially when side effects impact on your sexual life. Bear in mind that some HCPs are reluctant to touch upon the intimate lives of their patients, so it is important that you bring this issue to the table.



EFFECTS ON SEXUALITY

Sexual side-effects are common during and after cancer treatment and patients often shy away from them. Considering how common sexual side effects are and how negatively they can impact on your quality of life, sexuality is definitely something you should talk about with your HCPs.

You can start by asking your oncologist about which, if any, sexual side-effects can occur during or after your treatment. Ask about direct (e.g., effects on desire, arousal, orgasm

and body image) as well as indirect sexual side-effects (e.g. depression, fatigue). Ask what can be done to minimise these side-effects and what help is available to you and your partner. In many countries, sexual counsellors and therapists might help you overcome and deal with sexual side-effects.



PSYCHOSOCIAL SUPPORT

Psychosocial support includes mental health counselling, education, spiritual support and group support. These services are usually provided by mental health professionals, such as psychologists, social workers, counsellors, specialised nurses, clergy or pastoral counselors. These professionals might also refer you or your family to other relevant organisations and services. Ask your HCPs what services are available to you and your caregivers and for recommendations and referrals.



REHABILITATION

Rehabilitation helps you maintain your independence and perform daily tasks without struggling. You should ask your team of HCPs about local rehabilitation options. Many cancer centers and hospitals have on-site rehabilitation services. Depending on your needs, you may visit one or more specialists. These professionals are trained in specific areas of rehabilitation. Rehabilitation specialists can help you adapt to the temporary and permanent changes caused by your illness and/or treatment.



SOCIAL SUPPORT

Cancer diagnosis causes significant changes in patients and their families. Adjustments to your daily routine will have to be made. It is important that you look for all the existing help regarding social support in the community. Ask your team of HCPs for help and look for relevant services provided by patient organisations and cancer societies.



PATIENT ORGANISATION & PEER SUPPORT REFERRAL

You are not alone and there are many people facing the same struggles and issues you are dealing with. Cancer support groups provide a space in which cancer patients can talk about and exchange opinions with others going through similar experiences. You can ask your HCPs or search online for patient organisations and peer support groups active in your community.

5. USEFUL TIPS AND RECOMMENDED QUESTIONS TO ASK DURING A CONSULTATION

THINGS TO DO BEFORE THE CONSULTATION:

- Ask a relative, friend, partner, carer or advocate to accompany you to your appointments
- Make a list of questions you would like an answer to
- Bring a list of all medicines and pills you take, including vitamins and supplements
- Write down details of your symptoms, including when they started and what makes them better or worse

WHAT TO REMEMBER DURING THE CONSULTATION:

- Do not be afraid to ask your doctors to repeat and/or clarify anything they say
- Ask your HCPs if you can record consultations on your smartphone
- Ask a family member to take notes for you

BEFORE YOU LEAVE THE CONSULTATION, MAKE SURE YOU:

- Check you have asked all the questions on your list
- Know what the next steps are
- Ask who you can contact if you have any problems or further questions
- Ask for reliable sources of information about your disease and treatment options

AFTER YOU RETURN HOME FROM THE CONSULTATION:

- Keep all your notes safe – in case you ever need to refer to them
- Book dates for the next appointments in your diary
- Discuss the results of the consultation with your loved ones

SAMPLE QUESTIONS TO ASK DURING CONSULTATION

I. DIAGNOSIS

- ☐ What type of cancer do I have and where in my body is it?
 - ☐ What is the stage of my cancer? Has it spread to other parts of my body?
 - ☐ Can my cancer be cured?
 - ☐ What do the results of the tests mean?
 - ☐ What happens next?
 - ☐ Do you have/Where can I find written information about my disease and treatment options?
 - ☐ Where can I get reliable information about my condition?
-

II. TREATMENT

- ☐ Are there any other treatment options?
 - ☐ Where can I find information about planned clinical trials? How can I apply?
 - ☐ What are the pros and cons of the suggested treatment and its alternatives?
 - ☐ Which treatment would you recommend? Why?
 - ☐ What is the goal of the proposed treatment?
 - ☐ What are the chances of the treatment to be successful?
 - ☐ When do I get the test results showing if my treatment plan has been successful?
 - ☐ Who can I call if I need further clarifications?
 - ☐ How long will the treatment last?
 - ☐ What happens if I do not want to undergo any treatment?
 - ☐ Is there anything I should stop or avoid doing during my treatment?
 - ☐ Is there anything else I can do to help myself?
-

III. SECOND OPINION

- ☐ I trust you and appreciate your help thus far, but this is all so new to me, so I would like to get a second opinion before we move ahead. Can you recommend a specialist?
 - ☐ I am thinking of getting a second opinion. Will you help me with that?
 - ☐ If you were diagnosed with my condition, who would you see for a second opinion?
-

IV. LENGTH OF TREATMENT

- ☐ When is the surgery planned?
- ☐ How long will the surgery take?
- ☐ How long will I be hospitalised for?
- ☐ When do I start with chemotherapy?
- ☐ How many times will I get chemotherapy?

- ☐ How long does a chemotherapy session take?
 - ☐ What are the intervals between the chemotherapy sessions?
 - ☐ If I have questions during the treatment, who shall I approach?
 - ☐ How long does a radiotherapy session take? What is the interval between sessions?
 - ☐ How long will my treatment last?
-

V. SIDE EFFECTS

- ☐ Are there any side effects or risks connected to my recommended treatment (chemotherapy/radiotherapy/surgery...)?
 - ☐ What could be the impact of this treatment on my quality of life?
 - ☐ What are the common side effects of the proposed treatment (surgery, chemotherapy, radiotherapy, immunotherapy ...) and how often do your patients experience them?
 - ☐ Where can I get professional help if these side effects occur?
 - ☐ Will I need to adjust my daily routine (children, work, exercise...)?
 - ☐ Is it normal to feel... (fatigued, depressed, not aroused, etc.)? What can I do to overcome this?
-

VI. SEXUALITY

- ☐ Can my partner and I get professional help for these problems? Where?
 - ☐ What can I do if I experience vaginal dryness/erectile dysfunction?
 - ☐ Can I get help with my relationship and communication with my partner?
 - ☐ Is it normal that my recommended treatment affects my sexual desire?
 - ☐ Will my sexual desire come back?
 - ☐ How can/Will cancer affect my body image and sexual health?
 - ☐ What can I do if I experience pain during intercourse?
 - ☐ Are the sexual side-effects I am experiencing permanent? Will they go away on their own?
-

VII. PSYCHOSOCIAL SUPPORT

- ☐ Where can I get psychosocial support?
- ☐ I feel overwhelmed with this news. I do not know how to cope with it. What I can do?
- ☐ Who can I contact if I am worried about my treatment and symptoms?
- ☐ Who can I call to discuss issues that are stressing me out?
- ☐ Can you give me some advice on relaying information to my loved ones, friends, and colleagues?
- ☐ My family is distressed. Where can they get help?

VIII. REHABILITATION

- ☐ What kind of rehabilitation programmes are available to me?
- ☐ What help is available to help me regain my strength after treatment/surgery?
- ☐ Will I be impaired in any way? What can I do about this?
- ☐ Will I experience pain? What options are there to help alleviate the pain?
- ☐ Is there an exercise routine or therapy I should do? For how long?
- ☐ Is there any assistive equipment that will be beneficial for me to use?

IX. PATIENT ORGANISATIONS

- ☐ Are there any patient organisations in my community that I can turn to for support?
- ☐ Where can I find peer support?
- ☐ What services do patient organisations provide?
- ☐ Do patient organisations provide services to family members?
- ☐ What can patient organisations do for me and for how long?

X. OTHER QUESTIONS

- ☐ Who should I contact when I have financial problems?
- ☐ Where can I get support to return to work?
- ☐ When will I be able to return to my daily routine?
- ☐ Do you think I can get home care support? Where can you refer me to?
- ☐ Are there any other options other than care at home (e.g., hospice)?

CONCLUSION

When facing a life-changing cancer diagnosis, you are bound to have a lot of questions and cross paths with a variety of HCPs.

A healthy and open patient-HCP communication is a vital factor in determining patient safety and quality of care. Good communication is crucial in building trustworthy relationships that not only helps in therapeutic success by providing holistic care to the patient but also leads to satisfaction among both doctors and patients. This guide was designed to help you brainstorm questions and navigate through the complex health and cancer ecosystem.

The Association of European Cancer Leagues (ECL) and its member organisations are grateful to all patients who have contributed their ideas and experiences. We hope that this guide will help other patients get the best out of their consultations.

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NOTES



ECL: PATIENT SUPPORT WORKING GROUP

Association of European Cancer Leagues (ECL)
Chaussée de Louvain 479, 1030 Brussels, Belgium

📞 +32 2 256 2000 ✉ ECL@europeanleague.org
🏠 www.cancer.eu   [@cancerleagues](https://twitter.com/cancerleagues)

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