



A GUIDE FOR PATIENTS WITH ADVANCED CANCER

GETTING THE MOST OUT OF YOUR ONCOLOGIST

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Reviewed and endorsed by:





European Society for Medical Oncology

A guide for patients with advanced cancer

Getting the most out of your oncologist

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European Society for Medical Oncology

About ESMO

The European Society for Medical Oncology (ESMO) is the leading European professional organization, committed to advancing the specialty of medical oncology and promoting a multidisciplinary approach to cancer treatment and care.

Since its founding in 1975 as a nonprofit organization, ESMO's mission has been to advance cancer care and cure. We achieve this through fostering and disseminating good science that leads to better medicine and determines best practice. In this way ESMO fulfils its goal to support oncology professionals in providing people with cancer with the most effective treatments available and the high-quality care they deserve.

About the ESMO Palliative Care Working Group

The Palliative Care Working Group (PCWG) was established by ESMO to promote the integration of supportive and palliative care into medical oncology practice in order to improve patient care. The program of the PCWG includes policy, research, education, and incentive programs to improve the provision of palliative and supportive care in cancer centers and departments in Europe and around the world.

About the ESMO Cancer Patient Working Group

The main mission of the Cancer Patient Working Group (CPWG) is the optimization of patient care in Europe and worldwide, the continuous improvement of cancer-specific information and education, the strengthening of patient autonomy, and the support of patient rights.



Message from the Multinational Association of Supportive Care in Cancer

The Multinational Association of Supportive Care in Cancer (MASCC) is delighted to endorse this ESMO guide for patients with advanced cancer. Supportive Care in Cancer is the prevention and management of the adverse effects of cancer and its treatment. This includes management of physical and psychological symptoms and side effects across the continuum of the cancer experience from diagnosis through anticancer treatment to post-treatment care. Enhancing rehabilitation, secondary cancer prevention, survivorship, and end-of-life care is integral to Supportive Care. Hence this ESMO guideline is an excellent fit with MASCC.

Patients do find cancer and its treatment very frightening, and anything that can be done to make it less so is to be applauded. This is a clear, concise guide that demystifies some of the aspects of cancer care, and tells patients and their families what questions to ask to gain information to help them along the cancer journey.

MASCC looks forward to working with ESMO to enhance cancer care and reduce the impact of this disease on patients and families.

A handwritten signature in black ink, appearing to read 'D. Keefe', is positioned above the printed name.

Professor Dorothy Keefe
President
MASCC





Message from the Union for International Cancer Control and the International Psycho-Oncology Society

The Union for International Cancer Control (UICC) and the International Psycho-Oncology Society (IPOS) unreservedly endorse this initiative of the European Society for Medical Oncology (ESMO) to support those affected by advanced cancer.

This guide makes a valuable contribution to realizing the goals of the World Cancer Declaration by prioritizing the physical, social, and emotional needs of patients with advanced cancer. It also upholds the IPOS Statement on International Standards for Quality Cancer Care, which states that quality cancer care must routinely address the psychosocial impacts of cancer, to alleviate the distress experienced by a significant number of patients and their loved ones.

As part of a global movement, UICC and IPOS are united with ESMO in its commitment to work with clinicians, health professionals, and patients to provide a quality and standard of care that treats the whole patient.

Importantly, this guide acknowledges that a patient's confidence and trust in his or her treating oncologist is fundamental to preserving the best possible quality of life. Equally, this guide recognizes that oncologists have a special duty to ensure their patients can access a full range of assistance to cope with the complex challenges of advanced cancer. This includes emotional care and psychosocial support, clinical advice, and symptom and pain management. Indeed, for many patients and their families, the emotional impacts of advanced cancer are among the most challenging to address. This guide provides a foundation for holistic care, through practical guidance which aims to encourage a stronger connection between patients and oncologists.

Ultimately, this guide provides a critical tool to help improve patients' quality of life and enhance the effectiveness of treatment for advanced cancer. We commend this guide to cancer patients and their loved ones.

Dr Eduardo Cazap
President
UICC

Professor Maggie Watson
President
IPOS



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1: Introduction

This booklet is designed to help patients with advanced cancer and their family members to get the most out of their relationship with their treating oncologist. Advanced cancer is a cancer which cannot be surgically removed from its initial site or which has spread beyond its initial site.

Oncologists are dedicated to helping people deal with the challenges of their illness and to get the very best possible out of their lives.

Relationships with doctors, including oncologists, can be challenging, but often a part of the problem is not knowing how to work with them.

- What can I reasonably expect from them?
- What are the questions that I should ask?
- How do I present my problems, fears and concerns?

“This booklet has been developed to help you communicate with your oncologist”

This booklet has been developed to help you communicate with your oncologist and to help you address a wide range of issues that are relevant both for you as a patient living with advanced cancer and for your family.

The development of this booklet has been a collaborative effort between oncologists who work with patients living with advanced cancer, their patients and patient advocacy groups across Europe.

We hope and trust that you will find this booklet helpful.

Should you wish to offer feedback or make suggestions for future editions, please contact the editors at education1@esmo.org



2: Having an advanced cancer

Despite progress in medical care, advanced cancer is still a very common problem. For some patients, having an advanced cancer means having a disease which is no longer curable. For others, it means having the uncertainty of not knowing whether the disease will be cured.

In both these circumstances, advanced cancer is for most patients a frightening experience that is filled with uncertainties and a large number of challenging needs.

Patients with advanced cancer need:

- The best possible control of their disease to live as well and as long as possible.
- Meticulous control of their symptoms.
- Attention to their psychological and spiritual well-being.
- Attention to the needs of their family, including their psychological and spiritual well-being.
- Care that is sensitive to their individual cultural or religious concerns.

Patients with advanced cancer need a supportive relationship with a cancer specialist who is attentive to their needs and whom they can trust.

3: What is an oncologist and what is his/her role?

An oncologist is a medical doctor who is a cancer specialist. An oncologist is more than just a person who prescribes chemotherapy or other treatments in an attempt to control or cure cancers. Oncologists are “people doctors” who are committed to a holistic approach in order to help patients with cancer to live as long and as well as they can.

Giving advice about chemotherapy, radiotherapy or surgery is certainly a large part of the role of oncologists. They do that and much more.

“By developing a relationship with an oncologist, you open the possibility of using their skills, insights and professional relationships”

An oncologist is a care coordinator who works as part of a wider care team of medical, nursing and other healthcare professionals dedicated to the care and well-being of patients with cancer.

By developing a relationship with an oncologist, you open the possibility of using their skills, insights and professional relationships which can help you and your family to cope better with the challenges of living with cancer.

When meeting an oncologist

When meeting an oncologist, it is important to share with him/her information about who you are. Besides speaking about your illness, you need to share information about:

- Your family
- Your interests
- Your hopes
- Your fears
- The important goals that you would like to achieve
- The information that you would like to be given

Your relationship with your oncologist can be a powerful tool

- He/she can help guide you in decision-making about potential treatments.
- He/she can be your care coordinator to help utilize the range of services available to help you best cope with illness.
- He/she can be your advocate in dealing with many of the bureaucratic issues associated with access to care and services.
- He/she can be a powerful source of knowledge, guidance and personal support for you and your family.



Your relationship with your oncologist will continue for as long as you need it

A relationship with an oncologist is a long-term relationship.

Should your cancer be curable then you will still need care after treatment and a strategy for follow-up.

If your condition cannot be cured, then you will need an ongoing care relationship to keep you as well as possible for as long as possible and to support you and your family along this journey.

4: The oncology team and how to use it

Most oncologists work with a team of practitioners including nurses, social workers and psychologists.

Many oncologists work with additional services, which may include:

- Palliative care specialists
- Pain specialists
- Dietitians and nutritional counselors
- Spiritual care practitioners
- Rehabilitation therapists, including occupational therapy, physical therapy and speech therapy
- Lymphedema specialists
- Wound or stoma care specialists
- Complementary therapists
- Intimacy and sexuality counselors
- Fertility therapists
- Geneticists

Some centers may also offer special services such as:

- Cosmetic therapy (“look good, feel better”)
- Recreational therapy
- Music therapy

Social workers

In general, all patients with advanced cancer and their families should consider meeting the oncology social worker. Oncology social workers will help with any specific family issues; they may be able to offer advice regarding financial assistance and other special services. A social worker can often help you to sort out how to cope with problems such as anxiety and depression or feelings of hopelessness.

Nurses

Oncology nurses have specific expertise in the management of side effects from treatments or complications of cancer. They can be a wonderful source of support, guidance and information. If you feel that your needs or concerns are not being addressed by your oncologist, your oncology nurse can be a very effective advocate for you in the professional care team.

Palliative care specialists

Palliative care specialists are doctors and nurses with special expertise in managing the physical and psychological consequences of advanced cancer. Working with your oncologist, they can help develop care programs to optimize your comfort, function and support. Palliative care specialists are not only there to help patients who are dying, and their participation in care has been shown to be of value in helping patients to live better and, sometimes, longer.

Psychologists, psychiatrists or psycho-oncologists

Living with advanced cancer can trigger many concerns and negative feelings: anger, fear, sadness, anxiety about what lies ahead and, for some people, even feelings of meaninglessness and hopelessness. The skilled care provided by psychologists, psychiatrists or psycho-oncologists is often extremely helpful in dealing with these sorts of feelings.

“Most oncologists work with a team of practitioners including nurses, social workers and psychologists”

Chaplains and spiritual care

Spirituality means different things to different people: for some it relates to religious beliefs, for others it describes issues of connectedness, meaning and values that are unrelated to religion. Chaplains and spiritual care programs can help patients and their family members to deal with the challenges of advanced cancer by addressing this very powerful dimension of their lives.

Dietitians

For many patients there is confusion and misinformation about what is the right or wrong thing to eat. Patients commonly ask which foods are good or bad for cancer care. Cancer does affect eating in many different ways, either because of the disease itself or the treatments associated with it; some patients suffer from nausea, some from loss of appetite and others from profound changes in the ability to taste. Many of these concerns can be addressed by consulting an experienced dietitian.

Rehabilitation

Rehabilitation aims to improve your ability to function. While rehabilitation usually refers to physical function, it may also relate to psychological well-being. For patients with weakness, difficulty in using some parts of their body or difficulties in speaking or swallowing, a rehabilitation team can be critical to restoring the ability to function as well as possible.

Sexuality counselor or therapist

The effects of cancer and of the various therapies to treat it can affect one's feelings about physical intimacy and sexuality, as well as sexual function. Many centers offer special services to help patients who are dealing with these issues. Additionally, services may be available to address fertility issues and the symptoms caused by menopause in women or andropause (“male menopause”) in men, which may be a side effect of treatments.

Specialist care for wounds, lymphedema or stomas

Some patients have special needs such as poorly healing wounds, swelling of an arm or leg (lymphedema) or stomas, which may require special care and assistance.

5: Questions to ask your oncologist about your condition: getting the basic information

Cancer is not one illness. There are more than 300 different types of cancer. By understanding exactly what sort of cancer you have and which parts of your body are involved in the cancer, you will be in a better position to understand what is wrong with you and how you can best be helped.

Often, and particularly with highly emotional discussions, it is difficult to remember what the doctor has said. It is often useful to have a family member or friend with you. Many patients find it useful to take notes or even (if the doctor has no objections) to record the discussion.

The 4 most basic questions are:

1. What sort of cancer do I have? (What is it called?)
2. Where did it start?
3. Do we know if it has spread? If so, where has it spread to?
4. Are there treatments that can help me?

Sensitive questions

There are some questions that are particularly sensitive. These are questions related to the seriousness of the condition and the outlook for the future.

Many patients feel that they want and need this information in order to fully understand their condition, so that they can make the best-informed decisions possible regarding their treatment options and their lives in general.

Other patients feel so overwhelmed by their circumstances that they would rather not discuss these issues, or else they may want only very general information. If you don't want to discuss these issues now, tell your doctor. Just because you don't want to discuss these issues now, it does not mean that you never will.

“By understanding what sort of cancer you have, you will be in a better position to understand how you can best be helped”

Here are some questions that many patients find useful and important:

- Am I in any immediate danger of something terrible happening?
- Is there a chance of being able to cure my condition?
- What is the best that I can hope for?

- 
- If I need to prepare for the worst, what is the worst-case scenario for someone in my situation?
 - Are there treatments that can improve my outlook?

What should my family know?

Most patients invite family members to participate in these sorts of discussions, both to have support and because of the feeling of “being in this together”. Some patients, however, prefer privacy to allow them to ask sensitive questions that they would not want their families to hear. That is OK.

In general, families cope best and family members are best able to support one another when there is good and open communication.

Patients are often concerned about how or what to explain to their parents or to their children. The people you love will be very anxious if they feel that you are lying to them about your health or if they feel that you are concealing things from them. For these reasons we encourage communication.

If you need help in knowing what to say or how to explain things, your oncologist or one of his/her team members can help with this.

It is often useful to ask to arrange a family meeting in order to have a discussion with everyone who is involved.

Confidentiality

You are entitled to confidentiality and you must let your doctor know who he/she can or cannot talk to about your condition.

6: Questions to ask your oncologist when considering your options for anticancer treatments

There is no single best way to treat an advanced cancer that is appropriate for all patients. Making good decisions about treatments such as chemotherapy, biological treatments and radiation therapy requires having enough information to weigh up your options. It is your oncologist's role to explain the options that are available and the potential benefits or risks that are involved with each of them in order to help you decide on a treatment plan that is most appropriate for you.

Everyone makes decisions in different ways

- Some patients want all of the information and options laid out for them in order to make a decision either alone or together with the oncologist.
- Some patients want a more guided approach, with the oncologist telling them what the best treatment is.

Whichever way you like to make decisions, it is important to tell your oncologist how you want them to participate in your decision making.

“ Making good decisions about treatments requires having enough information to weigh up your options ”

Making informed decisions or giving an informed permission

Irrespective of the approach that you choose, ultimately when a decision is made you need to give your formal agreement for treatment (which is often called “consent”) and you should know what you are agreeing to.

For most people, this is a totally new situation and often patients and their family members don't know what information is needed to make an informed decision or how to give an informed consent to proceed with a treatment plan.

To ensure that you have the information that you need, these are some of the important questions to ask your oncologist about any proposed treatment:

General

- What type of therapy is this and what demands is it going to make on me and my family?
- Is this a widely used treatment that is recommended by international authorities or professional guidelines?

- What is the likelihood that this treatment will make me feel better or help me to live longer?
- If the treatment helps, when should I start to feel better?

Advantages

- What is the best that I can expect if this treatment works well?
- On average, how much does this treatment help patients to live longer?
- If the treatment does not help me to live longer, can it make me feel better and improve my quality of life?
- How often is this treatment helpful to patients?
- If it does help, for how long is it likely to help?

Potential risks

- What side effects am I likely to suffer if I take this treatment? How severe are they likely to be and how long will they last?
- Can the side effects be prevented?
- Are any side effects potentially dangerous? If so, how often do they happen? What can be done to minimize my risk from them? Are they reversible?

Are there other options that I could reasonably consider?

- More aggressive therapies?
- Less aggressive therapies?
- Experimental therapies?
- Complementary or alternative therapies?
- Symptom control without anticancer therapies?

7: Taking part in a clinical research study: should I consider an experimental treatment?

Even for patients with advanced cancer, in many situations there are established treatments that offer a high likelihood of benefit. In some cases, however, either the likelihood of benefit from standard treatments is small or the size of the benefit (particularly in prolonging life) is very limited.

Given the limitations of what current treatments may provide, medical research needs to push the boundaries of what can be done. This is critically important.

Progress in medicine depends on the cooperation of patients who are prepared to use their own situation to help generate new knowledge about the potential benefits and/or risks of newly developed drugs or treatment approaches.

People participate in clinical trials for a number of different reasons:

- In the hope that a new experimental treatment will be better than the treatment they would otherwise have access to.
- To participate in the “cutting edge” of medicine.
- In the hope that others may benefit from the knowledge gained from treating them.

In addition to receiving state of the art care, participation in research allows you to make a contribution to society, without which there would be no medical progress.

“Medical research needs to push the boundaries of what can be done.
This is critically important”

Participation in a clinical trial is not for everyone and some people are, with reason, concerned and dissuaded by:

- The unknown risk of side effects.
- The demands of extra blood tests, imaging examinations and questionnaires.
- The concern that their treatment may be determined in effect by “flipping a coin”, as in a trial that randomly allocates patients to receive either an experimental treatment or the standard treatment in order to compare their effectiveness.

Considering participation in a clinical trial

In order to make a decision on whether a research study is right for you, you should ask your oncologist about the sorts of studies that may be appropriate for your condition at the institution in which you are being treated or at other nearby institutions.

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- If you consider participating in a clinical trial, you will be given a detailed verbal explanation of everything that it involves as well as a printed version of this information for you to consider before making a final decision.
 - If you agree to participate in a clinical study, it is important that you understand that your signed consent is not a contract and that you are entitled to change your mind and to withdraw from the study at any time and for any reason. Your withdrawal from a clinical trial will in no way affect your medical care or change the attitude of your doctors in any way.

Tools to help find a clinical trial that may be relevant to you

Anyone can access information on the internet to find out if there is research under way that may be relevant to their condition. This information can be found in the major trial registries (see below). Should you find a clinical study that may be relevant to your condition and is of interest to you, you should discuss it with your treating physician.

Examples of major trials registries:

- www.clinicaltrials.gov – This is a registry of clinical trials conducted in the United States and around the world. It provides information about a trial's purpose, which patients may participate, the study center locations, and phone numbers for more details.
- www.clinicaltrialsregister.eu – This is a registry of clinical trials in the European Union (EU) member states and the European Economic Area (EEA). This site is much less useful than www.clinicaltrials.gov since it indicates only the countries involved, without giving information about the specific centers participating in the trials or providing their contact details.

8: Should I consider complementary medicine and alternative methods?

Suffering from advanced cancer will often make you feel helpless in the “battle” against the disease. Many patients search for additional treatments besides evidence-based medicine. They may seek help from these alternative methods in the hope either of increasing the likelihood of controlling the disease or of improving their well-being.

Some complementary therapies have been shown to be of great help to cancer patients, particularly for promoting coping and well-being. These include:

- Spiritual care
- Guided imagery
- Massage
- Relaxation techniques
- Yoga
- Acupuncture

Many approaches, however, lack evidence of effectiveness or are entirely unproven, others are useless approaches that are marketed to exploit vulnerable and needy patients, while some are even manifestly harmful.

“Your oncologist can assist you by suggesting useful approaches”

Alternative biological treatments and herbal remedies

- Most claims made by advocates and producers of herbal supplements are based on historical experience or laboratory studies that are not confirmed by clinical trials.
- There is little evidence to date showing that any botanical or homeopathic therapies can suppress or cure cancer in the clinical setting.
- Many supplements are often produced with minimal if any quality control.
- Some may interact with prescription medications, including chemotherapy, possibly decreasing the effectiveness of these medications or increasing the potential for side effects.

Your oncologist can assist you by suggesting useful approaches and discussing alternative methods to help clarify whether these are potentially helpful or not.

9: Second opinions

It is important for patients not only to receive the best of care but to have the peace of mind that the care they are receiving is indeed the best for them.

For many patients the information that they receive from an oncologist whom they trust will be quite enough to provide this peace of mind.

“Patients may benefit from seeking other medical opinions before making a final decision about treatment”

For some patients, this is not enough. Such patients may benefit from seeking other medical opinions before making a final decision about treatment.

Before seeking a second opinion it is worthwhile asking your oncologist if his/her recommendations have been discussed with other oncologists. Often, the recommendation made to you by your oncologist is suggested only after lengthy consultations with other expert colleagues (in what is called a “tumor board” or “multidisciplinary review” meeting). This is a very common practice in many, if not most, oncology centers.

The second opinion

If you still feel that you would like a second opinion, it is worth consulting with your oncologist, family doctor or surgeon to ask if they can recommend an oncology specialist who is an expert in your condition for another opinion. Sometimes patient advocacy groups can also provide information about second opinions.

If you plan to obtain a second opinion, it is worth taking the following steps:

1. Ask your oncologist for a summary letter regarding your situation and his/her recommendations for treatment.
2. When you attend the appointment for the second opinion, take the summary letter from the first oncologist and all of your important test results with you.
3. If you have had x-rays or scans, it can be important to have not only the reports but also the disks or films of the actual imaging studies.

10: Using the internet to get information about your illness

The internet gives access to an extraordinary amount of information. Many patients and their family members seek additional information about their disease or its treatment from internet sources.

The internet can be helpful for:

- Finding a specialized oncologist.
- Reading about guidelines relevant to your condition.
- Finding information on common side effects, and helping you to cope with everyday life during cancer treatment.
- Reading about new “cutting edge” research findings.
- Finding clinical trials.
- Sharing experience with other patients to reduce anxiety, loneliness and fear.
- Locating advocacy and information groups relevant to your specific condition.

The good and the bad

Although this can be very helpful to many patients, some information from the internet can cause harm for several reasons:

1. Unfortunately, not all of the information available on the internet is accurate, and in some situations the information can be extremely misleading.
2. Many sites on the internet are supported by commercial interests, with the intention of encouraging readers to purchase their specific products.
3. Even on websites that are supported by reliable and responsible authorities, you may be exposed to information about anticipated prognoses that may not be appropriate for your specific situation. Sometimes this can cause severe distress and confusion.

“ It is often worthwhile asking your oncologist to direct you to a reliable site ”

Get advice

If you are interested in seeking further information from the internet about your illness or its treatment, it is often worthwhile asking your oncologist to direct you to a reliable site that produces information in a language that you understand.

Practical tips in using the internet

- Remember that anyone can publish anything they want on the internet, whether true or false.
- Stick with well-respected health websites. They will usually provide links or references to their sources of information.

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- Websites that claim to be the only resource for all the facts on a subject are likely to be unreliable.
 - Make sure that the information you find is the most current available.
 - If the information that you read seems too good to be true, then it probably is. Try to find at least a second reference from a well-respected website to confirm your findings. If you can't find the same information in more than two or three well-respected websites, then it's probably questionable.
 - If you find a website that quotes patients speaking about the effectiveness of a treatment or therapy, you cannot be sure that those testimonials are real.
 - Learn to separate facts from opinions. For example, a doctor may suggest a treatment for you based on his/her opinion and experience while research studies and other evidence may show that another treatment generally works more often. The value of a physician's opinion depends on the expertise and credentials of the doctor who is giving it and, in many cases, on how much he/she knows about your individual situation.
 - Be very skeptical of websites that claim to have a secret or miraculous cure that doctors don't know about. Serious researchers don't keep cures a secret. They share them with the medical community so that all can benefit.
 - Review with your doctor any information that may influence your decisions or which is of concern to you.

11: Using patient advocacy and support groups

Patient advocacy groups are nonprofit organizations that focus on the needs of patients with cancer or specific types of cancer. They provide support, information and advocacy services.

A patient advocacy group can help you in a number of ways

1. Information: Booklets and websites that are developed by credible patient advocacy groups can be a very important source of reliable and helpful information that has been prepared specifically to help patients and their family members. This is especially true for rare cancers, where “grassroots” patient advocacy groups are often the only web-based information source.
2. Referral to local resources: Patient advocacy groups may be able to direct you to clinicians with specific expertise or to other care resources in the area in which you live.
3. Dealing with individual queries: Many patient advocacy groups will provide either telephone or online services to help address any questions that you may have relating to a wide range of issues, including treatment options, management of side effects, the existence of support groups or the availability of research opportunities that may be relevant to your condition.
4. Individual advocacy: Sometimes, patients need skilled assistance in dealing with procedural, regulatory or insurance problems that are making it difficult for them to receive the care they require. Many patient advocacy groups will offer the assistance of an individual counselor to help negotiate these problems.

Drug companies and patient advocacy groups

- Most patient advocacy groups go to great lengths to ensure that the information that they provide is accurate, balanced and not unduly influenced by drug company sponsorship.
- Patient advocacy groups that are supported by drug manufacturers should issue a warning (a disclaimer) so that readers are aware of this financial relationship. A disclaimer of this type does not mean that the information they provide is biased, rather that there is a risk that this financial relationship may (consciously or unconsciously) have affected the content.
- Sometimes drug manufacturers set up and develop patient advocacy groups as a marketing strategy to encourage patients to use their specific medications. The information provided by such services may be biased.

Patients and family members are generally advised to rely on nonprofit patient advocacy groups and those endorsed and supported by local cancer societies.

Support groups

In dealing with cancer, it is often helpful to know that you are not alone and that there are many other people dealing with the same issues as you. Cancer support groups provide a setting in which cancer patients can talk about living with cancer with others who may be having similar experiences.



Support groups link patients and/or their carers with other people in similar circumstances to help and support one another.

There are many different types of support groups. Some support groups are led by lay people, some by people who have had an illness and others by medical professionals such as physicians, nurses, social workers or health education professionals.

Special support groups

- Sometimes patients or their family members have specific concerns stemming from their particular situation in life, which may warrant a special support group that caters to their needs.
- Some support groups are dedicated to helping people with a specific illness or to assisting either women or men, younger or older patients, spouses, carers, or the children of cancer patients.
- Some support groups are designed to address specific issues such as fatigue, sexuality, finding meaning or enhancing dignity.

Online support groups

- Online support groups and forums are a good option for those patients who find it difficult to leave their home during treatment.
- People participating in such forums have the possibility of maintaining their anonymity.

Potential advantages from participating in a support group

1. Coping and information: A support group can provide and share a range of information on, for example, managing side effects, disease research and new treatment options. This can be particularly helpful for patients suffering from an uncommon form of cancer, when a group may help to gain access to information that is not readily available elsewhere.
2. Emotional support and well-being: Support groups and patient-to-patient networks can help people feel less isolated and distressed, and improve the quality of their lives. Many participants say that the experience gives them an emotional connection when they feel isolated from family and friends.

12: Looking after quality of life

Keeping you feeling as well as possible, both physically and psychologically, is at the very heart of your relationship with your oncologist.

Your oncologist has the expertise to help manage your pain and other physical or psychological problems that may arise. Should you have particularly difficult or complex problems, oncologists work with other experts such as pain or palliative care specialists, psychologists and psychiatrists, all of whom are dedicated to helping you.

Attending to your quality of life requires a partnership with your treating oncologist. Unless your oncologist knows what you are feeling, he or she will not be in a position to help.

“Attending to your quality of life requires a partnership with your treating oncologist”

Successful care requires close collaboration and open communication about your concerns and about what you are feeling. Here are some useful tips for communicating with your oncologist about these important issues.

Talking about pain

If you are in pain, it is important to share this information with your treating doctor. Not only is pain an important cause of distress and suffering, but knowledge of the pain can give important clues to the doctor that can help in the management of your illness:

- Where is the pain?
- Does the pain spread anywhere?
- What makes the pain better?
- What makes the pain worse?
- Does your pain interfere with your ability to move? If so, which movements or activities make it worse?
- What medications have you tried to relieve the pain?
- How much is the pain interfering with your ability to function?

If you have chronic pain, it is often helpful to keep a pain diary, recording the severity of the pain several times a day.

Certain sorts of pain may be warning signs of serious problems that may need urgent attention

- Back pain which suddenly becomes much worse.
- Pain in the hips or legs which becomes very severe when standing or walking.

- 
- Persistent headaches.
 - Severe stomach pain and diarrhea after chemotherapy.
 - Severe pain from mouth ulcers that makes it difficult to eat or drink.

Pain is not the only important symptom to report

Unfortunately, people living with advanced cancer often suffer from several symptoms that may make their lives more difficult. It takes time to sit down and talk about these. However, taking the time to talk about these problems is worth the effort, since there may be treatments that are able to help you feel better.

It is important to let your doctor know if you are suffering from:

- Shortness of breath or cough
- Constipation or diarrhea
- Fevers or chills
- Lack of appetite and loss of weight
- Difficulties with eating or drinking
- Drowsiness
- Fatigue
- Hot flushes, sexual dysfunction or lack of libido
- Hiccups
- Persistent sadness and anxiety or suicidal thoughts
- Feeling confused or having hallucinations
- Insomnia
- Nausea, dizziness or vomiting
- Double vision
- Tingling or loss of feeling
- Seizures
- Confusion or personality changes

13: Balancing your life

Ultimately, the aim of living with cancer is about being well enough to enjoy relationships, activities and time with your family and maximizing the opportunities that life gives.

It is often a struggle to find the balance between being a patient receiving treatment and being you and living your life.

The truth is that treatment is important, but so is your life! Looking after your priorities, your family and other important relationships is a big part of the struggle to keep life in balance.

Here are some important hints that sound so simple and yet in the turmoil of illness often seem to get overlooked:

- Look after your relationships with family and friends.
- If relationships are damaged by issues of the past, consider finding ways to mend them.
- Try to find time for people who make you feel good and who are important to you.
- Share your hopes, fears and important memories with the people who are dear to you.
- Tell the people whom you love how much you love them.
- Make time for things that give you pleasure.
- Prioritize the important things that need to get done: today, this week, this month, this coming year.
- Understand that people value you for just being you, not for what you can do.

“Treatment is important, but so is your life!”

14: Hoping for the best and preparing for the worst

Almost every patient with cancer wants to be cured. Often this is possible, but sometimes it is not.

Life is full of uncertainties that, for most of the time, we ignore. We like to live as if life will go on forever.

Sadly it doesn't.

Sometimes death approaches slowly, with ample time to prepare and to make changes and decisions. Sometimes the cancer or the treatments that are received can cause an unexpected turn for the worse and the situation may become suddenly life-threatening.

Preparing for the worst is not only about making advanced medical directives or healthcare proxies (these are discussed below). It is about:

- Making a will.
- Thinking about leaving some form of legacy of your life, your values, your hopes or important things about you that you want to be remembered for.
- Talking to loved ones about what you would want if things don't go well.
- Sometimes, this can be about expressing forgiveness or saying sorry to people you have argued with.

Preparing a legacy or an “ethical will”

- A legacy or an “ethical will” is a gift that you prepare for your family and friends to tell them what you want them to know.
- It can convey expressions of love, blessings, personal and family stories that you treasure; it can give words to what you value and want to be remembered for, what you hope your survivors will learn from you or want your children and grandchildren never to forget.
- Anything that you can prepare for your family and friends as a legacy is likely to be greatly appreciated by them when you are no longer with them.
- There are many ways to create a legacy: in writing, in an audio or video recording or in the form of an annotated album.
- Preparing a legacy is a deeply personal experience that often helps people focus on the value of the life that they have lived and the relationships and values that have been central to their life.
- An ethical will is often a work in progress and many people find it valuable to share the contents of their ethical will with their family members and friends during their lifetime. This sharing can be profoundly joining.



Making medical decisions in advance

Even though it may be difficult, it is often very helpful to talk with your doctor about how you would want to be cared for if you are in a life-threatening situation.

By having these sorts of discussions in advance, you can make the lives of your loved ones much easier.

Some people have very strong feelings about how they would want to be cared for if they were in a life-threatening situation.

It is worth giving consideration to two different situations that can arise.

1. Anticipated dying

Most commonly, life-threatening situations for patients with advanced cancer do not arise until the disease has spread to severely damage one or more of the body's vital organs. The unfortunate truth in this situation is that there are no good options, other than to ensure that you are made comfortable and free from pain or suffering.

Even the best of intensive care can do little to buy time in this situation if the underlying illness cannot be reversed. Most religions and cultures would support providing comfort and allowing a natural death, neither hastening nor trying to slow it down.

2. Unanticipated threatening events

The effect of the illness on the body and, sometimes, its treatment can cause sudden life-threatening medical crises for patients with advanced cancer. Some of these events may be reversible, some may have a very small chance of being reversed and some may not be reversible at all.

Patients have very different approaches to how they would want to be treated in this situation. Opinions are often influenced by any one of many factors, such as religious or cultural beliefs, fear of suffering, fear of death, unfinished life plans or the advanced stage of the disease.

- Some patients would want every possible treatment tried.
- Some would want to try some treatments but not others. For example, some patients give advanced directives that they would want to have artificial feeding, but would not want to be dependent on a machine to help them breathe.
- Some say that they would want aggressive treatments to be tried but, if they were not responding, they would want these stopped and replaced with comfort measures only.
- Some patients indicate that they would not want aggressive therapies, rather comfort measures only, allowing them either to recover with simple measures or to die in comfort.



When doctors don't know what the patient would have wanted, often they have to guess or to ask family members, who themselves may not know what the patient would have requested if he or she could communicate.

This causes severe distress to everyone involved.

“It is helpful to talk with your doctor about how you would want to be cared for if you are in a life-threatening situation”

Making your wishes known

To be ready for a situation in which you are too ill to be able to speak for yourself, you can make your wishes known either by preparing an advanced directive or by nominating a specific person to be the decision maker in emergency situations.

1. Advanced directive (sometimes called a “living will”)

An advanced directive is a document that is stored in your medical record (with a copy also kept at home), which records your wishes should you be in this sort of situation. You can prepare an advanced directive with your oncologist or one of his/her staff. Should you wish, this can be changed at any time.

2. Healthcare proxy (personal advocate)

Some patients would rather not think about these issues. Another option is to ask a friend or relative to be your spokesperson and decision maker, should you not be able to speak for yourself. This person is called a healthcare proxy.

This is a big responsibility and often family members or friends feel very uncomfortable about this type of role, especially if you have told them that you would not want aggressive therapy.

If you choose this approach, it is best to discuss these matters in as much detail as possible with the nominated person so that they really know what you would want.

15: When treatments are not helping

After several trials of different treatments, patients whose cancer cannot be cured will often reach a stage when further attempts at treating the cancer with chemotherapy, biological therapies or even radiotherapy may potentially cause more harm than they help.

There is an important distinction between treatment and over-treatment.

- Treatment can help and, in balance, the likelihood of benefit outweighs the risk of harm.
- In the situation of over-treatment, that important balance is lost. Over-treatment is very unlikely to be of benefit and often carries excessive risk of harm from side effects that may affect your quality of life or even shorten your life.

When time is limited by an incurable illness, this may not be a good use of your time and your physical and emotional energies.

“ In situations in which the disease can no longer be controlled, quality of life becomes even more critical ”

Why it is so difficult to stop treatments

- It is normal to associate new treatments with hope. Unfortunately, there are situations in which hope can be misleading and you are more likely to be harmed by new treatments than helped by them.
- Just as it takes courage to try a new treatment, it also takes courage to say “No more, it’s time to stop”.

Things to consider in this situation

- If you are in this situation, your remaining life is precious and you are likely to be better off using your time and energies doing important things with family and friends than spending time in hospitals or clinics receiving treatments that are unlikely to be of benefit to you and which may instead harm you.
- If you are not sure that what your oncologist is saying is correct, ask for a second opinion.
- Although it is your life, you cannot insist that an oncologist gives you a treatment if he/ she feels it will harm you without benefit.
- If you are having difficulties in coping, either physically or emotionally, ask your oncologist if he/she can arrange for a palliative care consultation or for help from a psychologist, chaplain or social worker.



This is not giving up

- Just because you may not need any more anticancer therapies (because there aren't any), this does not mean that there is no more treatment.
- Your oncologist and the team with whom he/she works will continue to help you to live as well as possible by trying to control your symptoms, as well as offering the necessary support to help you and your family to live out your life in as much comfort as possible at all times.
- This sort of palliative care is of vital importance and it is essential to good cancer care.

Stopping treatment does not mean stopping care

- In situations in which the disease can no longer be controlled, quality of life becomes even more critical than before.
- Problems relating to physical symptoms, distress and family coping are critically important at this stage.
- Often patients will benefit from the assistance of a palliative care or hospice team to help coordinate the best of care either at home or, if necessary, in a hospital or hospice.

16: If there are problems in your relationship with your oncologist

Sometimes patients feel frustrated that their needs for information, care, communication or access are not being adequately met.

We hope that this booklet will help you in asking the appropriate questions and in developing a strong relationship with your care team and in particular with your treating oncologist.

Trying to resolve problems

If there are problems with any of these aspects, here are several useful suggestions:

- Ask the oncologist for an appointment with enough time set aside to discuss the problems that are arising. Prepare for the meeting by listing your specific concerns and the things that you want to discuss.
- It is never a good idea to try to have this sort of conversation without planning or in the hospital corridor.
- If you cannot make an appointment with the oncologist, consider discussing the problem with your oncology nurse or social worker and ask if they can help act as your advocate.

Changing your oncologist

For various interpersonal reasons, some doctor-patient relationships just don't work.

If you feel that your care needs are not being adequately addressed or that there is an interpersonal mismatch between you and your oncologist, it may be reasonable to consider changing doctor, if this is possible.

Other members of the care team, such as oncology nurses or social workers who know you and the various oncologists with whom they work, may be able to suggest an oncologist with a temperament and approach that is more appropriate to your specific needs.

Appealing to rights

As a matter of last resort, some patients feel so frustrated that they feel it necessary to advocate for themselves based on an understanding of their rights. Information about patient rights in Europe is available from the "European Charter of Patients' Rights", which can be found at the website: www.patienttalk.info/european_charter.pdf

A. My healthcare team

The name of my oncologist:

Contact details: Office phone number:

Fax number:

Mobile number:

Emergency phone number:

Email:

Other persons involved in my care:

| | Name | Office phone number | Out of hours phone number |
|------------------------------|------|---------------------|---------------------------|
| Nurse | | | |
| Palliative care | | | |
| Social worker | | | |
| Dietitian | | | |
| Home care | | | |
| Spiritual care | | | |
| Physical therapy | | | |
| Occupational therapy | | | |
| Psychologist or psychiatrist | | | |
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In a unique partnering of oncologists, patients and patient advocacy groups, ESMO has produced this guide to help patients with advanced cancer and their treating oncologists.

For patients and their family members, it provides practical advice regarding cancer care, communicating with oncologists, important questions to ask, getting information and the challenges of living with an advanced cancer.

For practising oncologists, the guide will serve as a tool to help focus important discussions with their patients and to assist in addressing the many issues their patients are confronting.

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www.esmo.org/useful-links/patients-support



European Society for Medical Oncology