



A GUIDE FOR PATIENTS WHO HAVE JUST BEEN DIAGNOSED WITH CANCER

This Guide had been provided by the Anticancer Fund as a service to patients who have just been diagnosed with cancer. We recommend patients to consult their doctor. The information described in this document is based on scientific research and has informative purposes only.

More information about the Anticancer Fund: www.anticancerfund.org

For words marked with an asterisk*, a definition is provided at the end of the document.

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1. DIAGNOSIS AND TREATMENT CHOICE

When your doctor first tells you that you have cancer, it can be a very stressful situation. You may not remember many details. It is often difficult to take everything in, so you may want to see the doctor a few times before deciding on treatment. Your doctor may use medical terms you do not understand. It is okay to ask your doctor to explain something again. You can also check a word's meaning in the glossary of our website: (<http://www.anticancerfund.org/glossary>).

1.1 Questions for your doctor (general practitioner (GP), oncologist, surgeon)

Before you see the doctor, it may help to write down your questions. Taking notes during the session or recording the discussion can also help. Many people like to have a family member or friend to accompany them to take part in the discussion, take notes or simply listen.

A list of suggested questions:

- What type of cancer do I have?
- How extensive is my cancer?
- What treatment do you recommend and why?
- Are there other treatment choices for me? If not, why?
- What are the risks and possible side effects of each treatment?
- How long will this treatment last? Will I have to stay in hospital?
- How much will this treatment cost?
- Will I have a lot of pain with the treatment? What will be done about this?
- Are the latest tests and treatments for my type of cancer available in this hospital?
- Are there any clinical trials of new treatments?
- How frequently will I have check-ups?
- Are there any complementary therapies that might help me?

1.2 Second opinion

Many people hear a diagnosis of cancer and think they must make a decision and dive into treatment the next day. While this can be true for certain types of lymphoma and leukemia, for the average patient, a few weeks to get another opinion and consider your options is realistic. There is no cookbook to follow when treating a cancer and you may encounter different treatment options for the same patient, even within the same institution. Every patient is different and each case should be dealt with individually. A second opinion can present different treatment options that were not known about or offered by the first physician or it can act as a quality check to confirm the first suggested treatment. There are many reasons to get a second opinion, including having a rare type of cancer or unknown primary site, the fact that you live in a rural area that does not treat many cancers, the fact that you have been told "there is nothing we can do", or the fact that you just don't feel comfortable with the first doctor you saw.



Second opinions are also a way to educate yourself about your options. If one doctor says treatment A is the best, but doctor number 2 does not agree, ask them to explain why. Many patients fear offending their doctor by getting a second opinion. A good doctor understands the need to research all of your options, particularly when dealing with something as important as cancer. If your doctor discourages you in getting a second opinion or infers that you can't get better care somewhere else, all the more reason to get another opinion. You do not need the permission of your doctor to get a second opinion. Do not let your oncologist intimidate you or make you feel unsure. It's your right and duty to get a second - or even third - opinion!

Before seeking a second opinion it is worthwhile asking your doctor if his/her recommendations for a specific treatment have been discussed with other doctors (oncologists, surgeons, etc.). Often, the recommendation made to you by your doctor 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.

Educate yourself about the "standard" therapies for your tumor type. The European guidelines are available on the Anticancer Fund website for each cancer type for both professionals and for patients (<http://www.anticancerfund.org/cancers>). The 'Guides for Patients' (<http://www.anticancerfund.org/guides/cancertype>) help patients and their families better understand the nature of cancer and explain the best treatment choices available according to the type of cancer. 'Guides for Patients' are currently available for acute myeloblastic leukemia, bladder cancer, breast cancer, cervical cancer, chronic myeloid leukemia, colorectal cancer, endometrial cancer, esophageal cancer, follicular lymphoma, liver cancer, melanoma, non-small cell lung cancer, ovarian cancer, pancreatic cancer, prostate cancer and stomach cancer. Further Guides for Patients will be made available on a regular basis and the texts will be updated based on changes in the ESMO Clinical Practice Guidelines. For the United States, the National Comprehensive Cancer Network provides guidelines for treatment options that are available on their website: www.nccn.org.

There are a number of ways to find a doctor for a second opinion:

- Your doctor or GP may refer you to one or more specialists. At cancer centers, several specialists often work together as a team.
- A national medical society, a nearby hospital, or an academic center can usually provide the names of specialists

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Next steps & Questions to ask:

If you plan to obtain a second opinion, you should take the following steps:

- Ask your doctor for a summary letter regarding your situation and his/her recommendations for treatment
- When you attend the appointment for the second opinion, take all your important test results with you
- If you have had x-rays or scans, take not only the reports but also the discs or films of actual imaging studies with you

Write down the questions you want to ask ahead of time, or take someone with you for support and to help you remember the questions and answers. Some people bring a tape recorder to record the appointment (ask for permission to do this in advance) or bring a friend or relative along with you.

Here are some questions you may want to ask:

- What benefits/risks can I expect from this therapy? Do the benefits outweigh the risks?
- What side effects can be expected?
- Is the proposed treatment in line with the national guidelines? If not, why do you expect this treatment to be better?



1.3 Clinical trial

A clinical trial or a clinical study is a research study conducted with patients to evaluate whether a new treatment is safe (safety) and whether it works (efficacy). Clinical trials are performed to test the efficacy of drugs but also non-drug treatments such as radiotherapy or surgery and combinations of different treatments.

If you see an oncologist who encourages you to participate in a clinical trial of an experimental treatment (e.g. a new medication) compared to a placebo or a drug not typically used for your tumor type, but you know that drug X is effective for your tumor type, you can ask appropriate questions. Clinical trials are extremely important for improving cancer care, but you must weigh up the risks and benefits of each option for your situation. In most cases, if you are offered a clinical trial, it should not be your only option and you should also have the option of a "standard therapy".

Participation in a clinical trial is not for everybody and some people are concerned about:

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

More information on clinical trials is available on the Anticancer Fund website (<http://www.anticancerfund.org/trials>).



1.4 Your relationship with your doctor (GP, oncologist, surgeon)

Your relationship with your doctor can be a powerful tool

- He/she can help guide you in making decisions about possible treatments
- He/she can be your care coordinator to help utilize the range of services available to help you cope with illness
- He/she can be your advocate in dealing with many of the bureaucratic issues associated with 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 doctor will continue for as long as you need it

- A relationship with a treating doctor is a long-term relationship
- Should your cancer be curable, you will still need care after the treatment and a strategy for follow-up
- If your condition cannot be cured, then you 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



1.5 Most important sources

- CAMEO

CAMEO

Complementary Medicine Education & Outcomes Program

The Complementary Medicine Education and Outcomes (CAMEO) Research Program is a collaborative initiative of the University of British Columbia and the BC Cancer Agency (BCCA) research program at the Vancouver Centre of the BCCA. The CAMEO program was developed to address the needs expressed by cancer patients in BC for complementary and alternative medicine (CAM) information and support in making decisions about CAM.

The mission of this research program is:

“To integrate and evaluate evidence-informed CAM education and decision-support strategies within the context of everyday conventional cancer care, and facilitate the development of new CAM research.”

- ESMO



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

Since its foundation in 1975 as a non-profit 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.



2. DEFINITIONS

Experimental therapies

Experimental therapies are new treatments that are being tested in patients via a clinical trial protocol.

Guidelines

Guidelines are a set of recommendations used by doctors as reference documents for the best standards of care to guide the diagnosis, follow-up and treatment of different cancer types. The medical information provided in the 'Guides for Patients' on our website (<http://www.anticancerfund.org/guides/cancertype>) is based on the ESMO Clinical Practice Guidelines.