

I have cancer, what now?

The first steps after the diagnosis







Why me?	4
Waiting for the results and starting the treatment	_ 5
Who can you turn to?	_ 6
Treatments	_ 7
Beware of false promises	_ 8
Managing side effects	_ 9
Do you want to have children?	_10
Costs associated with treatment	_11
I need α wig	_12
I need an external breast prosthesis	_12
Tips for your medical appointments	_13
Sick leave and returning progressively to work	_14
Summons for α check-up	_15
Treatment abroad	_15
Post-operative care	_16
Who should I talk to about the diagnosis?	_17
Asking for and accepting help	_18
Family support	_18
Special leave	_18
Finding support: Who can I contact?	19

Being diagnosed with cancer is a distressing experience. You can feel helpless and lost in view of the medical questions and social uncertainties.

Everyone reacts differently to a cancer diagnosis. You may feel shock, anxiety, anger, helplessness, sadness, injustice or simply not want to believe it. It's important to accept all your emotional reactions, as they are completely normal and legitimate. Above all, be patient and kind to yourself, because adapting to a life with cancer and the changes it can bring, takes time.

The Fondation Cancer is there to help and support you and your loved ones during and after the illness. Various offers and services for patients and their families are available from the Fondation Cancer and numerous information and brochures such as the *Practical Guide* and *Coping with cancer - Life during and after treatment* are also available online on our website cancer.lu.

This guide has been specially designed to answer the most common concerns you may have after a cancer diagnosis and to give you some **initial guidance** on the steps to take at the beginning of the illness. If you have any further questions or need emotional or psychological support, don't hesitate to contact the Fondation Cancer's psychosocial service or ask your hospital's care team to see the psychologist of the oncology department.

Why me?

It's only natural to ask the question "Why me?". As human beings, we need life events to be understandable, controllable and meaningful. The experience of cancer often generates unpredictability and helplessness. Identifying probable causes and developing a subjective explanatory model for the genesis of cancer can make the disease more understandable and controllable, and thus reduce the feeling of loss of control.

However, this search for the why can also lead to selfblame, a feeling that does not help you at all cope with the disease. Be aware that cancer is a complex, multi-factorial disease; there is no single cause or triggering event.

Don't make yourself feel guilty! Rather than blaming yourself, be indulgent and take care of yourself. If you're suffering from feelings of helplessness or guilt, don't hesitate to ask for emotional support from the Fondation Cancer's psycho-oncologists.



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Waiting for the results and the start of the treatment

Waiting for the results and the start of the treatment is often a particularly difficult time. It can seem long and stressful, because the unknown often generates uncertainty.

Whether you suspect or have been diagnosed with cancer, it's perfectly normal to want to start treatment as quickly as possible. Be aware that the majority of cancer diagnoses are not emergency diagnoses. It is essential that doctors have as much information as possible about your cancer in order to determine the best treatment for you, and this takes time. The complexity of cancer treatment and the need to provide comprehensive, individual care for each patient require the collaboration of several specialists from different disciplines. These specialists work together in *Tumor Boards*, multidisciplinary meetings designed to draw up an individualized treatment plan.

To help you get through this waiting period, try to carry on with your usual activities to distract yourself and relax as much as possible.

It may take some time before the results are available. Check with your doctor to find out how long the results of your examination or biopsy will take. If you do not hear from your doctor after this time, contact them to find out why.



Who can you turn to?

You have a free choice of doctor in Luxembourg. Normally, your GP will refer you to a specialist, bearing in mind that not all cancers need to be treated by an oncologist. On the website of the *Société Luxembourgeoise d'Oncologie*, slo.lu, you will find the list of its members.

All hospitals in Luxembourg have an oncology department:

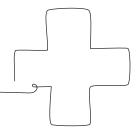
- <u>Centre Hospitalier Emile Mayrisch</u> (CHEM) Esch/Alzette
- <u>Centre Hospitalier Luxembourg</u> (CHL) Luxembourg City

The Clinique du Sein has obtained the OnkoZert certification from the German Cancer Society (Deutsche Krebsgesellschaft - DKG) as a Centre of Excellence for breast cancer.

Hôpitaux Robert Schuman
 Luxembourg City (Zitha & Kirchberg)

The HRS's *Prostatakarzinomzentrum* has obtained the *OnkoZert* certification from the German Cancer Society (*Deutsche Krebsgesellschaft* - DKG) as a Centre of Excellence for prostate cancer.

- <u>Centre Hospitalier du Nord</u> (CHdN) Ettelbruck
- Centre François Baclesse (CFB), Centre National de Radiothérapie Esch/Alzette



Treatments

There are different types of cancer treatment (operations, chemotherapy, radiotherapy, targeted therapies, hormone therapies, immunotherapy, stem cell transplants, etc.). Every cancer is different, and so are the treatments. Your medical team relies on the international guidelines for your personalised treatment.

If you would like a **second medical opinion** on the proposed treatment, you should ask your healthcare team to make your medical file available to you.

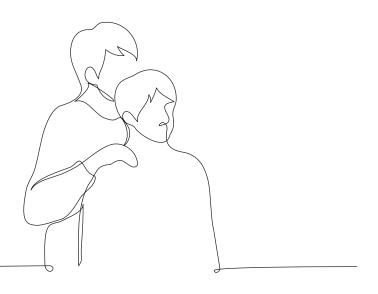
If you are looking for information on treatments, you can consult the Fondation Cancer's brochures on chemotherapy or radiotherapy in hard copy or under the heading *Publications* on our website.

If you're looking for more information, first of all make sure you're browsing reliable and scientific websites. Here are a few suggestions:

- cancer.lu
- cancer.org
- cancer.net
- cancerresearchuk.org
- cancer.be
- e-cancer.fr

- liquecancer.ch
- cancer.ca
- krebsinformationsdienst.de
- krebsliga.de
- nccn.org
- <u>ligacontracancro.pt</u>

Every cancer is different, and so are the treatments.



Beware of false promises

Having cancer is a challenging experience and leaves you vulnerable. There are complementary treatments and support services that can help you cope better with your treatment. However, be wary if someone makes you promises of an easy cure while insisting on abandoning your scientifically-proven "traditional" treatment. Unfortunately, there are no miracle solutions! Warn your doctor about any additional treatment you are taking, even food supplements or herbal medicines, as they may interact with your treatment.

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Managing side effects

Any treatment can cause side effects, but not necessarily. Talk to your medical team about them, as many side effects can be limited or avoided by preventive treatments or practical advice. Feel free to consult our brochures *Radiotherapy* and *Chemotherapy* or *Managing side effects* on our website <u>cancer.lu</u> for more information. The Fondation Cancer's psychologists can also offer you advice and strategies to help you deal better with the undesirable side effects.

As well as psychological support, the Fondation Cancer offers other supportive care to relieve side effects and improve your well-being and quality of life:

- A nutritionist offers <u>free onco-nutritional</u> <u>counselling</u> to help you achieve a balanced diet and alleviate side effects affecting the digestive system.
- An oncoesthetician offers <u>free counselling and cosmetic treatments</u> to alleviate the effects of therapy on the skin and improve self-image and well-being.
- Physical activity and relaxation are good allies in the fight against fatigue. You can find out about the wide range of sports' groups for people with cancer in the <u>Help section</u> under <u>Patient groups</u> <u>and activities</u> on our website and on the website of the <u>Fédération Luxembourgeoise des Associations</u> de Sport de Santé [FLASS], <u>sport-sante.lu</u>.



Do you want to have children?

Unfortunately, some treatments can harm your fertility. If you're young and haven't yet completed your family plan, it's important to take steps to preserve fertility before starting treatment. Talk to your oncologist about this, as there are available solutions. There is an **onco-fertility service** for men and women at the CHL and a fertility preservation service for men within the *HRS Urological Group* at Kirchberg.

Costs associated with treatment

If you are affiliated with the CNS, the costs of chemotherapy, immunotherapy, targeted therapy and radiotherapy are fully covered. However, other costs may be added which are not reimbursed at 100 %. If you have supplementary insurance, you may be entitled to **additional reimbursements or cover**.

If you have to go to hospital for repeated medical treatment, such as chemotherapy or radiotherapy, the CNS may cover **the cost of a series of transports by taxi**. To do this, the doctor must apply to the health insurance scheme to cover the cost of serial transport. You must use a taxi company approved by the CNS; the list of companies is attached to the agreement sent by the CNS.

Anyone on a low income is entitled to *Tiers Payant Social*, a system designed to **facilitate access to medical care** by avoiding the need to pay in advance the medical charges. To take advantage of the *Tiers Payant Social* scheme, contact the relevant social services office in your municipality of residence. For more information, consult our online *Practical Guide*.

However, other costs may be added which are not reimbursed at 100 %.

I need a wig

You are at risk of losing your hair as a result of certain chemotherapy treatments and would like to buy a wig. The *Caisse Nationale de Santé* (CNS) refunds a fixed sum after prior agreement. First of all, you need a medical prescription of which you will send a copy to the CNS. Once you have received the CNS's authorisation, you can buy a wig and send the original prescription, the authorisation and the invoice to the CNS to get refunded. For further information, check out our *Practical Guide* or the *Find practical information* section of our website. We also offer a selection of free caps at the Fondation Cancer.

I need an external breast prosthesis

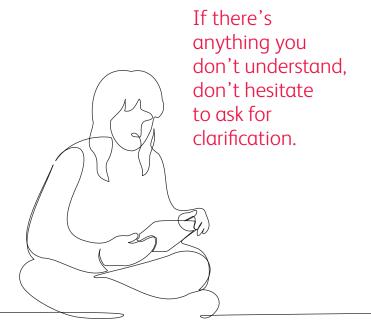
After a mastectomy, you may need an external breast prosthesis. To get refunded, you need a medical prescription. For better advice, you can contact your breast care nurse at the hospital or an orthopaedics shop. For more details, consult our *Practical Guide* or our website under the heading *Find practical information*.

Tips for your medical appointments

Prepare yourself for the medical appointments. The best thing to do is to have a notebook that you take with you each time, in which you write down all your questions and the side effects of any medication you are taking. That way, you're sure not to forget anything and you can also note down the doctor's answers. If there's anything you don't understand, don't hesitate to ask for clarification. Rephrase briefly in your own words to avoid misunderstandings. Keep a file of all test results and medical reports.

Ask **someone you trust** to accompany you to your medical appointments.

Understand that your doctor is not always available for you. If you have a lot of questions to ask, make an appointment for a calmer conversation.



Sick leave and returning progressively to work

If you are on sick leave due to cancer, the normal procedure applies. You should know that, while you are obliged to inform your employer of the duration of your sick leave, you are not obliged to communicate the reasons for your absence. Experience has shown however, that an attitude of trust and open communication is useful when returning to work after a long period of absence.

If you have been on sick leave for more than four weeks and are thinking of returning to work, you can take advantage of a *progressive return to work for therapeutic reasons*. This allows you to return to work at your own pace and capacity. Provided your employer agrees, the doctor must submit a request to the CNS. For more details, consult our *Practical Guide* or our website under the heading *Cancer and work*.

Sometimes, continuing to work can also be beneficial in helping you to cope better with the disease. If you feel that continuing to work will have a beneficial effect on your health, you are not obliged to take sick leave. If you wish to work during treatment and have your doctor's agreement, it is a good idea to discuss this openly with your employer so that you can plan a realistic scenario and have enough leeway for the therapy and recovery phases.

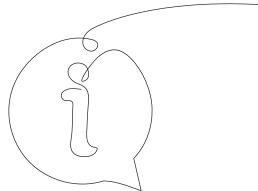
For more details, see our guides <u>How to manage</u> cancer at work for employees and employers.

Summons to the medical check-up

Over a two-year period, you can be on sick leave for a maximum of 78 weeks, during which time you will receive sick pay equal to 100 % of your salary. After six to eight weeks' sick leave, you will automatically receive a summons to attend a medical check-up by the *Caisse Nationale de Santé* (CNS). This is a standard procedure. The examining doctor will carry out a clinical examination. As they do not know your situation, it is important to bring your medical file with you so that they can get an overall view of your health condition and anticipate your future employment situation.

Treatment abroad

If you need to undergo treatment abroad, your doctor in Luxembourg must submit a request for **prior authorisation (S2)** to the Social Security Medical Board. If the request is accepted, you will receive a certificate from the CNS authorising your transfer abroad.



You can contact a home care service to coordinate your care at home.

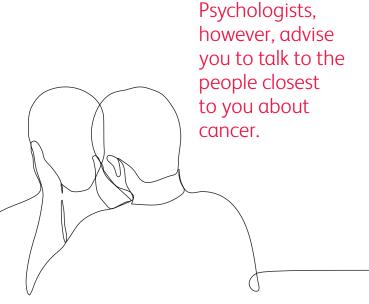
Post-operative care

If, after surgery, you need help with wound dressings or injections, the doctor may issue a prescription for a *nursing service at home*. You can then contact a nursing service at home to coordinate your care at home. If after an operation your general condition does not allow you to return home, the doctor can make a request to the *National Post-Oncology Rehabilitation Centre* in Colpach. All they need to do is fill in and send them the application form available on their website: rehabilitation.lu

Who should I talk to about the diagnosis?

Who you confide in and talk to about the disease is a very personal choice. Psychologists, however, advise you to talk to the people closest to you about cancer. If you have children, it is essential to tell them the truth and talk about cancer in a way that is appropriate and adapted to their development. To protect their children, parents sometimes try to hide the illness from them, but children soon realise that their parents are worried and concerned. A child left in the dark imagines disaster scenarios that can be more traumatic than clear, appropriate information about a parent's cancer. Not being aware of what is happening can lead to feelings of exclusion and loneliness. If you're not sure how to tell your child and need advice, contact the Fondation Cancer's psychologists or consult our brochure *I've got* cancer: how do I tell my child? or our website under

the heading How do I talk about cancer?



Asking for and accepting help

Cancer is not a disease that you go through alone. Accept the help that is offered. Those around you want to help but often don't know how. Dare to ask for practical help and communicate openly what you need, such as doing the shopping, taking the children to football, preparing a meal, etc.

Family support

If you are a parent undergoing treatment (postoperative, chemotherapy or radiotherapy) and are finding it difficult to look after your children (under the age of 13), you can apply for family assistance to help you with the day-to-day running of the family home by relieving the partners of their parental duties during the difficult period of treatment.

For more information, contact the Fondation Cancer or visit our website under *Family Support*.

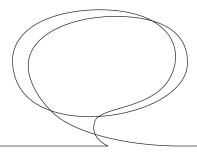
Extraordinary leaves

If you require personal care or assistance for serious medical reasons certified by a doctor, your loved ones are entitled to **extraordinary leaves** known as **caregiver's leave**. For more information, see our <u>Practical Guide</u> or visit our website under the <u>Extraordinary leaves</u> section under <u>Healthcare</u>.

Find support at the Fondation Cancer

Facing cancer is not easy. Having the right support can help you cope better, because cancer is not something you go through alone. If you have any questions or need help, contact the Fondation Cancer's psychosocial service. Here are the services we offer free of charge to cancer patients and their next of kin, so that we can be at your side as best we can during and after the illness:

- Psychological counselling
- Cognitive rehabilitation
- Onco-sexology counselling
- Onco-aesthetic treatments and workshops
- Onco-nutrition counselling
- Family support
- Financial support
- Talking, relaxation and sports groups for patients
- Information and booklets for patients



We're here to help.



The Fondation Cancer, for you, with you, thanks to you.



Fondation Cancer

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