
Eurocarers' Cancer Toolkit



The essential care and cancer toolkit

Tips and tools for people taking care
of someone with (breast) cancer



Eurocarers' Cancer Toolkit





Introduction

“Diagnosis of cancer is striking and unexpected – it turns your whole life upside down.”¹

If you are taking care of a relative or friend affected by cancer, you may have a lot of questions about cancer and what it means for your loved one as well as yourself. You may find it difficult to face the situation, both emotionally and practically.

No matter whether you are taking care of your relative full-time or from time to time, at a distance or in his/her presence, we have developed this ‘toolkit’ with you in mind. And even though it may not answer all of your questions, we hope that it will:

- Provide you with some key information
- Help you to take stock of the situation
- Encourage you to evaluate and organise the support you may need

As a relative of a person affected by cancer, you play a key role in her/his life.

Supporting them through this ordeal can be a personal source of satisfaction, though it also creates its own set of challenges.

100

million informal carers in Europe

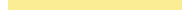
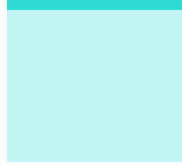
People taking care of a loved one affected by a chronic disease or a disability are referred to as “informal carers”. It is estimated that there are more than 100 million informal carers in Europe.

This ‘Cancer Carers’ Toolkit builds on the experience and knowledge of informal carers looking after people with cancer, as well as cancer patients and health professionals throughout the European Union. It is based on research and evidence, and is in line with the recommendations made at the EU level by the cancer community.

In addition, the [Country information sheets](#) provide details about your rights and the support available to cancer carers in a number of countries.

“A diagnosis creates tension in the family – you need time to recuperate and think through the new roles, new perspectives, new challenges. Furthermore, it is essential to understand the prognosis and the current stage of cancer diagnosed.”

¹ All quotes gathered through a survey and interviews of informal carers of a person with cancer conducted by Eurocarers between November and December 2017.



Coping with caregiving



What is cancer?

Cancer is the name for a collection of related diseases characterized by the excessive growth of cells.

These cells grow beyond their usual boundaries; invade adjoining parts of the body, spreading to other organs. These excess cells are able to multiply without stopping and may form abnormal growths, **usually called tumours**. Other common terms are **malignant tumours and neoplasms**. There are in fact many subtypes and each requires a specific management strategy.

There are more than 200 different types of cancer,

affecting almost any part of the body, and each has its own name and corresponding treatment. As cancer tumours grow, some cancer cells break off and travel through the body via the blood or lymphatic system, forming new tumours in distant parts of the body away from the original tumour. This makes cancer an extremely challenging and serious illness. When this happens, it is called metastatic cancer, as the process by which cancer cells spread to other parts of the **body is called metastasis**. For many types of cancer, it is also called stage IV cancer.

Second

cause of death globally

Cancer is the second leading cause of death globally and accounted for 8.8 million deaths in the world in 2015.

In the European Union, almost 1.3 million people died from cancer in 2014. This was more than one quarter (26.4 %) of the total number of deaths.

The good news is that **new and innovative treatments are helping people eliminate the disease or turning the cancer into a controlled and manageable chronic disease**. The reality is though that cured people as well as those with chronic cancer may require prolonged carers support just as much as those undergoing active treatment.



What is cancer?

Risk factors

A series of individual and environmental factors are highlighted by research as being associated with a higher risk of cancer. These include: **tobacco, chemicals (carcinogens), obesity, infections, exposure to radiations, and autoimmune diseases.**

Some dietary habits such as heavy consumption of red meat, chronic alcohol consumption, and long-term exposure to food additives are also considered as generating a higher risk of cancer. In addition, heredity can play a role.

The prognosis is the likely course that the cancer will take. It is determined by a number of factors, including the size, location and stage of the cancer, the type of cancer, treatment options and their effectiveness, the person's age and health status...



Prognosis and dietary habits

“Cancer is a fluctuating condition with **long treatment cycles**. So, the carer may move in and out of caring due to periods of remission, or the nature of the treatment.”

Understanding the main types of treatments

The person affected by cancer may be proposed one of several of the treatments below:



Surgery

Surgery involves removing all or part of the cancer with an operation. It is an important treatment for many cancers.



Hormonal therapies

Hormonal therapies work by altering the production or activity of particular hormones in the body.



Chemotherapy

Chemotherapy uses drugs to treat many different types of cancer. It is most commonly given as an injection into a vein or as tablets or capsules.



Hormonal therapies (targeted biological therapies)

Targeted (biological) therapies interfere with the way cancer cells grow and divide.



Radiotherapy

Radiotherapy is the use of high-energy rays, usually x-rays and similar rays (such as electrons) to treat cancer.



Stem cell and bone marrow transplants

Stem cell and bone marrow transplants are used with high-dose chemotherapy to treat and control some cancers.

What is cancer?

Curative therapies / palliative and supportive care

The majority of people with cancer receive chemotherapy as well as surgery or radiation therapy. The aim for curative therapies is to eliminate all cancerous cells and “cure the cancer,” resulting in “complete remission.” Complete remission means that tests, physical exams, and scans show that all signs of your cancer have disappeared. Depending on tumour characteristics, treatment goals can also include controlling the disease rather than curing it.



Palliative care is for people living with a terminal illness where a cure is no longer possible. It may also be used for people who have a complex illness and need their symptoms controlled. Although these patients usually have an advanced, progressive condition, this isn't always the case. **Palliative care aims to improve the quality of life of these patients and their families,** through the prevention and relief of pain and other problems associated with the illness.

What is breast cancer?

There are different types of breast cancer:

Ductal carcinoma in situ (DCIS) is the earliest form of breast cancer. DCIS is when there are cancer cells in the ducts of the breast. These cells are contained (in situ) and have not yet spread into normal breast tissue. DCIS may show on a mammogram and is usually diagnosed through a breast screening.

Lobular carcinoma in situ (LCIS) is not breast cancer, although its name can be misleading. Changes in the cells lining the lobes show a woman has an increased risk of developing breast cancer later in life. But most women with LCIS don't get breast cancer. They do however have regular check-ups with breast examinations and mammograms.

80%

of invasive breast cancers start in the lobes of the breast

Invasive breast cancer means the cancer cells have spread outside the lining of the ducts or lobes into the surrounding breast tissue. Most invasive breast cancers (80%) start in the ducts of the breast. About 1 in 10 invasive breast cancers (10%) start in the lobes of the breast. This type can sometimes be difficult to diagnose on a mammogram because of the way it grows. Some women may need a magnetic resonance imaging (MRI) scan.

Uncommon types of breast cancer:

Inflammatory breast cancer: This is when cancer cells grow along and block the tiny channels (lymph vessels) in the skin of the breast. The breast then becomes inflamed and swollen.

Paget's disease of the breast: this shows as a red, scaly rash (like eczema) on the skin of the nipple. Women with Paget's disease may have DCIS or invasive breast cancer.



What is cancer?

A widespread disease

Though it also concerns men, breast cancer is the most common cancer in European women. 1 in 8 women in the European Union will develop breast cancer before the age of 85. An average of 20% of breast cancer cases in Europe occur in women when they are younger than 50 years old; 37% occur between the ages of 50–64 and the remaining cases in women above this age. Breast cancer therefore affects many women during their years dedicated to working and raising a family.

It is estimated that 91,585 women died from breast cancer in 2012 in the European Union. The increasing number of breast cancer cases may be due to changes in lifestyle habits: for example a more **sedentary lifestyle, weight gain, obesity and sociological changes**, such as women having fewer children and having them later.

The prognosis is determined by a number of factors, including the size of the breast cancer, the stage of the breast cancer, the type of the breast cancer, the person's age and health status... New and innovative treatments are helping people diagnosed with breast cancer live longer than ever before. Still, breast cancer may come back or spread to other parts of the body after treatment.

You may want to know more about the disease and treatments. While many websites provide information on cancer, it is important you rely on information that is trustworthy. Check the sources of information listed in your country information sheet if available, or ask your general practitioner to direct you to information sources you can trust.

1/8

European women will develop breast cancer

20%

Younger than 50 years old



The cancer carer's journey

"My advice would be to be well informed in advance about what the carer's job means concretely, e.g. what are the tasks, risks and burdens. To become a carer is a serious decision. Be aware of all aspects and be ready to prevent potential difficulties."

A variety of roles

Each situation is specific, and will depend upon the type of cancer, the prognosis, and the family situation... and in how far your loved one is prepared to **speak openly about the disease and ask for help**. Here, people who have been caring for someone with cancer, describe some of the roles and tasks they have typically undertaken.

First, they help the person on a daily basis as their autonomy has been reduced because of the disease. This entails helping with shopping, cooking and cleaning, dealing with administrative tasks, and also with personal care when needed.



Daily tasks



Administrative tasks



Emotional support

They also provide emotional support to the person with cancer and other relatives. Indeed, **they are often the ones who have open communication with the cancer patient and other family members, relatives and close friends about the cancer diagnosis and prognosis**. When supporting a relative with cancer, they engage with health and care professionals and are involved in discussions regarding treatment options.

In case of at-home treatment, they may ensure the coordination of health and care interventions, facilitate the person's adherence to treatment (for example making sure he/she goes to his/her medical appointments, takes his/her medicine, as well as carrying various healthcare tasks such as giving injections, changing dressings, and helping manage the side-effects of treatment.

"I have been a link between the outer world and the patient, (...) explained treatment and prognosis details where there was no time for it from a professional, participated in running the household and activities."

Supporting a person with cancer may also involve contributing or helping to manage the financial costs linked to the illness and its treatment, and planning for the future caring situation.

The cancer carer's journey

Facing stigma

“The disease still represents a certain barrier to healthy active people.”



People taking care of a person with cancer are sometimes confronted with negative attitudes towards cancer, or experience discrimination in their social life or work place. Such attitudes mainly come from a lack of information and knowledge about cancer and the role of carers.

When it comes to **Breast Cancer**, people may have false understanding and think it is now easily curable, and therefore underestimate the burden of treatment, as well as the threat to life and the tiredness or fatigue that may be associated with the diagnosis itself and the subsequent treatment. Such views may also be true for other family members, friends and employers.

Evaluate what support you need and find ways of putting it in place

“Ask for help from other carers, professionals, family and friends. We usually underestimate the level of help family and friends are willing to provide.”



Ask for help from other carers

Think about the actual needs of your loved one, and how this may evolve over time. Taking care of a person with cancer may imply various roles and tasks, some of which you may not be prepared to handle. You may feel under pressure to take this role. Caring activities may also be difficult to combine with your professional and personal responsibilities. You may think about asking support from your family, friends and neighbours, finding out about statutory support, or getting support from civil society organisations.

Naturally, children live in hope; this means that young people who take care of a relative may need particular support, allowing them to build their own life through education and social activities.

Be yourself.

You cannot hide the soul and the sorrow

Caring for a loved one with cancer can be overwhelming; indeed you may experience many different feelings. You may find it useful to try and talk about your feelings with the person you are taking care of, if it is relevant, and with other external persons. If you are feeling isolated, you may find support with civil society organisations helping people with cancer. This can be face to face, online or over the phone.

The cancer carer's journey

"The whole family was affected when my husband had cancer, but the focus was only on the patient."

When cancer affects one member of a family, the whole family is impacted. Emotional support may therefore be needed for all members of the family.



Talk about your feelings



Cancer organisations

Deal with uncertainty

Managing these different roles is made all the more difficult by the changing nature of the disease as well as of the needs of the person, particularly as they may go back and forth between treatments, periods of recovery, and ups and downs. Uncertainty about the situation of the person with cancer may last several years, therefore it is important to mind your own needs and projects as much as possible. Besides all else, they are a source of energy, diversion, social and financial support.

"My advice would be not to put too many things in your life on hold, despite the uncertainty."



Ups and downs



Diversion and support

Breast cancer

People affected by breast cancer are mostly women. Many are also actively raising a family or taking care of other relatives (parents, grand-children...). You may need to take over this role, or arrange for someone else to take on these responsibilities.

Try and discuss the best way to manage the patient's usual caring tasks. If you find this difficult or feel uncomfortable doing so, do not hesitate to ask for external help.



Role of carers



External help

The value of being a carer and living well

Being a carer sometimes makes it difficult to take care of yourself. Priorities will change as disease condition progresses and looking after yourself takes usually last place on a long list of heavy duties. Caring for a loved one isn't an easy task, but it is important to understand the value of being a carer and living well. **Being in good psychological and physical shape helps you provide better quality care.** Below you can find useful tips for looking after yourself:

During the day, **find leisure time even if it is only for one hour or less and do something that you enjoy** indoors or outdoors (reading a newspaper, having a relaxing bath, learning a new language, doing some exercise or relaxation, going for a walk, going shopping).

"Remember this is a marathon rather than a sprint!"



Do something that you enjoy

Take a break. Once a month arrange to take a day off. Arrange your break with the rest of your family, a neighbour, a friend, a care professional or an agency, in order to make sure that someone else will be there for the person you care for.

Call a friend or relative regularly. Try to stay in touch!

Exercise regularly. If you don't have much time, even 30 minutes can make a difference. If you are an internet user you can watch a video and work out at the same time.

Try to follow a **balanced diet.**

Whenever you aren't feeling well (mentally or physically), **get advice from your family doctor.** Don't let a problem grow!

Create a support network. Get in touch with other carers with similar difficulties, through carers or condition-specific organisations. Participate in group or individualised interventions. It can help you understand the situation and handle emotions as anxiety, depression and guilt.



Maintaining a good level of wellbeing

(physical and mental health)



Coping with stress, addressing depression

Coping with stress

Stress is part of everyday life and, for many carers, stress can be a major factor affecting their health.

Stress is caused by the many demands made on our time and energy, and the expectations we have of ourselves. Not all stress is negative – stress can alert you to potential dangers and can also spur you on to achieve a goal or complete a task. However, sometimes the balance tips too far and the pressure becomes so intense or so persistent that you may feel unable to cope.

Stress can make it hard to handle the demands of caring. You can become more and more exhausted, tense and irritable, putting a strain on relationships. This can make you feel you are losing control over your life and that there is no way of regaining this control.

“The first step in dealing with stress is to recognise it is happening”

The first step in dealing with stress is to recognise it is happening. You may have so little time to yourself that you don't realise it at first. When you do start noticing the symptoms of stress (see below), do not struggle on, hoping it will go away. Everyone reacts to stress differently, and each body sends out its own different red flags. The sooner you deal with the problem, the better, and just talking about how you feel can help you find a way to deal with it.

The symptoms of stress can be both mental and physical, and can vary from person to person:



Mental symptoms can include anxiety, anger, depression, lack of appetite, sleeplessness, crying often, tiredness and difficulty concentrating.



Physical symptoms can include chest pains, cramps, muscle spasms, dizziness, restlessness, nervous twitches and breathlessness.

Over the long term, **some of these stress symptoms may affect your health** and put you at risk of high blood pressure, which can lead to heart attacks and stroke.



Coping with stress, addressing depression

Coping with depression

There are steps you can take to help tackle depression and move on. What works will be different for each individual but here are some ideas:



Don't keep it to yourself. If you are depressed, try telling someone about it. It often helps to talk things over with someone you trust rather than keeping it all bottled up.



Do some exercise. Get out of doors, even if only for a walk. This will not only help keep you fit but may also help you sleep better. Try to keep active – whether that is housework, 'Do It Yourself' or your normal routine. All of these can help you take your mind off thoughts that may make you more depressed.



Look after yourself. Eat a healthy diet and steer clear of alcohol as this can make your depression worse. It's also important to get enough sleep.



Meet with other people who have experience depression and hear how they coped. Self-help groups can often provide advice and training on relaxation and information on complementary therapies.



Keep hopeful. Remind yourself that you are suffering from an experience that many other people have gone through. You will eventually come out of it, although you may find it hard to believe at the time.

Coping with stress, addressing depression

Treatment

If you feel that you may be depressed, see your General Practitioner (GP). It is important to see your GP sooner rather than later, so you can start having treatment and start feeling like your old self again.

If your GP thinks you have mild depression that may improve, they might simply suggest that they see you again in a couple of weeks' time. If your GP thinks you need treatment, there are two types they may prescribe:



A short course of medication – for example, a short course of anti-depressant drugs to help lighten your mood to allow you to cope more effectively. These need to be taken two to four weeks to have an effect. Antidepressants can work well, and help you to feel and cope better, but you may have to try different doses – or different types – to find the best one for you.



A talking treatment – such as counselling, cognitive behavioural therapy or psychotherapy. These give you a chance to talk through difficulties and feelings and can help you to learn how to manage your stress or depression by using a variety of techniques.

If your GP feels that you have severe depression, they may suggest a talking treatment and antidepressants. Seek advice and consider all of your options before deciding on a course of treatment.

Relaxation techniques

When we are thinking of relaxation, we usually think of doing activities that we enjoy such as sleeping, watching TV, going out with friends. It is true that giving time to ourselves can act as relaxation, but there are also **specific techniques that can help us reduce stress quickly** even if we are at work or at a bus stop, such as relaxation breathing techniques, progressive muscle relaxation, guided imagery, Tai Chi and others. Ask health professionals for advice.



Relaxation breathing techniques

Maintaining your health status

Physical activity is essential for maintaining a good level of health and wellbeing, especially if you are spending many hours and efforts in caring for a person. It helps to relax the body, gain some time for yourself and to reduce stress. Over the long-term, it also helps to reduce the risk of chronic diseases related to heart, stroke, hypertension, diabetes and so on.

This does not mean you have to go to the gym or attend specific fitness sessions: we know how much difficult it is to conciliate your life with other, personal activities. The most important thing is to be active regularly and avoid behaviours that might influence your health negatively.

Some tips for maintaining and improving your physical health:



Make it social physical activity is better if played with others. Go running with friends or do fitness in a group. You can meet people and make new friends.



Develop a routine being active should not be boring, but it is important to know you have specific dedicated moments in your week. This helps you to organise both your life and caring activities.



Limit time dedicated to passive activities watching TV or surfing the web are nice pastimes, but please be careful that they don't become your main activities in your free time. Your body needs movement!



Use "alternative" transports we all know how cars are important nowadays for doing everything. But please do not forget to use, whenever possible, also public transports and bikes. And of course, walking.



Increase your physical activity gradually do not think that you can do in a single day what you usually do in two or more. Please remember that you have to respect your physical limits and not over burden your body. If you want to do more activity, set an objective and make a plan: one that you can reach gradually, in a reasonable period of time.

Please remember to consult your general practitioner or a health professional if you are not sure about the type and amount of physical activity that better suits your body.

In general, do not forget to have regular check-ups and keep under control any signs coming from your body that might be related to stress or health problems. It is important not to delay consultations and visits because your health is extremely important and nobody can take your place in looking after it.



Caring and working



Working while caring isn't an easy task

Trying to be on time with work tasks and to also be a devoted carer generates stress, which is not always easy to manage. A key factor to combine work and care is to raise awareness among your colleagues and employers. Sometimes people do not realise what you are going through; they may often need more information! **Work and care reconciliation is the topic of this section.** You will find advice on this so challenging issue.

It may feel as if you are juggling two jobs when you are holding down a paid job and caring for a friend or relative but work can be important for your wellbeing, income and for maintaining social contacts.



There are things you can do to cope with the pressures of work and care. **As a working carer you are likely to need some support at work**, and often different levels of support at different times – from access to a telephone to check on the person you care for, to taking leave to help out when someone is being discharged from hospital.

The good news is that **carers have some statutory rights** and more and more employers are realising the benefits of supporting carers.

More employers are realising the benefits of supporting carers

Carers' rights at work

You may have the following rights guaranteed:

- The right to request flexible working
- The right to time off in emergencies
- The right to parental leave if you have a child
- The right not to be discriminated against or harassed.

Your employment status can affect your entitlement to these rights. If, for example, you are self-employed, on a short-term contract or employed through an agency you may not be covered by these rights. If this applies to you it is important to seek advice.



Carer's rights at work

A good employer

In addition to your statutory rights, your employer may offer more support. This will be outlined in your contract and the organisation's policies. For example, you may be able to use leave arrangements, paid or unpaid, at the discretion of your employer to cover intensive periods of care.

If you are thinking of giving up work, a career break (or sabbatical) allows you to keep your options open, ensuring you can go back, and keeping you in touch with the world of work. Some employers offer paid and/or unpaid career breaks, often after a specified period of service with them, so check your organisation's policies.

Sometimes the support you need is very simple like access to a telephone or information and advice. Many carers find the ability to work flexibly is the most helpful kind of support, so speak to your manager about this. Flexible working can include working from home, compressed hours (e.g. working longer but fewer days) or starting and finishing work earlier/later.



Statutory rights



Career breaks



Flexible working

Thinking of leaving work?

If you are thinking of leaving work it is important to consider the full implications.



Will you manage with less money?



Will you lose valuable skills if you leave?



Do you want to give up the independence and social contact you have through your work?



How would leaving work affect your future pension entitlement?

Then think about ways around the problem, could you:



Make a request for flexible working?



Take paid or unpaid leave to think about your long-term options?



Buy in care?



Take a career break?



Ask for extra help from social services?



Get more help from friends, family or neighbours?

Talk to your employer

Remember that employers value skilled, experienced and committed members of staff and are keen to keep them. Your employer may be able to help in ways you have not considered. **Talk to them about your situation**, directly or through your HR/personnel officer or union or staff association representative.



Ask for help with caring

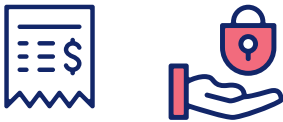
Social services are the department in your local council responsible for providing support for the elderly and people living with disabilities, as well as their families and carers. Carers may have a right to an assessment that looks at the help they need to manage their caring role.



Carers' rights at work

Find out about buying in private care

If you are not able to get help from social services or are given direct payments (instead of services) to make your own care arrangements, you may be able to buy in care services yourself. To get the help you need, you can either use an agency or recruit the help yourself.



The right to choose

Remember that making alternative care arrangements so that you can work can create conflict and/or cause feelings of guilt. What you decide must be right for you as well as others. You have the right to choose, and that means being able to choose to give up work as well as staying.

If you do decide to leave work, **make sure you check all your options before you resign**, for example can you take a career break, voluntary redundancy or early retirement?

Returning to work

If you have given up work (or not worked at all) because of your caring responsibilities you may want to work or return to work once your caring role ends, or you may decide you want to combine care with work.



Returning to work

Recognising skills

If you are not sure what you would like to do, **start by recognising the skills and interests you have.** Think about what you have learned from:



Any paid work that you have done



Tasks and responsibilities involved in your role as a carer, a parent, and running a home



Any other activities that you do, for example, voluntary work, committees etc.

Then identify your interests, think about:



What you enjoy doing



How you would like to use your skills



Things you miss doing that you once did, e.g. previous work

Think about short and long-term goals and make a plan of what you would like to do. Make sure the plan is achievable – include the small steps as

well as your long-term goals. Once you know what you want to do, you can look for the right kind of support to help you.

Carers' rights at work

Recognising skills

You may feel that you need to gain confidence to use your skills in new ways. There are training courses available on topics like confidence building, stress managing, assertiveness training.

Think about what employers want and value your own experience. Identify the transferable skills you have gained through caring and match these to employers' needs.

Skills you may have developed include:



Managing a budget



Time management



Planning and problem solving



Prioritising, organising and negotiating



Communicating with professionals



Caring e.g. doing personal care and healthcare tasks



Listening and providing emotional support

**Coping with cancer
together through
the different
phases of
the disease**



Cancer treatment

“I had a struggle to find out if the recommended medication was available in the country”

Finding the right information and the best treatment

When supporting your loved one during diagnosis and treatment, you may find it difficult to navigate the complexity of the health care system. You may have to become the advocate of the person with cancer so that he/she can access the right

information and treatment. Do not hesitate to contact patients’ organisations in your country. They are a great source of information and may help you or guide you to relevant knowledge.

Treatment at-home

“Carers should not underestimate the difficulties. However, they should also realise that they are more able to perform certain tasks than they would have thought.”

An increasing number of patients receive their treatment at home rather than staying in the hospital. In many cases, at-home treatment relies on the availability and capacity of the relatives to play an active role. A range of concrete tasks may be involved: including personal care tasks, insuring adherence to treatment (make sure the person takes their medicine, goes to medical appointments...), coordinating health interventions (making appointments, communicating with health professionals...), completing medical tasks as part of the curative or palliative treatment, helping to manage the side-effects of certain aggressive

treatments, contributing to the well-being of the person, ... These tasks may be quite technical and may be tiring over the long term. Besides, for some the treatment can be very complex, especially when cancer is associated with other diseases

Taking an active role in at-home treatment therefore is an important decision. Make sure you have a clear understanding of the tasks it will involve, and that you have the capacity to handle these. Ask for detailed information and training from health professionals on how to manage these tasks safely and effectively. Useful training videos and booklets may be available. Don't take on too much yourself. Find out what help is available from health and care services, to ensure you and your loved one are getting any statutory support you are entitled to.



Cancer treatment

Coping with the side-effects of treatment

The person you are taking care of might experience a range of side effects during cancer treatment, notably extreme tiredness, hair loss, mouth problems, eating problems, pain. **Some people with cancer may not want to speak about their pain as they think it won't help.** But there are usually ways of managing it, and the earlier the pain is treated, the more effective treatment usually is. You may help the person you care for by monitoring the side effects and pain, and then asking health professionals how to cope with them.

Eating well is more important than you think

During cancer treatment, many people may experience eating problems (mouth and throat problems, too tired to cook or eat, bowel changes that affect one's diet, feeling sick, heartburn and indigestion, changes to one's appetite, taste or smell...). Besides negatively affecting a cancer patient's quality of life both during and after treatment, these problems may cause weight loss, which may negatively impact the efficiency of the treatment. **Ask for advice from health professionals**, including specialised nutritionists if necessary, on how to ensure balanced nutrition for the person you care for.



Nutritionist

Contributing to informed choices

A journey through cancer entails making a series of difficult choices, notably regarding treatment options and arrangements. While the persons with cancer and their relatives can often feel they have no control over the situation, the possibility to **make informed choices can help regain a bit of control.** You may help the person you care for make informed choices by discussing with him/her, finding information and advice, seeking a second medical opinion... Importantly, you may help him/her assess and describe what is important for maintaining his/her quality of life. Cancer and other health problems may affect one's capacity to express himself and make choices, in which case you may need to seek guidance or legal advice.

Some decisions may be overly difficult. **Make sure you do not impose your views on the person you are taking care of.** If ever tensions arise in the family about decisions regarding treatment, do not hesitate to seek external support and counselling. **Cancer charities and support organisations often have advice on Advance Care Planning** and other tools to help carers make decisions and plan ahead.



Advance Care Planning

Cancer treatment

Clinical trials

Some people are offered the chance to be part of a clinical trial, as part of their treatment. **Doctors use trials to improve cancer treatment and care.**

There are benefits and risks to taking part in a clinical trial. During and after the trial the person treated with cancer will be followed up carefully. This means he/she may need to have regular tests. For some people this is reassuring. Others would prefer not to have more hospital visits and not take part in the trial.



Clinical trial

There is no right or wrong decision about taking part in a trial. You may help the person you care for to make this decision by discussing with him/her or writing down a list of the pros and cons.

For some people this is reassuring. Others would prefer not to have more hospital visits and not take part in the trial. There is no right or wrong decision about taking part in a trial. You may help the person you care for to make this decision by discussing with him/her or writing down a list of the pros and cons.

Communicating with health professionals

As the informal carer of a person with cancer, **you are part of the health and care team.** It is important you establish good communication with health and care professionals so that you can get the information, you and the person you care for need.

Asking questions can make it easier to cope during diagnosis and treatment. Knowing what is happening can make you feel more in control of your caring role.



Ask questions

You probably have lots of questions. It can help to be prepared by writing down a list of questions to ask. Don't worry about having to ask all your questions at once. You will have other chances to ask them. It's also okay to ask the same question again. The most important thing is that you understand what the doctor is telling you. It may be helpful to be with the person with cancer when she/he talks to healthcare professionals and take notes or record the conversation while the healthcare professional talks.

Cancer treatment

Maintain the relationship

“Cancer is over medicalised. Sometimes we forget about humanity and our relationship with the person with cancer, independent from the disease.”

“Humour is a strong medicine and despite having a seriously ill person in front of you, still let her keep smiling with you.”

Care for people with cancer is often provided by close relatives (spouses or children). The treatment may potentially impact the personality of the person with cancer and strain both relationships and the family dynamic. Even if it seems difficult, safeguarding quality time with your relative living with cancer, and **sharing positive moments can help maintain a good relationship**. If you think that your relationship is being impacted overly negatively, do not hesitate to seek counselling and support.

Cancer might challenge intimacy with your partner. Do not feel embarrassed or be afraid to ask questions to healthcare professionals about how to cope with these difficulties. **Any healthcare professionals you speak to will have already spoken to lots of other people experiencing these issues**. They are there to help, and it's very likely they've helped other people in similar situations.

About Breast Cancer treatment



Breast Cancer Units

It is recommended at EU level that hospitals develop specialised **Breast Cancer Units**, equipped with multidisciplinary teams. These units should be considered first when choosing where to get cancer care.



Professional support

The **physical implications of the treatment**, which entails the loss of feminine attributes (hair, breast in some cases...), mood swings due to some oncological medicine, might also represent a challenge to the relationship. Professional support may be required.



Personalised support

For men with breast cancer, the information and generally available help may seem less appropriate. Don't hesitate to seek **personalised support**.

Dealing with the financial burden of the disease

Depending on the stage of the disease and the health insurance of the person you care for, cancer can be costly, especially at an advanced stage and when associated with other diseases. Besides, the person you care for or yourself may have to reduce their working time, hence the income from work may decrease as well. In addition, health care expenses may only be partially covered, and the cost for medicine or therapies that are meant to improve the comfort of the patient may not be reimbursed. Additional costs such as child or elderly care or home care may also be required, in the case when the person with cancer is not in a position to manage family responsibilities as they used to do. **Money worries** can put a strain on the person with cancer and the carer, **negatively impacting the quality of life for both.**



In these circumstances it is important to plan ahead, and seek information about possible financial support or advice on budget management from public authorities, welfare agencies, insurances, employers and cancer organisations. Make sure you have considered all other options before borrowing money.

Your life after a period of caring

Supporting a survivor

More and more people with cancer recover from it after a period of treatment, which is a relief. However, they may still require support within the post-treatment period. The treatment may have a long-lasting impact on the body and mind of the person treated, and it is important that the general practitioner is aware of the treatment received and is able to help with these potential side effects. Also, the fear of recurrence may strongly impact the daily life of the person who was treated for cancer, as well as yours. The patient may

also feel abandoned by the health service as often the care and support stop when the person with cancer is declared cancer free. Carers can experience this too.

Reintegrating normal activities (work, study, leisure...) may be challenging for the person, who may be fatigued, and find it difficult to adapt. **Time as well as continuous medical and psychological support may be needed before returning back to normal life again.**



Your life after a period of caring



After Breast Cancer

“Quite a few breast cancer survivors have difficulty in coming to terms with losing their breasts.”

For women, the case of breast loss during the treatment can cause a psychological burden, and difficulties in their emotional and sexual life.

After breast cancer, some women lack the self-confidence to be their ‘old-self’ again, back at work. This requires understanding employers and colleagues. In many cases, professional support can prove helpful.

Finding your own way

“I had to start from scratch, step by step. I decided to focus on the things I can do and want to do that give me energy. It started with doing things with friends.”

Whether your loved one has overcome cancer or not, a caring spell is generally a difficult and life-changing experience. It is normal to feel extremely tired, or even a bit unwell when you stop caring. Often people keep going while they are needed as a carer and the full impact only hits them when they stop. **Some carers express the need to reorganise their life and their priorities.** You may also have difficulties coping with bereavement, if the person you cared for passes away.

If you’ve left work to take care of your loved one, it may be difficult to get back into employment. It is important to realise that, even if your caring experience is not officially recognised, you have been developing skills which are generally valued by employers (para-medical skills, ability to coordinate and communicate with health professionals, time and budget management...). **An employment counsellor might help you valorise your experience on the labour market** (see also section on Work and Care).



Palliative care and the end of life

It might be that the cancer of the person your care for is not or no longer responsive to treatments that aim to cure and control cancer, and that palliative care is proposed. Though it is recommended that there is continuity of care, this situation may imply a change of health care team you are in contact with.

In case the person is approaching the end of their life, don't hesitate to ask for more precise information from health professionals, in particular oncology nurses and your general practitioner about what is going to happen. If the person you care for is treated at home, **make sure you have all the information and help you need** to help with the treatment and pain management.

“The hardest part was losing him twice: first emotionally as his personality changed due to the side effects of his treatment and later on physically, when he died.”

Though it can be very satisfactory to accompany a loved one until the end of life, **looking after someone who is dying can be an emotionally and physically demanding role to take on**. Especially since carers are already dealing with multiple losses along the different phases of the disease. In order to prevent over exhaustion and loneliness, you might need acute support during this period. **In some countries, carers have the right to apply for specific leave or benefits** allowing them to care for a relative who is receiving end of life care.

“We don't know death any more, and we don't accept it anymore either.”

Different relatives may have a different perception of the health situation of your loved one. It may be useful to have an open conversation with health professionals explaining prognosis and likely trajectory, involving the large family.

Many bereaved people will manage this life challenge with their inner resources and the support of their friends and family. But grief is often misunderstood, it can prove extremely difficult, and many people in such circumstances may feel very lonely. It is important to be aware that support around bereavement can be accessed after the death of a loved one, and can be helpful during this ordeal. **In some countries, some bereaved people have the right to apply for specific benefits.**

Once the immediate grieving has passed, some experienced carers find it meaningful to engage in voluntary work, and take part in peer support or advocacy activities. By doing so, they share their knowledge and commit to greater recognition of the invaluable contribution of informal carers to supporting people with cancer.

References and acknowledgments





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World Health Organisation

www.who.int/cancer

European institutions

European Partnership of Action Against Cancer

<http://www.epaac.eu/>

European Commission Initiative on Breast Cancer

<http://ecibc.jrc.ec.europa.eu/>

Cancer Control Joint Action

<https://cancercontrol.eu>

Civil society organisations

Association of European Cancer Leagues

europeancancerleagues.org

Cancer Caring Coping

www.cancercaringcoping.com

Eurocarers

www.eurocarers.org

European Association for Palliative Care

www.eapcnet.eu

European Cancer Organisation

www.ecco-org.eu

European Cancer Patient Coalition

www.ecpc.org

Europa Donna

www.europadonna.org

European Oncology Nursing Society

www.cancernurse.eu

InformCare - The EU Information Hub on Informal Care

www.eurocarers.org/InformCare

Macmillan Cancer Support

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