

What does
survivorship mean?

Let us explain
it to you.

ESMO Patient Guide Series

based on the ESMO Clinical Practice Guidelines

esmo.org

In collaboration with



Survivorship

An ESMO-ECPC guide for patients in collaboration with IPOS

Introduction

Survivorship is a unique and ongoing experience, which is different for each person and those close to them. A key to survivorship is to regain, as far as possible, the important aspects of your life before cancer, and to find new pathways to a satisfactory life going forward. This Patient Guide on Survivorship is created by European Society for Medical Oncology (ESMO) and European Cancer Patient Coalition (ECPC) in collaboration with International Psycho-Oncology Society (IPOS) in order to help you and people like you at this important time in your life.

In this guide you can find information on support in coping with the new reality, life after initial treatment, preventive health, and follow-up care. It also enables keeping a personal health record / survivorship care planning.


Definition

Survivorship focuses on health and the physical, psychological, social and economic issues affecting people after the end of the primary treatment for cancer. Post treatment cancer survivors range from people having no disease after finishing treatment, people who continue to receive treatment to reduce the risk of the cancer coming back and people with well controlled disease and few symptoms, who receive treatment to manage cancer as a chronic disease. Survivorship care includes issues related to follow-up care, the management of late side-effects of treatment, the improvement of quality of life and psychological and emotional health. Survivorship care includes also future anticancer treatment where applicable. Family members, friends and caregivers should also be considered as part of the survivorship experience.

Survivorship is a unique and ongoing experience, which is different for each person and those close to them. A key to survivorship is to regain, as far as possible, the important aspects of your life before cancer, and to find new pathways to a satisfactory life going forward. This patient guide on survivorship is created in order to help you and people like you at this important time in your life. You may find it helpful to involve close friends and family members as you consider the issues raised in this guide.




**I savour every
moment now**



I am enjoying life, again



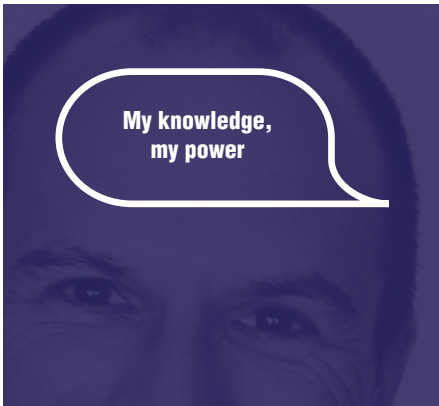
**I cherish more the
people and things which
are important to me**



**I worry that cancer
may come back and
want to know more**



**Good source
information on how to
improve health counts**



**My knowledge,
my power**

Express your feelings

How do I feel?

My relationships have changed since the cancer

My confidence has been affected

Other

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Chapter A

Support in coping with the new reality - Who can help me?

1. Cancer rehabilitation

Cancer **rehabilitation** is one of the first important steps in survivorship. Cancer and its treatment produce a multi-dimensional impact on patients' lives, affecting the physical, sensorial, cognitive, psychological, family, social and spiritual functional levels. **Rehabilitation** is part of cancer care, and has been recognised as a cancer patient's need and right along with cancer treatment. It is a way to minimise the impact and **side-effects** of cancer and cancer treatment at the many affected levels, to help patients in optimising their quality of life and in recovering the normalcy in their lives.

Rehabilitation programmes may be proposed as an outpatient programme, mostly provided by specialised **caregivers**, or carried out in specialised clinics. Their goal, is to help people recover many psychological and physical aspects of their lives and to remain as productive and independent as possible. **Rehabilitation** is valuable for everyone who is recovering from cancer treatment, those living with cancer and their families in:

- Improving physical and psychological strength to help offset any limitations caused by cancer or cancer treatment.
- Regaining good physical condition in order to return to everyday life.
- Improving self-management to reduce stress, improve sleep, improve emotional balance and well-being.
- Regaining self-confidence.
- Becoming more independent and less reliant on **caregivers**.
- Learning to manage possible **side-effects** from **chemotherapy, hormonal therapy, targeted therapies, immunotherapy** and/or **radiotherapy** to minimise the effect of these side-effects on everyday life.
- Learning how to have a balanced diet, good nutrition and preserving or achieving healthy weight.
- Learning how to manage sexual life.
- Learning how to preserve **fertility**.
- Reducing the number of **hospitalisations**.

Rehabilitation programmes will vary in content, extent and form, depending on availability and choice. They may be proposed even when you have already returned to work, or in a block before you do so. Most will be outpatient-based and some may be proposed through a medical inpatient institution.

Ask your doctor and **caregiver** about **rehabilitation** options available to you. A rehabilitation programme targeting your specific needs can be organised by the health **caregivers** in cooperation with the **social workers** and the patient and family.

2. Patient support groups

As you move through the survivorship experience it is extremely important to know that you are not alone. Family, friends and community resources can be useful to help you cope with physical, emotional and psychological issues, which may arise as you try to return to “normal life”. However, many survivors find it helpful and comforting to share their concerns and to talk with people who know what they are going through from first-hand experience. Cancer support groups are meetings for people with cancer and those touched by the disease. Even though a lot of people receive support from friends and family, the number one reason they join a support group is to be with others with similar cancer experiences.



There are many cancer patients' organisations in Europe which provide useful resources for cancer survivors, including specific patient support groups. Getting in touch with your local or national patient organisation is a good starting point to identify what kind of patient support group or other services are available for you.

By following the link below you can learn more about how the European Cancer Patient Coalition unites the largest European cancer patient communities, covering almost all types of cancer, from the rarest to the most common.

<http://ecpc.org/about-us/our-members>

Reasons to join the support group

- Support groups allow you to talk with other cancer survivors about your experiences, which can help you reduce stress and learn about coping strategies you may wish to use in the future. Group members can share feelings and experiences that may seem too strange or difficult to share with family and friends.
- Group dynamics often create a sense of belonging, helping you to feel better, more understood and less alone.
- You can receive help and advice on how to cope with problems that can arise at work and in relationships with your friends and family.
- You can get access to and discuss a wide range of practical information. This may include advice and useful information about how to deal with **side-effects** of therapy, how to manage pain and how to communicate with health care providers.

Types of support groups

There are different types of support groups, where you may find the kind of help and support that you are looking for and which works best for your needs.

First, there are categories of support group which depend on the person who leads the group:

- Peer-led or self-help groups are facilitated by group members.
- In a professionally-led group, a trained counsellor, **social worker**, or **psychologist** may facilitate the interactions among the members.
- Informational support groups – led by a professional facilitator – provide cancer-related information and education. These groups often invite speakers, such as doctors, who provide expert advice.

Groups may also be designed for specific audiences, including:

- All individuals with cancer.
- People with one type of cancer, such as breast cancer.
- People of a certain age group or gender.
- People who have a specific stage of cancer.
- **Caregivers**, such as family members and friends.
- People with rare types of cancer.

A new possibility in recent years is online support groups, which have become popular. People meet through chat rooms, list servers or moderated discussion groups and interact with each other via email. These groups are an alternative for people who live in isolated places, people who have mobility difficulties, people who don't feel comfortable sharing feelings in person or people with a rare type of cancer where finding others with a similar illness experience may be more difficult. Many cancer advocacy organisations have online support groups as well, for example:

<http://ecpc.org/about-us/our-members>

<http://acor.org>

Another alternative could be telephone support groups, where everyone dials in to a phone line, like a conference call.

Where to find the support group and patients' associations?

There are many ways to find support groups or information about support groups. You can ask your **health care providers** (**oncologist**, **oncology nurse** or family doctor) or **social workers** to suggest a group for you. You can also do an online search. Here is a helpful link to online information about patient groups in Europe:

<http://ecpc.org/about-us/our-members>

How to choose a support group - Which support group is right for me?

For each person there are different criteria which will help you to choose the right and most suitable support group for you. Here are some questions which you may ask the contact person of each group:

- How many members are in the group?
- Who attends the group (survivors, **caregivers**, family members)?
- What is the content and the format of the meetings?
- Will information shared be kept private and confidential?
- Who leads the group?
- Where and how often do the meetings take place?
- What can I hope to gain from joining this group?
- Is the main purpose to share feelings, or do people also offer tips to solve common problems?

What if I don't want to join a group?

Support groups do not suit everyone, and you should not feel pressured to join a group. Not joining a group because it doesn't fit with your personality or circumstances will not have a negative effect on you. However, remember that spending time with friends or family members is helpful for most people.

Contacting your local or national patients' association also can be very helpful as a way to find other support resources.

3. Psychological support of the patient and his/her family

Receiving a cancer diagnosis often triggers a strong emotional response. Some people experience shock, anger, helplessness, hopelessness and disbelief. Others may feel intense sadness, fear, a sense of loss, loss of dignity and a perception of being a burden to others. For the family members, it is often a very stressful period as well.

Psychological support for the survivors and for family members is an important part of survivorship. It helps you in reducing and better managing the emotional impact of having experienced a life-

threatening disease and its demanding treatments and in improving your quality of life and well-being. In many oncological institutions, you can find specialists (**psycho-oncologists**), who are usually part of the clinical team and work with your **oncologist**. You can receive help through the use of **psychotherapeutic interventions** such as stress management, cognitive therapy, counselling and planning of activities.

Furthermore, you can receive psychological support through specialists and other survivors also in support groups. For many survivors, the relationship with **health care providers** and the existence of a caring and loving family play an important role in the psychological support.



4. The role of the health care professionals (i.e. oncologist, family doctor, oncology nurse)

During the treatment period, the **health care professionals** best understand and are able to explain problems and difficulties you are facing. Often, while undergoing treatment, patients will become emotionally attached to their **health care professionals, oncologist or oncology nurse**. Their role does not end at the conclusion of the main therapy. They can play an active role in the survivorship experience. They can offer useful advice for detection and management of treatment- or tumour-related symptoms. They can be advisors, who can also offer psychological and emotional support and can help you to cope with psychological and physical difficulties in the post treatment period. Many of these professionals also have the knowledge and the ability to help you to organise and optimise your survivorship experience. Stay in touch with your **health care professionals (oncologist, oncology nurse, psychologist or family doctor)** and let them help you further as a part of your survivorship experience.



CHAPTER B

Life after initial treatment - How can I get my normal life back?

1. Perspective and self confidence

Many survivors feel that their life has radically changed after the diagnosis of cancer. You struggle with questions: “Why me?”, “What should I do if the tumour comes back?”, “Am I a different person now?” and many other questions. These feelings and questions may threaten your self-confidence and your beliefs. There are many ways to help you to regain your perspective and find answers to your questions:



- Re-evaluating priorities, patterns and goals in life:** Many survivors recognise the period of survivorship as a “wake-up call”. Questions arise such as: “Is my role in my family sufficient?”; “Am I as close to my family and to my friends as I should be and wanted to be?”; “Does my job make me happy?”; “Have I fulfilled all of my goals and dreams?”; “What are the most important things in my life right now?”. Write down your questions, and take time to carefully reflect on the answers. They may come to you as you meditate about them.
- Doing things that you always wanted to do:** Many survivors try to find the meaning of life through travelling, meeting new people, experiencing new cultures and making new friends. Also, new hobbies such as yoga, music, meditation and painting can give you fulfilment. Think about what you have always wanted to do and see if you could do it now!
- Looking for spiritual support:** Many survivors, even those who didn’t consider themselves religious, look for support and guidance in faith and spirituality.
- Discussions:** “Live” and through blogging: The publication of experiences and the sharing of feelings with people who have similar experiences makes many survivors feel stronger and gives them back their perspective on life. Furthermore, many people help and advise other survivors and, in this way, they may also regain their self-confidence.



2. Changes in family and relationships

Cancer brings many emotional, psychological and physical changes to your life and can affect your relationships with your partner, your children, as well as your friends. You may be surprised to realise only after the main treatment is over that you are no longer comfortably nestled in your social environment. Friends or family may have become more reserved, sometimes even due to fears: about their own health or being unsure how to talk to you about your illness and not wanting to upset you. Some people also try to be independent and not ask for help during their treatment and this can lead to family and friends feeling uncertain about their role and how to respond. The need to regain closeness with your family members and your friends may be obvious to you, but at times it can prove to be quite a challenge. Some survivors may even experience the need to avoid the people who used to be very close, either because it reminds them of how their life has changed, or because of disappointment that they did not receive the support they expected from others. Furthermore, the cognitive and physical sequelae of cancer can also alter relationships with the family/friends.

Parenting and family life

Living with and beyond the cancer and the need to cope with the challenges of this situation may profoundly influence your life style/philosophy of life, and may bring into question many former goals and achievements of your life. This may particularly affect the way you re-organise your family life and the time and importance you devote to your family.

Many cancer survivors experience a new-found closeness and intimacy with their loved ones.

These individuals often report actual personal and interpersonal growth from their cancer experience (also referred to as post-traumatic growth or benefit finding). Conversely, some people feel disconnected from their partner, or feel disappointed that their partner does not understand their desire for closeness and support.

For those who have children, there are additional issues associated with survivorship. Children are the most significant people in the lives of their parents, but cancer treatment can have a big impact on parenting roles.



For months or even years, the demands and difficulties of the disease and the treatment may have largely dominated your everyday life and affected the time you were able or had wished to spend with your children. You may feel guilty due to your lack of presence/availability. This can affect your confidence about parenting and negatively impact your relationship with your children.

Of course, these issues not only apply to your core family, but also to other relatives and to your social environment in general.

How can you respond to these issues?

Try your best to be yourself: open, honest and as relaxed as possible.

Be honest with the members of your family, including your children! Express your feelings, your fears, the things that you are holding back. “Opening up” will also help you significantly in creating closeness and increasing mutual affection. Let your children know that you realise that this has been a tough time for them too, and acknowledge the things they have done to help the family get through it.

Don’t try to suddenly become the “perfect parent and the perfect partner”, to compensate for what happened during the treatment. Your family will probably much prefer to get back the person they knew before you got sick, with or without imperfections.

You might try to spend every minute with them, now that you have overcome your cancer. Don’t overload and exhaust your family. Don’t be too anxious to make up for the lost time, or to desperately try to get all you can for the time you have left. Try to relax, and act relaxed with your family. This will offer and ensure you quality time and will allow you to enjoy every moment with your family members.

Friends

Friends are also a very important part of our social life. Throughout your cancer diagnosis and treatment, and as you enter the state of survivorship, your friendships may have changed. Maybe some friends have disappointed you, not being as present and supportive as you expected during your hardship. Maybe you tried to be independent and not ask for help from anyone during your treatment. Try to give them and yourself a second chance, try to openly discuss your feelings: a “true” friend will be open to discussion and you may lay the basis of a new, even closer friendship. The period of survivorship could also provide the chance to make new friends and meet new people. This could help you regain and exercise your social abilities and feel that you are moving forward.

3. Your sexual life after cancer

Sexuality and body image

The negative impact of cancer on sexual life and attractiveness is often underestimated during the period of main therapy. Many survivors experience the loss of their sexual function or their sexual desire due to the disease itself, through the **side-effects** of the treatment (e.g. pain, premature menopause, nausea) or simply because of changes in physical condition, for example, fatigue. Some treatments, even those not directed to the **pelvic area**, can affect sexual function. Moreover, other physical changes – not directly related to sexual function – can also affect your sexuality and the way you feel about your body. For example, losing a testicle or a breast, having a **gynaecological operation**, having a **colostomy** or a **tracheostomy**, losing hair or having a scar after an operation can severely affect your self-confidence.

Physical exercise and psychological support can both help you to regain your self-confidence and feel desirable again.

In some settings, patients may feel uncomfortable discussing their sexual concerns with their partners, or even with their doctors. They may feel embarrassed to raise the topic or feel that, compared with cancer, these issues are not important. However, sexuality is a central aspect of human life and is an important part of who you are. Further, when sexual problems occur, they tend to get worse not better over time if left unaddressed.

Ask your doctor or nurse to support you in dealing with sexual concerns. He or she may provide you with direct help, and/or refer you to a **health care provider** with more specialised expertise (**psychologist**, **urologist**, **gynaecologist**, sexologist, etc.). Some of the physical problems that lead to sexual dysfunction can be treated with medication, others respond to behavioural interventions, while emotional concerns can be addressed through **psychotherapy** and/or counselling.

In conclusion, your social and sexual life may or may not undergo significant changes during the active phase of your cancer treatment. Often it is only when you have completed treatment that you stop to reflect on changes in your body and relationships. Just as your body may need **rehabilitation**, your soul and your social life may also need revival. Communication is the key to being able to work on these issues – reflecting on how you feel, talking with an intimate partner and seeking professional assistance all facilitate recovery.

4. Having children / Fertility after cancer

Decisions about having children

Most people say that having had cancer has not changed their attitude about having children. However, deciding to have children after cancer is always a big decision. Furthermore, there are a number of factors which may affect the ability to have a child after cancer.

Generally, pregnancy after cancer treatment is considered safe for both mother and baby. Furthermore, pregnancy is not proven to increase the risk of **recurrence**, even in diseases where this was previously believed to be the case (i.e. breast cancer). However, before you decide to have a baby it is useful to talk with your doctor and take his/her advice on the right time to become pregnant.

The exact length of time post treatment that female survivors should wait before trying to become pregnant is not clear. It depends on the type and stage of disease, on the therapy received, the need for ongoing diagnosis, and further treatment plans. Many women want to know about their risk of disease **recurrence** in the absence of pregnancy, before making a decision to conceive. Of course, the age and physical condition of the survivor also play an important role in this decision. A two-year period after the end of the active treatment appears adequate for many. It is recommended that you consult with your **health care providers** before making a decision about having children after cancer.

For male survivors, there are no specific guidelines or restrictions about trying to have a child during survivorship. Unlike oocytes in women (which are fully “functional” at birth), spermatozooids are produced continuously, and may thus be affected by **chemotherapy** or **radiotherapy**. For this reason, your **oncologist** may recommend a delay before planning a pregnancy to allow recovery of normal sperm viability and function. Also, some treatments have a higher risk of causing **infertility**.

You may have been encouraged to undergo a form of **fertility** preservation (i.e. **cryopreservation** of

spermatozooids or oocytes) before your treatment was started. Unfortunately, **infertility** is not always predictable, and **fertility** preservation is not always accessible, depending on local infrastructure, reimbursement, urgency of treatment and other issues.

If you are no longer able to conceive naturally, but still wish to have children, remember that there may be alternatives. These could include assisted reproduction techniques. Talking about this can be challenging, and it is important to obtain information and advice from your doctor who can recommend specialised support and services appropriate for your situation, such as:

- Assisted reproduction (for women having reduced numbers of eggs [oocytes] in their ovaries).
- Surrogacy and gestational carriers (another woman can carry the baby-embryo of the couple).
- Donor eggs (oocytes) and donor sperm (for women with low ovarian reserve and for men who did not store the sperm before starting a toxic treatment).
- Testicular sperm extraction (for men who do not have mature sperm in their testicles).
- Adoption.

Discussing these options with your partner may not be easy.

In conclusion, discussing your desire for pregnancy with your doctor could help you to find the best time and the optimal conditions to have a child. Your **health care provider** can also advise you in considering alternative ways to have children and/or refer you to a **fertility** specialist.

5. Returning to work, finding new hobbies and interests

Going back to “a normal life” – When cancer survivors use this expression, they very often mean getting back to work, or finding a new job. Even if work is not an issue, leisure activities are: resuming previous interests and hobbies or finding new ones is very important and can make you feel better and more alive. Both will be paramount in your aim to get “back” to the lifestyle you had before your cancer was diagnosed.

Going back to work

Getting back to work is certainly different for every individual, but a number of the challenges, problems and advantages are shared by many. The following text will discuss these aspects.

You may love your work, you may have to work (for financial reasons), or both: getting back to work is a priority for many cancer survivors. The primary interest is probably to secure your (family's) living expenses. From a psychosocial point of view, work can provide the opportunity to reconnect with and to regain relationships with friends and colleagues and is a source of self-worth and purpose for many people. Work certainly also helps to focus on something other than cancer and to reassure and reinforce your feeling of getting back to your old life and to the lifestyle you used to have.



Survivors can experience a number of different work-related scenarios:

- Some may have continued to work throughout their treatment.
- Others may have altered the pattern (hours/schedule) or the type of work they do.
- Others still may have lost their job during treatment.
- Many may have significant loss of **performance status** (physical fitness) or may have developed **comorbidities** as a result of the therapy or the cancer itself, which may prevent them (temporarily or permanently) from getting back to the same occupation they had before. Moreover, it may be difficult to foresee, for you and even for your **caregivers**, when, or even whether, this will improve.

Getting back to normal activity may be uncomfortable. It may be associated with the fear of not being able to endure the stress and intensity of the work. Fortunately, many will experience that, although reintegration may be tough, they will still manage to get back to their former work performance.

Looking for a new occupation may be an interesting option for some, a necessity for others.

Your final decisions about work should be made after taking into consideration your financial resources, your health insurance, the nature of your work and the nature of your treatment and recovery. In many places, **social workers** as well as specialised agents from public health and pension companies may provide help, as well as patient interest groups (cancer charities). You may need their help to have a sufficient overview of all of the options that are available to you.

Preparing and planning your return

If you have stopped working because of your therapy, the first step is to discuss with your doctor whether you are ready to return to work. Your doctor will need to know how do you feel. You will also have to describe the work you wish to resume. Several important factors will help to determine when it is right for you to resume work:

- How reasonable is the assumption that you will stay free of disease in the (near) future?
- Are there **side-effects** or consequences of your cancer which could affect your performance and ability to get back to your work?
- What is your physical condition?

It is clear that a physically demanding job will be difficult to resume if you feel weak and fatigued. You may, in that case, need a longer recovery time and/or specific **rehabilitation**.

Supposing your doctor considers you are able to work and that your former workplace welcomes you back, the next step is to talk with your employer. In case you are worried about taking on a full workload there may be an opportunity to discuss a suitable transition plan. You might propose to set up a meeting with your supervisor and the human resources department, or even the company's work **physician**.

You may or may not wish to share your diagnosis in your work environment. As the diagnosis is highly confidential, this decision is entirely up to you and will depend on your confidence and relationship with your co-workers.

It is very much in your interest to have clarity with your employer about your physical and psychological limitations. This is essential to setting up a realistic transition plan and to finding suitable solutions. You may also discuss the possibility of flexible work arrangements such as part-time work, teleworking, job sharing or reassignment to another position. Furthermore, you can also establish your need for periodic work breaks to take medications, in consultation with your medical team. Larger enterprises might have policies in place for such situations, therefore it is wise to check with your human resources department.

Before providing some benefits in your working environment, the employer may request documentation of your limitations and **comorbidities**. Nevertheless, the employer has no right to access or to ask for your medical records. It is possible that an employer may deny some requests for accommodations, using the excuse that they could be financially damaging. However, in that case, the employer should also determine if there is an easier and less costly arrangement, that could meet your needs.

Not all EU countries have established legal frameworks for the reintegration of cancer survivors in the workplace. However, more and more countries are developing specific legislation to support and protect cancer survivors' return to work.

In Italy, for example, the law allows patients working in the public and private sector to switch from full-time to part-time while under treatment and to revert to full-time according to their needs and capabilities. Within the same legal framework, relatives (**caregivers**) of cancer patients are given priority access to part-time applications if requested, as long as there are positions available within the company.

Similar provisions exist already in France and the UK. All EU governments have been asked to implement similar measures in the framework of the EU initiative CanCon (**www.cancercontrol.eu**).

Talking with colleagues and dealing with the new balances in the work environment

It is entirely your decision when and how to tell your colleagues about your cancer experience, if you decide to talk about it at all. It is a very sensitive matter and only you should decide how you are going to handle it. You should also consider that talking with your colleagues and sharing your concerns about your possible limitations and your plans about work with them may help your colleagues to understand your condition. It is important to keep your explanations simple and let people know how your return to work will affect them.

In many cases, you will have to deal with new balances in the work environment. Others may have taken over, or will take over your responsibilities. Maybe they will receive a promotion that you counted on earlier. Try to talk about your concerns and future vision and hopes with your employer. Maybe the employer can offer you a plan or strategy for your future. It is also important to try to talk with other colleagues and especially with those you are very close to. Some employers and colleagues may not respond well. Their reactions may relate to their lack of familiarity with cancer or with the competition of the work environment, but you should find at least some understanding from people who may be protective, supportive and caring towards you.

Dealing with discrimination

It is possible that some survivors will be treated unfairly and may have to deal with discriminatory behaviour. It is very important to recognise such behaviour and to deal with it actively. You should keep in mind that there are laws and regulations that prohibit discrimination which have been made for your protection.

Some examples of potentially discriminatory behaviours are:

- Isolation from other colleagues, or from colleagues who used to be close to you.
- Unexpected underestimation of your work ability and of your work efficacy.
- Having a job promotion withheld without explanation.
- Lack of understanding and/or flexibility concerning your requests to be absent because of your medical appointments.
- Statements from management or from colleagues that your productivity and performance are below the company standards or that your requests may financially damage the company.

Besides the laws and regulations that you can fall back on, you can also proactively and directly lower the risk of discriminative behaviour by:

- Trying to be motivated and expressing openly that you intend to reach your normal standards of work.
- Refreshing your job skills.
- Talking with your supervisor and your colleagues before your return and clarifying with them your limitations and a feasible transitional programme.
- Getting advice from other survivors on how to return smoothly to work.
- Asking your doctor to provide you with a letter confirming your ability to return to work or defining as precisely as possible any restrictions in your abilities.

Finding a new job

Some cancer survivors may have lost their job during treatment. The cancer experience may lead other survivors to revise their life expectations and reshape their career priorities. That could cause them to question whether they should continue on their current career path. Finally, there are also survivors who are unable or unwilling to return to their previous work environment. In all of these situations finding a new job is either a necessity or the better solution.

Important issues to consider when looking for a new job in the survivorship experience are:

- Try to find a job that is compatible with your new life priorities and your new life expectations.
- Try to find a job which ensures you enough flexibility to attend to your medical appointments and needs.
- Try to be honest and open with your new work colleagues, including your employer, about your condition and your possible limitations. A healthy and honest relationship is also the way to ensure supportive and understanding behaviour from your new colleagues.
- You should know that the employer has no legal right to ask you about your medical history, including the cancer period. The employer must also share about your history of cancer and any other medical information confidential. However, the employer does have the right to ask questions about your abilities and questions related to your capacity to fulfil special duties.

- Seek help from a career counsellor or a **social worker**, to advise you or to give you some tips about the interview process.
- Try to find cancer survivors who have changed their work environment. You can receive very useful advice about where to look for work, how to behave and what questions to expect. They may also suggest a support group that addresses work-related issues. In such support groups, you may find tips on finding part time work or other social support, as well as networking with potential employers and information about potential job openings.

Finding new hobbies and interests

Let's not forget: there's not only work but leisure in life!

Maybe you were a surfer, a mountain climber or a model-maker in your leisure time before getting sick, and maybe you are not able to pursue your hobby due to your physical condition and consequences of treatment. We already mentioned that your cancer experience could reset your life priorities and stimulate a need to look for new centres of interest. Maybe now is even the time to do things that you always wanted to do in your free time!

It is important to find interests and hobbies, which can give you pleasure and enhance your sense of well-being. Finding new hobbies such as sports activities, dancing, painting, travelling, can help you improve your physical and mental health. Achieving new goals (becoming closer to friends and family members) can make you feel stronger and can help you regain your self-confidence.

6. Managing your finances

Treating cancer is very expensive. Direct cancer treatment costs are fortunately covered in most European countries entirely by the health system or insurance. Nevertheless, reimbursement is not uniform in all European countries and new and sophisticated therapies, in particular, may be not be reimbursed in some cases. Supportive treatments (psychosocial services, anticough medicine, **pain killers, gastric protectors, gastric tube feeding** etc.) may require the patient's financial contribution to some degree, in addition to consultation and diagnostic fees, etc. Even though these contributions will mostly represent a small percentage of the total costs, they may still be substantial for the patient's budget. Loss of income due to the inability to work may add a further major financial strain. These conditions may cause financial stress and make it difficult for many people to pay both medical and household expenses.



Managing your finances and dealing with financial difficulties are very important aspects of the survivorship experience. For many people, it is a major concern to be addressed as a priority as soon as the active treatment period ends.

Do you have ongoing expenses? Are you worried about not being able to deal with them? In that case, compile all of your expenses and try to set priorities. It is very important to organise the expenses well (i.e. into categories such as household bills, medical expenses, taxes or credit cards). Can you postpone certain payments to a later point of time? What has to be paid immediately? If you realise that your current income is insufficient to cover your ongoing expenses, try to find alternatives. Some of them could be:

- Talk as soon as possible to your creditors in order to obtain more favourable payment conditions.
- Some insurance policies offer (under certain circumstances) to pay bills directly instead of them being settled first by the patient: inquire whether this could be possible in your case. If required, ask your doctor to prepare a supporting document.
- Examine the existence and eligibility criteria for forms of public assistance (i.e. temporary grants, supports or a disability pension).
- Some support may be provided by patient groups and other non-profit organisations.
- Your local or hospital **social worker** may help you in these inquiries.
- Consider other sources of income.
- Maybe you can find help through your family or friends.

CHAPTER C

Preventive health - What lifestyle changes can I make to achieve optimal physical and emotional health?

All survivors should be encouraged to achieve and maintain a healthy lifestyle. The reason for this is that research has clearly shown that a healthy lifestyle is not only associated with better physical health, but also with an improved quality of life and a longer overall life expectancy. Furthermore, several studies show a relationship between healthy lifestyle and prevention of a new cancer, as well as reduced risk of cancer **recurrence** and longer survival.



Because cancer survivors are at increased risk for second cancers and other medical conditions that can affect both physical and mental health, you are encouraged to follow recommended lifestyle guidelines. These include engaging in regular moderate to vigorous physical activity, achieving and maintaining a healthy body weight or losing weight if you are overweight, minimising alcohol intake, avoiding smoking and other tobacco products as well as practicing sun safety. You should also pay special attention to the recommended **immunisation** (vaccination) regimens and the prevention of infections.

Cancer survivors may be motivated to make lifestyle behaviour changes for a number of reasons, including:

- Reducing the risk of **recurrence** of original disease or risk of a second primary cancer.
- Reducing the risk of cancer-related late **side-effects**, such as physical and emotional problems that may develop long after completion of treatment.
- Managing persistent symptoms and **side-effects**, such as cancer-related fatigue, that linger after the completion of treatment and that respond well to practices such as exercise.
- Reducing the risk of other chronic diseases, such as **diabetes** and cardiovascular diseases.
- Improving overall health and well-being (quality of life).
- Reducing the risk of mortality.

Many cancer survivors have unanswered questions about what is safe and what is not safe to do regarding eating and exercising, both during and after the completion of treatment. For example, you may be asking yourself the following questions:

- Should I change what I eat and, if so, how?
- Should I try to lose or gain weight?
- Should I take vitamins or other dietary supplements and, if so, which ones?

- Is it safe for me to exercise?
- If it is safe for me to exercise, what types of exercises should I do, how often should I exercise and how strenuous should my exercise regimen be?
- What sources of information on diet and exercise should I seek out and trust?
- In addition to diet, exercise and weight management, what other lifestyle changes should I make?
- Should I change my priorities in life?

1. Healthy lifestyles

Practicing a healthy lifestyle is an important step in reducing your risk of cancer **recurrence** and second primary cancers, as well as improving your overall well-being, including your physical and emotional health. A healthy lifestyle includes following established recommendations like engaging in regular physical activity, eating a healthy diet, achieving and maintaining a normal body weight, and managing stress. In the sections below, we will review each of these factors in greater detail and provide advice and tips on how to achieve your goals in each area.

Physical activity

One of the cornerstones of a healthy lifestyle is physical activity. Physical activity and exercise should be tailored to your abilities and preferences. According to doctor-approved recommended guidelines, you should engage in at least 150 minutes of moderate-to vigorous physical activity per week. This could include 150 minutes of moderate exercise or physical activity, such as walking, stretching, dancing, water aerobics and yoga, or 75 minutes of vigorous exercise per week, such as biking, hiking, jogging, running and swimming.

It is also recommended to minimise the amount of time you engage in sedentary behaviours, such as sitting for a long period in front of a computer or television set. Instead, try to seek more active alternatives while you are at home or at work. For example, instead of taking the lift, use the stairs. You could also choose to walk or ride a bike instead of driving a car or taking public transportation. Finally, be sure to get up and walk around for 5 or 10 minute each hour, even if you are busy. Research suggests that just getting up and moving around from a seated position several times a day reduces your risk of several physical conditions and improves your overall health.

Remember that exercising regularly not only improves your physical health, it can also help reduce **anxiety**, fatigue and stress and can improve your self-confidence. It could also help you either to lose weight or maintain a healthy weight. Exercising is also associated with significant reduction in the risk of heart disease, **diabetes**, and high blood pressure. Furthermore, studies have shown the possible correlation between exercising and prevention of **recurrence** of several different types of cancer. This risk reduction is independent of your exercise level in the past! Even if you never were a big “exerciser”, starting and continuing to be physically active as of now will give you the same benefits over time.



You may feel that your motivation to exercise is reduced or you have some limitations that prevent you from being physically active. Challenge the idea that exercise must mean walking, jogging or going to the gym. Any activity is good for you and could include things like gardening, playing with grandchildren or doing housework. Some strategies and methods in order to increase your motivation and overcome possible limitations include:

- Motivational counselling.
- Personal training.
- Fitness expert recommendations.
- Doing activities with others or as a group (peer support).
- Talking with other survivors and letting them explain the changes they have noticed in their quality of life through physical activity.

Nutrition and weight management

Having a balanced diet and maintaining or achieving a healthy weight is an important part of a healthy lifestyle. Eating more healthily and having a normal weight are associated with reduced risk of heart disease, obesity and **diabetes**. In addition, some research has proven that cancer survivors who eat more healthily may have a reduced risk of cancer **recurrence**.

Giving advice or recommendations about nutritional habits is difficult, because you each have your own personal preferences. Nevertheless, there are some tips to help you in having a balanced diet:

- Try to eat mostly plant-based food – this means limiting the amount of animal products and adding more fruits and vegetables.
- Increase the daily intake of fruits, vegetables and whole grains – a good rule of thumb is to try to consume 5 servings of vegetables and 2 servings of fruits daily (1 cup, e.g. of broccoli = 1 serving). Also, try to eat more pulses (beans or legumes).
- Reduce the intake of processed foods, red meat, fats and alcohol.
- Reduce intake of energy-dense foods, such as sugary drinks, fast-food, and sweets or candies.
- Limit consumption of alcohol (e.g. beer, wine, or spirits) to no more than two drinks per day for men and one drink per day for women.



- Reduce the portion size and increase the meal frequency.
- Reduce snacking habits and the frequency of eating out.
- Increase the variety and ensure the adequate intake of **nutrients**.
- Dietary supplements are NOT recommended for cancer survivors.

Another aspect of the healthy lifestyle is weight management. Weight management refers to your ability to achieve and maintain a normal body weight for your height, age, and gender. You can look up what is considered a “normal weight” for you based on your personal characteristics on the internet. Of course, you should always consult with your family doctor and perhaps a dietary specialist such as a registered dietician who is familiar with the unique needs of cancer survivors before changing your diet. It is generally recommended to choose a diet that is in line with accepted lifestyle recommendations for cancer survivors and that can help you achieve the normal weight. One issue to deal with is whether you need to lose or gain weight. For some survivors, trying to regain the weight you lost during the therapy period may be the goal. However, for others, it may be recommended that you try to lose some weight to get to the normal body weight. In most circumstances achieving and maintaining a healthy weight can positively affect your everyday life and can increase your self-confidence, not to mention lowering your risk for a number of physical health conditions.

If you find weight management difficult, it is a good idea to seek help from a trained professional. You can be advised by specialised providers (for example nutritionists) and you could discuss weight management strategies with them, focusing on how to gain or lose weight depending on your weight status. Again, the goal is to achieve and maintain the normal weight.

In some cases, for other health problems such as **osteoporosis, cirrhosis, ophthalmological disorders**, arthritis, etc. and inadequate diet, the use of supplements is necessary. If you don't have such a problem, you should bear in mind that supplements should not substitute for regular meals and intake **nutrients** through your food/meals.

Stress management

Remember that some stress is a normal part of life and stress helps us to manage to get to appointments on time and keep important deadlines. However, for some people, high levels of stress can affect quality of life. Learning to manage your stress can improve your quality of life and your self-esteem.

Tips to manage stress:

- Ask for expert help (**psychologist** and **psychiatrist**).
- Talk about the stressful things with your friends.
- Ask for advice from other survivors, about ways they have managed their stress.
- Participate in support groups.
- Get involved with other activities such as meditation, yoga, exercise, new hobbies etc.



In addition to seeking help from others regarding stress management, there are number of practices you can easily learn and use on your own to control stress. These include:

- **Deep breathing:** Often, when you become stressed, you may notice that your breathing becomes quick and shallow. This may actually increase your heart rate and make you feel more stressed. To counter-act this effect, an easy strategy to use is to deliberately slow down your breath through a technique called deep breathing. To do this, find a comfortable position, and close your eyes. Take a deep breath, inhaling slowly until you feel your abdomen fill to capacity. Then, slowly release your breath; for some people counting to 5 as you breathe in and out helps. Repeat this practice 3 or 4 times until you feel a calmness and relaxation that comes over your body.
- **Guided imagery:** An effective strategy to manage stress is to distract yourself from the stressful situation. For example, if you experience pain, fatigue, or **anxiety**, you can use a technique called guided imagery to distract you from that symptom. Here's how it works: Sit or lie down in a comfortable position in a quiet place. Then, use your imagination to create in your mind a place where you feel calm, relaxed and happy. In other words, go to your "happy place" in your mind. For some people, it might be the beach while for others it might be a flower-filled meadow. All that matters is that it is YOUR place of happiness and serenity. Try to really imagine yourself in that place by focusing on all the sensory characteristics, such as the visual sights, the sounds, the smells, and the tactile feeling of being in that place. This strategy has also been shown to be effective in managing symptoms as well as controlling stress.
- **Learning to deal with unhelpful thoughts:** Common sources of stress are fear about your health and your future. These thoughts are natural, however sometimes they can become intense and dominate our thinking. When this happens, the thoughts are unhelpful. To deal with these unhelpful thoughts, try to be aware of your thinking and use some "self-talk" to address it. Here's how it works: when you notice that a fearful thought enters your mind, allow yourself to acknowledge that this thought is understandable given what has happened. For example, if you have the thought "I am afraid that I cannot cope with the long-term **side-effects** of my cancer and its treatment", allow yourself to think "Well, I guess most people in my situation would feel anxious about that." Just not being self-critical is likely to help you to feel less stressed. The next step is to ask yourself if there are any other ways to look at the situation, for example: "Do I have anyone I could ask for help?" or "Maybe I should discuss this with my doctor so that we can work out how to handle things?" or even "I can't be the first person who has felt like that - maybe I can find out what have other people done." Using positive self-messages is also useful.
- **Progressive muscle relaxation:** When we are stressed, our body often becomes tense, perhaps even without us noticing it. To counteract this effect, you can use a strategy called progressive muscle relaxation. Here's how it works: Moving progressively through the major muscle groups of your body, starting with your head and neck and moving down your body to your legs and feet, you first tighten those muscles and hold that position for 5 seconds, taking notice of how it feels for those muscles to be constricted. Then, you release the muscle, focusing on how it feels to be relaxed. The idea here is to begin to be able to recognise how it feels to be stressed versus how it feels to be relaxed, and to ultimately be able to put yourself in a state of relaxation through this strategy.

There are many other methods you can use to manage the stress, including both pharmacological (e.g. medications) and non-pharmacological (e.g. behavioural strategies such as those described above). First, try talking with your family members and **health care providers** to get suggestions and help in managing your

stress. You may be surprised how willing they are to help. In addition, it is a good idea to go online and read about other self-help methods you can use to control the stress. There are many reliable sources online with excellent suggestions. Give a few of these techniques a try and see what works best for you!

2. What to avoid

Reducing alcohol consumption

Reducing or even avoiding the consumption of alcohol is also an important aspect in order to achieve a healthy lifestyle.

Excessive consumption of alcohol decreases your **performance status** (physical fitness) and can lead to behavioural changes and problems in your work place as well as your personal relationships. Furthermore, it has long been known that high alcohol consumption is associated with an increased risk of **cirrhosis** and neurological problems.

Studies have also shown that drinking alcohol can increase the risk of developing a number of cancers, such as cancer of the mouth, throat, **larynx (voice box)**, **oesophagus** (tube that connects the throat to the stomach), liver, breast and large bowel.

Moderate alcohol intake could have positive effects to heart function, but this aspect should be weighed against the other risks that have been mentioned regarding cancer.

Smoking cessation

It is widely known that smoking is directly associated with many types of cancer, among them lung, throat, mouth, **oesophagus**, bladder, **larynx**, pancreas. In addition, smoking increases the risk of heart disease, high blood pressure, lung disease (**chronic obstructive pulmonary disease**) and sexual dysfunction.

Tobacco contains nicotine, a highly addictive substance which can make it difficult to stop smoking or using smokeless forms of tobacco.

While some tobacco users can stop on their own, many individuals need help to quit. Fortunately, there are numerous strategies and products on the market today to help with smoking cessation and ending tobacco use. Remember that, although some people will be able to stop smoking on their first attempt, for many this is not the case. If you try to stop and don't succeed, don't be disheartened as many people find that they are successful if they persist.

Here is some useful advice for smoking cessation:

- The most effective method for smoking cessation is the combination of behaviour therapy and pharmacological therapy (medications such as nicotine patches or gum). In other words, the combination of professional support with the use of nicotine substitutions.



- Smoking status should be documented in the personal health record. In case of relapse after a period of successful smoking cessation, don't give up. Set a new quit date, seek help from others or join a smoking cessation programme and use nicotine replacement products if necessary.
- Acupuncture or other alternative smoking cessation strategies might help you.

Avoidance of excessive exposure to UV radiation

Nowadays, it is widely known that the excessive exposure to UV radiation can cause skin problems and, especially, can increase the risk of melanoma, which can be a deadly form of cancer. Despite this knowledge, research has shown that the level of motivation for skin cancer prevention is low not only in the general population, but also among cancer survivors.

It is, therefore, very important to be motivated and to keep in mind some simple things in order to avoid skin cancer. The avoidance of excessive exposure to UV radiation is considered to be of primary importance. If you plan to be exposed to sunlight, use sun protection strategies including avoiding peak UV hours (between 10 am and 3 pm), applying sunscreen lotion (at least 60 SPF), wearing UV protective cloths including a hat, sunglasses, and long-sleeve shirt. Be sure to reapply sunscreen lotion after bathing or sweating as its efficacy wears off with water and perspiration.

Avoiding worsening side-effects through the use of specific drugs

For many survivors coping with **side-effects** caused from cancer or the treatment is a reality. These **side-effects** could be kidney problems, sexual dysfunction, **peripheral neuropathy (polyneuropathy)**, digestive problems, **immunosuppression** and **thromboembolism** risk.

The use of certain drugs could worsen these **side-effects**. In order to avoid such a situation, have in mind to:

- Get advice from your **oncologist** when in doubt about the risk of using a new drug.
- When getting treatment for another disease, remind your family doctor in order to avoid the prescription of a drug which will interact with your cancer treatment.
- Ask your pharmacist about the possible **side-effects** of drugs which do not need prescription (over-the-counter medications) or for the possible **side-effects** of supplements.
- Read carefully the leaflets in the drug packs.

3. Infections and vaccinations

Infections may have been a serious threat to you during your active treatment. Since many anticancer treatments significantly lower your body's capability to fight back infections, because they are "**immunosuppressants**", your **oncologist** most likely discussed with you certain precautions to take (i.e. staying away from infected persons, etc.) during therapy. Your **oncologist** also most certainly advised you to ask for medical assistance in case of fever or other signs of acute infection. As treatments vary quite substantially both in their general risk to affect your immunity and exposure to very specific infection risks (i.e. fungal infections, etc.), the advice given to you is not necessarily the same as that given to the patient next to you in the waiting room... Some patients may even have to refrain from eating raw vegetables or cheeses!

So, now that you enter survivorship, you may ask yourself what your present risk for infection is and whether the same behavioural rules which applied during your treatment still remain valid?

Let us be clear: this booklet will not give you a clear answer to this, as it very much depends both on your type and stage of cancer, your past treatments, but also how old, how “fit” you are and whether you have any other diseases (i.e. chronic bronchitis, **diabetes**), etc. To know exactly what you may (still) need to watch out for, please discuss this individually with your **oncologist** and family doctor. We will, however, try to give you some general considerations.

How will I have to deal with infections? What do I have to do to prevent them?

Your **oncologist** has certainly warned you about your risk of potentially serious infection with rapid evolution, while you were still on active treatment.

The good news for most of you is: if you are no longer receiving active treatment, the risks of infection will taper off and, progressively, you will be able to lead a “normal life” again, meaning that you will no longer require specific precautions at some point in time. In medical terms, you will slowly come from a state of immune deficiency (the inability to properly fight back infections) to one of being “immune competent.”

The crucial point is that it will not happen overnight, just after the last active treatment has ended; it will happen GRADUALLY.

So when will you know that you have come back to a normal immune defence, and how will you know?

In fact, you may not necessarily feel the answer, or see it in your regular medical analyses, in the blood or elsewhere.

Some cancer treatments do not significantly compromise your immune defence system (e.g. **anti-hormonal treatments**, some **targeted therapies**).

Many chemotherapy regimens (i.e. adjuvant treatment for colorectal cancer) will need only weeks until the immune system has recovered enough to provide you with sufficient protection: in case of symptoms, you may still wish to seek medical advice, but you will most probably be able to cope with your infection just the way you did before; if the infection does not seem serious (i.e. a common cold), you may treat it with over-the-counter remedies, wait for symptoms to improve and seek medical review if symptoms worsen or persist.

On the other hand, a risk of prolonged **immunosuppression** will be a consequence of some intensive treatments, such as an allograft: your immune depression will be long-lasting and severe and you will have to be particularly observant about infectious symptoms, avoid crowded places, certain foods, etc.

There are treatments (i.e. lymphoma treatments), which may seem very “harmless” in their **side-effect** profile, but may keep you at risk for some specific infections even for years (e.g. specific respiratory infections).

Finally, some patients may have long ago terminated their “active” treatment, but still remain under immune depressants (cortisone, immune modulatory drugs, etc.).

So, how do you know?

You should ask your **oncologist** about your risk for infections. Even though he/she will most certainly not be able to predict whether you will get sick or not in the near future, he/she will be able to point out your probable risk, and discuss with you and your family doctor possible infections to be especially considered in case of specific symptoms.

If you have completed your **chemotherapy** or other form of active treatment only recently, and not had a chance to discuss these items with your **oncologist**, it might be wise to stick to the same precautions you were supposed to follow DURING the treatment, being:

- Talk as soon as possible to your doctor and describe your symptoms.
- In case of high fever or acute problems with breathing try to go as quickly as possible to the hospital.
- Your doctor may prescribe an antibiotic treatment immediately in the case of a suspected severe infection. For patients with severe acute or chronic immune deficiencies this can be life-saving!

Let us emphasise: You have accomplished your active treatment, you are in survivorship now. This means that you most certainly should GRADUALLY come “back to a normal life” again, which obviously includes public transportation, meeting friends in social settings or going to a swimming pool.

Time and good medical advice will bring you confidence on your road “back to normal”.

Vaccinations (=immunisations)

Of course, you are able to prevent certain infections through vaccinations. Think about the yearly flu vaccination generally carried out throughout Europe.

Oncologists and family doctors encourage the administration of most vaccines. Of course, whenever possible, these are best carried out before treatment starts, since the efficiency of the vaccine may not be the same under immune depressing treatment. This is not always possible. Many vaccinations can be performed safely during treatment. You may want to check now which vaccines you already received in the near past!

The recommendation for vaccinations remains fully valid during survivorship and covers people with all cancer types as well as transplant survivors. Your family doctor is qualified to check your vaccination status and identify potential vaccinations you should undergo, or you may consult with your **oncologist**.

Measles, Mumps, Rubella, and Varicella vaccine should be administered if **immunisation** is no longer sufficient. This vaccine should NOT be administered during **chemotherapy**. **Tetanus** and **diphtheria immunisation** titres should be checked, a booster administered if necessary. **Pneumococcal** vaccine should be made outside the treatment period (since this vaccine is often not efficient when applied during “stronger” **chemotherapy**). Polio should be administered as inactivated vaccine. **Influenza** (flu) vaccine should be administered annually. **HPV** vaccine can be administered where appropriate, also **hepatitis A, B** vaccines.

It is not always clearly predictable whether a vaccine will work in your body as well as in an “immune competent” person.

Most vaccines are safe to administer: They do **not** contain any “living” germs being inactivated or not.

They can have different **active ingredients** (inactivated viruses, such as the flu vaccine), vaccines made of only parts of bacteria (such as the vaccine of diphtheria-tetanus-pertussis), sometimes only as **antigens** (**purified**, such as the vaccine of pneumococcus) or genetically engineered (**recombinant antigens**, such as the vaccine for hepatitis B).

Caution should mainly prevail concerning the use of (**attenuated**) **live** vaccines (which are fortunately nowadays rare in general use, but may still be without alternative for some diseases such as yellow fever, measles/mumps/rubella, some polio, etc.). Live viral vaccines should be administrated 4 or more weeks before **chemotherapy** and 3 or more months after cancer treatment. In case you still receive **monoclonal antibodies** against **B-lymphocytes**, you should wait for 6 months after having ended this treatment. Other conditions may require similar caution: ask your **oncologist**.

Ask your **oncologist**/family doctor about the appropriate time to apply these vaccines.

CHAPTER D

1. Detection and management of treatment- or tumour-related symptoms

Most of you expect to experience **side-effects**, mainly during the treatment phase. However, you may discover that some of these **side-effects** can linger for long periods after treatment ends and may take time to settle. These are sometimes referred to as long-term, persistent or chronic effects of cancer. Still other effects of cancer can develop weeks, months or even years after therapy ends. These are often referred to as late effects of cancer. These latter are generally specific to certain types of treatment and usually develop within a defined period of time.

Talk with your doctor and let him/her know that you want more information about cancer's long term and possible late effects. Your doctor will be able to help you with ongoing effects, and also tell you if you are at risk of developing any late occurring **side-effects**, depending on the type of cancer and therapy you have taken, possible genetic or family risk, and your overall health. Your doctor may also help you to distinguish true **side-effects** of cancer from symptoms not related to your treatment or disease, such as those due simply to getting older.

Chemotherapy-induced nausea and vomiting

Chemotherapy-induced nausea and vomiting remains an important adverse effect of treatment, despite recent advances in prevention. It is classified as acute, delayed and anticipatory (days or weeks after therapy). The risk of having nausea or vomiting depends on the particular **chemotherapy** agent, on the type of tumour and on the existence of other therapy (surgery, **radiotherapy**, etc.).

New drugs for the management of **chemotherapy**-induced nausea and vomiting have significantly improved the control of these symptoms and therefore the quality of life. Your doctor will inform you, if you are at high risk for having nausea and vomiting and will give you the necessary instructions on how to deal with it.

There should not be a high risk for you to develop or continue to have nausea and vomiting AFTER your treatment has been completed. Some patients experience nausea and occasionally vomiting when exposed to smells, sights or situations which remind them of their past **chemotherapy**. This type of nausea and vomiting responds well to psychological treatments. If this reaction affects you it is important to ask your doctor for a referral for assistance. Should this response occur much later on, nausea and vomiting may very well also signal other disorders (e.g. gut infection, etc.). Talk to your doctor about these experiences to ensure they are appropriately addressed.

Pain and peripheral neuropathy

Pain is one of the most serious concerns for the majority of cancer patients (and therefore for doctors as well). Pain is a highly prevalent symptom in patients with cancer. Many of you will have to deal with pain even after the end of the treatment. Pain is considered chronic when it persists for over 3 months. Adequate pain relief can be achieved in 70-90% of patients when treatment guidelines for cancer pain are followed. When pain occurs, help should be sought for this symptom as soon as possible to avoid, when possible, the pain becoming chronic (which may be more difficult to treat). There are many options for drugs to alleviate pain symptoms, the choice of which will depend on the cause, type and level of pain you are experiencing. Describe to your doctor the exact symptoms you are having and their effect on your ability to function. These details can

help to better inform the decision about which treatment may be right for you. Generally, **physicians** will start with mild or low dose pain medications and only move up to something stronger if you do not experience relief from your symptoms. Opioids (including true “morphines”) are effective analgesics for moderate to severe cancer pain. Use of morphine needs special prescription procedures as these drugs are potentially addictive and abusable drugs. When prescribed for a medical reason and professionally supervised, these drugs are, however, very efficient and may be maintained for a long duration safely with few **side-effects**. Your doctor will explain to you in detail all possible **side-effects** and risks associated with their use. (Your doctor will assume responsibility for risk assessment and management when these drugs are prescribed for medical purposes).

Patients treated with certain **anti-hormonal medications** for breast cancer (so-called “anti-aromatases”) may experience bone or joint pain and be worried. If you are concerned about this side-effect discuss management with your doctor.

Peripheral neuropathy is a disorder that occurs when the nerves that connect your central nervous system (brain, spinal cord) to the rest of your body are damaged. This damage can be caused by specific drugs and, although less common, by **radiation therapy** or by the tumour itself. Unfortunately, several essential chemotherapeutic agents can cause long lasting neuropathy, even after treatment has been stopped. Characteristically, you will note symptoms evolving from the ends of your extremities: You can develop numbness, tingling, a feeling like you're wearing a tight glove or sock, sharp/stabbing pain, thinning of the skin, muscle weakness etc. arising in the hands or feet, gradually progressing to the limbs and arms if the condition worsens. These symptoms, although usually improving gradually post-treatment, may be irreversible. Full recovery can take months, or even years. Symptoms can be alleviated with systemic **pain killers** or with local therapies, even though they may be difficult to treat. It is important to discuss these symptoms with your doctor even if they seem very mild.

Bone loss with the possibility of subsequent osteoporosis

“Bone” pain and joint pain could be also a common **side-effect** for many of you. These **side-effects** appear mainly in cancer survivors who received **hormonal therapy** and steroid (cortisone) therapy and secondarily in survivors who received specific chemotherapeutic drugs. It can, however, also be a general consequence of immobilisation, weight loss, etc.

You might want to determine with your doctor first, what exactly your pain is due to, as joint and muscle pain may simply be due to prolonged immobilisation and lack of exercise. Remember what it feels like to hike or ride a bike after you have remained inactive: you'll experience pain which should progressively taper off or lessen as you reasonably continue to train.

If you suffer from degenerative joint problems, such as arthrosis, muscle wasting or are taking some medications such as steroids, your symptoms may worsen in the long run, which again may require more careful exercise training. You may wish to seek expert advice on how best to recondition your body (physiotherapist, exercise physiologist, etc.).

Finally, you may suffer from a condition called **osteoporosis** which is also common in the general



population. It is important to state that only some of you will actually experience symptoms from **osteoporosis**, as this disease may long remain silent and only manifest itself in case of complications (such as fractures).

Osteoporosis can be detected through a specific radiological examination called osteodensitometry.

Osteoporosis, which represents progressive bone loss that leads to thickness and weakness of the bones, results, as a consequence, in high risk of bone pain and bone fractures. Postmenopausal female cancer survivors may be at increased risk for developing **osteoporosis**.

We would like to suggest special caution to this group of survivors.

Ask your doctor if you might be at risk for **osteoporosis**. Your doctor will give you advice both for diagnosis and management (regular measurement of bone density, regular intake of medication, everyday habits that can strengthen the bones).

There are specific drugs which slow the bone loss and reduce significant the risk of bone fractures. Additionally, you can minimise the risk of **osteoporosis** by making changes in your everyday life such as eating foods rich in calcium and vitamin D, avoiding smoking and – most of all – engaging in regular physical activity.

Mucosal, dental and soft tissue problems of the head and neck

Skin, mucosal or soft tissues can also be affected during treatment. The most common complaints are sore mouth, swollen gums and dental caries. Most of these effects recede over time, although full recovery can take weeks or months. If you have experienced marked weight loss as a result of treatment you may require review of dental prostheses. Patients who have been treated for head and neck cancer often experience dry mouth through salivary gland loss of function and need to follow regular mouth care to reduce the chance of developing dental caries. This regimen needs to continue long-term. Ask your dentist and your **oncologist** for advice if you have persisting symptoms.

Skin toxicity

Dry skin is frequently observed after **chemotherapy**. Some treatments may also cause eczema-like or acne-like skin toxicity (specifically several **targeted treatments**, but also some **chemotherapy** drugs). Usually, these disorders will either resolve spontaneously, or respond to hydrating lotions. Some may require specific treatments (i.e. antibiotics) according to your doctor or **dermatologist**. Make sure your **dermatologist** knows that you are/were receiving anti-cancer agents, so there is no confusion about your condition in term of other possible diseases.

Lymphoedema

All of us drain lymphatic fluid via lymphatic vessels throughout our body. These vessels pass through lymphatic nodes and remain (even though located mostly superficially under the skin) unlike blood vessels, invisible to us in normal times.

Whenever this drainage system is impaired, the lymphatic fluid may become blocked and will accumulate, leading to tissue swelling (which we call lymphoedema). Symptoms of peripheral lymphoedema include extremity swelling, skin changes, limb pain and discomfort, restricted range of motion, and non-pitting oedema.

As the treatment of cancers often not only need the treatment of the local tumour, but also of its surrounding lymph node areas, these may then affect the regional drainage.

Lymphoedema may be the consequence of surgical removal, or regional **irradiation**. It may unfortunately also sometimes be a consequence of a cancer's lymphatic spread. Finally, it may be caused by local infections and other non-cancerous conditions.

Lymphoedema affects mostly the arms and legs, mainly in people treated for breast cancer or genitourinary cancers. However, other parts of the body can also be affected by the lymphoedema, (i.e. including below the chin or in the face), again, depending on the nature and treatment of the cancer.

Multimodal therapy for lymphoedema consists of general measures, such as **physiotherapy**, and compression therapy. Successful conservative treatments may need to be administered in clinics with expertise in the treatment of lymphoedema. Pharmacological treatments are not generally used as no drug has yet been shown to be beneficial.

Cardiovascular problems

Heart problems and drug-induced cardiac toxicity

Many patients will have cardiovascular diseases (such as high blood pressure or coronary heart disease) which they “brought along” when entering anticancer treatment. These conditions may have worsened during and after the treatment for diverse reasons, some treatment-related, others not. Potential risk factors for the development of heart problems are **radiation therapy** (to the area of the heart) and specific types of **chemotherapy** (i.e. anthracyclines), or **targeted therapies** (i.e. trastuzumab or sunitinib). You may have been informed about these **side-effects** before start of these specific treatments.

Survivors who may have a higher risk include those:

- Older than 65.
- Who had heart problems before cancer treatment.
- Have other **comorbidities** like overweight or **diabetes mellitus**.
- Who received higher doses of certain chemotherapies and/or **targeted treatments** (specifically including trastuzumab and anthracyclines).
- Who received treatment (for instance for Hodgkin's lymphoma) as a child.

For some cancer drugs (like those mentioned above), regular cardiac function monitoring (mainly echography) by a **cardiologist** is routinely recommended. Ask your doctor whether you should undergo a specialist's exam.

New shortness of breath on exercise or at rest, swelling of the legs or palpitations could be a sign of possible heart problems.

Some drugs used to treat cancer (such as drugs targeting the vascular growth factor receptor) may strongly raise your blood pressure (even more if you had high blood pressure at the onset of your anticancer treatment). Some patients may even experience accelerated hypertension or a hypertensive crisis, meaning a severe and rapid rise in blood pressure to potentially acutely harmful levels. This condition requires immediate medical treatment (if not available at home, then in a hospital!). Discuss with your doctor whether you should monitor your blood pressure more closely, which actions you could perform at home, and when to seek medical assistance. Your doctor will also instruct you whether to seek specialist advice because, as mentioned above, drugs that target the vascular endothelial growth factor are a common cause of high blood pressure. Examples of these drugs include bevacizumab, sorafenib and sunitinib. The risk of high blood pressure decreases, often rapidly, to normal levels once a person stops taking these drugs.

Don't forget that you can also play a role in maintaining good cardiac health; striving for a healthier diet and lifestyle habits (smoking cessation, exercise etc.) can be of great importance.

Deep vein thrombosis / Pulmonary embolism

As a cancer survivor, you may be at higher risk for deep vein thrombosis (DVT). In this condition, a blood clot forms in a deep vein, mainly in the lower limbs. If not treated properly, this clot can break off, travel to the lungs and block a blood vessel. This is called a pulmonary embolism (PE) and is a potentially life-threatening condition, if not recognised early enough and treated.

Risk for DVT and PE varies according to cancer type, stage, treatment and degree of immobilisation. You are generally at higher risk if you have ever experienced a DVT or PE before.

Look out for swelling in a foot, ankle, leg, or (less frequent) arm. You may notice pain, cramps, tenderness and tightening (often in the calf), redness (but sometimes also discolouration), and a warm and heavy sensation in your leg. Usually, these symptoms are one-sided (e.g. affect the right or left leg, not both at the same time).

In case of PE, you might experience light-headedness, sudden shortness of breath, irregular heartbeat, one sided chest pain and/or coughing up blood. These symptoms may vary in intensity. They are also not only experienced in case of DVT/PE and may be due to other conditions.

In case you experience any of these symptoms, be sure to speak to your **health care professional** IMMEDIATELY. The suspected diagnosis of DVT and PE will have to be confirmed by blood and ultrasound/radiological tests. The sooner diagnosis has been established and treatment initiated, the better the outcome and the chance to avoid complications.

Treatment is anticoagulant therapy during a prolonged period.

You can lower your risk for DVT/PE by keeping moving and staying well hydrated. Smoking cessation can also contribute to lowering risk. Some patients may benefit from compression socks/stockings. Discuss with your doctor about prevention measures.

Fatigue

Are you still feeling tired, without energy? Fatigue is the persistent feeling of emotional, physical, mental or psychological tiredness or exhaustion. It is one of the most common **side-effects** of cancer treatment. Fatigue is typically a multi-dimensional symptom (may show in a variety of different forms) and may have multiple contributing causes. Duration and intensity may vary markedly from patient to patient, depending not only on the type of cancer and treatments received, but also on other contributors such as existing diseases and medications taken for these, living and working conditions and psychological status.

There is unfortunately no simple medical treatment for this troubling condition. However, a number of studies have shown that behavioural interventions, in particular physical activity, can help alleviate cancer-related fatigue. An individualised programme of moderate aerobic exercise for cancer survivors with fatigue is highly recommended. Walking programmes are generally safe for most cancer survivors. Patients can begin this or other types of programmes after consulting with their doctors, without any formal exercise testing (electrocardiogram – ECG, a stress test). Patients at higher risk of injury (e.g. those with neuropathy, cardiomyopathy, or other long-term **side-effects** of anticancer therapy) may require exercise tests beforehand, and should be referred to a physical therapist or exercise specialist prior to embarking on an exercise programme. Breast cancer survivors with **lymphoedema** should consider meeting with an exercise specialist before initiating upper-body strength training exercises.

For the majority of survivors who are going to initiate an exercise programme, a re-exercise cardiovascular screening is not necessary, except for some specific categories of high risk groups such as:

- People with **diabetes mellitus** or cardiovascular heart disease.
- Patients who are at high risk for a cardiovascular disease because of other diseases or application of specific treatments (for example survivors who have had **radiation** of the **mediastinum**, or survivors who have taken anthracyclines).

It may however still be a useful test, as for anyone in the general population.

In addition, cognitive-behavioural interventional methods and yoga and/or mindfulness-based stress reduction methods can be very useful in the treatment of chronic fatigue and many survivors have reported a remarkable improvement of their symptoms using these techniques.

Other conditions may lead to fatigue (i.e. sleeping disorders will make you more tired during daytime; treat them and you may experience less fatigue!). However, it is important to note, that simply getting more sleep does not always reduce cancer-related fatigue.

Sleep disorders

Sleep disorders, such as trouble falling asleep, problems maintaining sleep, poor sleep efficiency, early awakening and excessive daytime sleepiness, are prevalent in people treated for cancer. Sometimes the problem can become chronic, persisting for months or years after completion of cancer therapy. Sleep is potentially affected by a variety of factors such as physical illness, pain, immobilisation, **hospitalisation**, drugs and other treatments for cancer, as well as the psychological impact of a malignant disease. **Depression** is common in people treated for cancer and problems with sleep are a common symptom of **depression**.

Maybe this is a time to seek psychological assistance! Your diagnosis and treatment may have affected you far more than you may have anticipated or perhaps permitted. Behavioural therapy has been shown to provide good results for management of sleep disorders. Try also to find time to engage in things which might improve your psychological well-being and reduce stress, such as hobbies or yoga.

In order to deal with sleeping disorders, sleep inducers (“hypnotics”) of various forms may also help you, at least for a limited time, even though they may carry the risk of addiction. Use of these medications, of course, should always be chosen based on which would be best for you, and prescribed by your doctor.

Cognitive function - “Chemo-Brain”

Many survivors complain of memory loss, difficulties concentrating, problems making complex decisions or juggling multiple tasks that we will refer to collectively as cognitive function problems. Some of you may prefer to use a more lay term, “Chemo-Brain,” to describe the difficulty you experience with trying to think clearly after cancer treatment (even though some survivors may not have received **chemotherapy**). Cognitive problems can appear in survivors who have had **chemotherapy**, who have had only **hormonal therapy** or to those who have had **radiation** to the brain or cranial surgery. Other factors, that can affect cognitive function could also be sleep disorders, **anxiety/depression**, fatigue, pain and pain medications or other physical illness. It is often difficult to understand causes except physiological, such as cognitive change (e.g. changes in brain function or structure) from other influencing factors such as fatigue due to treatment schedules, disease related fears and depression, etc.

Common cognitive problems reported in the post-treatment period are:

- Memory impairment (trouble remembering things).
- Inability to concentrate.
- Changes in executive function (lower ability to process information, make decisions), problems with multi-tasking.
- Difficulty learning new material/Reading comprehension.
- Troubling working with numbers (calculating).

We do not know why some people experience “chemo-brain” and others do not. Researchers are actively studying this area. The following strategies may be helpful:

- Perform challenging tasks at the time of day when you feel most refreshed.
- Divide tasks into smaller problems. Make notes and be prepared to ask for assistance.
- Avoid having the radio on when driving.
- Allow phone calls to go through to voice-message. Listen and respond to the call when you feel fresh and can concentrate. Take notes as you are talking.
- Develop habits and routine. For example, always leave your reading glasses beside the phone and you will know where to find them.
- Make notes for yourself of things to do/remember, and place them where you will see them.

Some computer programmes are showing promise in helping survivors improve their cognitive function after cancer. Your doctor can refer you to these or for psychological help as needed.

Depression and anxiety

Many people who have been treated for cancer experience **depression** or **anxiety**. Being upset or worried about the diagnosis and treatment are normal. For most people, these feelings improve over time. However, if you feel sad or worried most of the time, you cannot enjoy things, or you are avoiding friends and family or feel gloomy about the future, you may be depressed or anxious. People who are depressed or anxious often say things like "This just isn't me." "I just can't seem to shake these worries". There are a number of things which can contribute to becoming depressed or anxious.

- Past problems with **depression** or **anxiety**.
- Feeling isolated or lacking support.
- Having a lot of caring roles.
- Worry about money.
- A lot of complications during treatment.
- Ongoing **side-effects** of treatment or pain.
- Major changes in work, family or social life.

Becoming depressed or anxious is not a sign of weakness or that you aren't trying to help yourself. The good news is that treatments for **anxiety** and **depression** are usually effective. Talking therapy, including cognitive-behaviour therapy, is an effective therapy in reducing **anxiety** and **depression**, although some people may also benefit from medication. It is too important to suffer in silence. If you feel that you are struggling, ask your family doctor or **oncologist** for a referral for specialist treatment.



Fear of recurrence

Worry that the cancer could come back is normal and probably the most universal long-term effect of cancer. Fear of **recurrence** may rise dramatically as you make the transition from active treatment to recovery. Worry that the cancer will come back now that treatments have stopped, leaving the caring environment, concern about who will be monitoring you, the struggle to cope with the lingering effects of the disease and its treatment and pressure by family and friends to 'be normal,' can all contribute to heightened **anxiety** as treatment ends. For most people the worry reduces over time, but for some people it persists and dramatically affects their



quality of life. Sometimes people ask for extra tests, or repeatedly check their body, or seek out every piece of information they can find (much of which is not accurate or scientific information!). The first step in dealing with this fear is to see it as normal rather than trying to fight it, and trying to accept that a degree of worry is part of life. Recognising that there are triggers to this worry (such as **follow-up** visits, unexpected aches and pains, reading about deaths of prominent others with cancer), can also help to 'normalise' this response when it occurs. This awareness may be enough to help you feel more confident, but if this doesn't help, seek psychological treatment. Getting help understanding what you are worrying about and ways to address this can be important in regaining a sense of control, and reduce worry.

Eye problems

Patients may complain of not seeing clearly during or after **chemotherapy**. While this problem should always lead to an eye specialist's exam, one frequent cause is a worsening or the development of a cataract (a thickening of the eye lens which leads to loss of transparency), a condition which can be easily remedied through simple surgery.

Hormone (endocrine) system problems

When we speak about the hormonal or endocrine system, we mean on a range of hormone producing organs like the hypothalamus and the hypophysis in the brain, the thyroid gland, parathyroid glands, the insulin producing part of the pancreas, the adrenal glands and the sexual glands. In many therapeutic circumstances, endocrine function can be suppressed, both temporarily and definitively (after surgical removal, **radiation therapy**, **chemotherapy**, **immunotherapy**, etc.). You may thus encounter symptoms according to the lack of the natural hormone that otherwise would have been produced.

We'll share some examples with you.

Hormonal insufficiencies (i.e. thyroid dysfunction)

Surgical removal of an endocrine gland necessarily leads to the lack of the corresponding hormone production. Whenever possible, this lack will be compensated by the intake of the corresponding hormone (prescribed to you by your doctor).

Less evident, but also quite frequent are endocrine deficiencies after locoregional **radiotherapy**. An example is the thyroid gland located in the head and neck region. The thyroid is at risk of being irradiated – at least partially – if adjacent tissue is being treated. Thyroid insufficiency ("hypothyroidism") is a possible consequence.

New treatments such as **immunotherapy** with so-called "check point inhibitors" may alter the function of the hypophysis, thyroid gland and other endocrine glands, potentially creating dysfunction of the thyroid, adrenal or other glands.

Some hormone deficiencies may not show immediately and may only be found after specific symptoms arise. In some cases this can happen years after the therapeutic intervention took place.

According to the treatment you have received, your doctor should regularly screen the most common endocrine functions with common blood laboratory tests. Other deficiencies may reveal themselves through characteristic symptoms. When in doubt, inquire!

Infertility

It is evident for everyone that surgical removal of the woman's ovaries or man's testicles will lead to **infertility**.

Unfortunately, **chemotherapy** and **radiation therapy** to the **pelvic** and genital areas, but also **hormonal therapy**, can also lead to **infertility**. This depends on age and, foremost, on the treatment intensity of specific anticancer agents. Normally, whenever possible, a **fertility** consultation with at-risk patients, with discussion about means to cryopreserve ovaries or sperm, will take place before the start of treatment. If this has not occurred, options for childbearing may be more limited. However, consultation with a **fertility** expert should still be pursued if exploring ways of having children remains of interest.

Amenorrhea, menopause

Many female survivors will experience lighter or fewer regular menstrual periods or notice amenorrhea: the complete stop of menstrual periods. In many and mainly the younger survivors, the menstrual period will eventually return. Be advised, that, even in the absence of menstruation, you may have regained **fertility** and are "at risk" of becoming pregnant! There is also no clear timeline when menstruation may re-occur. In some women, it may not even have stopped throughout **chemotherapy**, while in others, it may re-occur after weeks or months! Finally, some women may experience premature menopause, especially when those above 40 years of age undergo **chemotherapy**. You should consult your **gynaecologist** about your risk of permanent menopause and possible treatment options. Please note that while the risk for definite menopause is not apparent in a regular blood exam, there are specific tests which may help your **gynaecologist** to appropriately advise you.

Men who receive **hormonal therapy** for prostate cancer or who have their testicles removed because of testicular cancer can experience symptoms similar to menopause ("andropause" characterised by limitation of sexual libido, flushes, **adipose** changes, etc.). Furthermore, **radiation** of the **pelvic area** or the intake of specific chemotherapeutic drugs can cause **infertility**, with risk factors similar to those described above for women (**chemotherapy** intensity, age). A **urologist** will give you medical advice on **infertility** and possible solutions to cope with "andropause".

In some patients, hormone suppression is key to prevent cancer **recurrence** (i.e. androgen deprivation in prostate cancer or anti-oestrogen therapy in hormone receptor positive breast cancer). In many other patients, these complications are reversible, and many can be alleviated or corrected by medical interventions.

Sexual dysfunction

Sexual dysfunction is important issue in cancer survivors. The problems can range from painful sexual intercourse due to medical or psychological causes, premature menopause, amenorrhea, **infertility**, body image changes, altered patterns of intimacy which are already described in this guide.

In addition, the lack of sexual interest (libido) and impotence are frequent after anticancer treatments. They may not have anything to do with hormonal or other organ dysfunction. Instead, they may be caused by a lack of self confidence in patients who for a long time had to focus on their cancer. Getting back to finding pleasure in sexuality may not be as easy as it sounds.

Concerns about libido and sexual function should be discussed with your doctor who might arrange review by a **gynaecologist** or **urologist** or another specialist. A **psychologist** or sexologist may help you also with these problems.

Urological problems

Some cancers and some cancer treatments may cause urinary or bladder problems. Symptoms that can appear include urinary incontinence (difficulties controlling the function of the bladder), trouble urinating despite feeling the urge to, pain or a burning feeling when you urinate, blood in your urine, bladder spasms, cramps or general discomfort in the **pelvic area**. Please note that a simple urinary tract infection may lead to the same complaints so ruling this out is important to addressing the problem!

Any treatment affecting the region surrounding the bladder may lead to these problems, e.g. treatment for prostate cancer, (colo)rectal cancer, bladder cancer, cancer of urethra, gynaecological cancers such as cervical cancer and uterine cancer. Brain or spinal cord cancers (and their treatment) can affect nerves that help control the bladder or pelvic muscles and may thus cause similar complications. As a consequence, **radiation therapy** to the **pelvic area**, will include the bladder; surgery to the **pelvic area** may also do so, directly or indirectly by damaging muscles or nerves that help control urination. Some chemotherapies may specifically irritate the bladder mucosa. **Antihormonal treatments** may lead to hormonal changes which will influence neighbouring organs: e.g. breast cancer treatment can cause hormonal changes that dry out the urethra.

Remedies depend on the circumstances which led to the complications and need to be dealt with on an individual basis. Possible interventions may include bladder training, physical therapy and medicines. Do not forget to hydrate yourself adequately: some urinary problems may “dissolve” when you remember to drink more water!

Gastrointestinal problems, digestion

Diarrhoea, constipation or an irregular gastrointestinal transit are common problems after many anticancer treatments, in particular, if treatment occurred for a gastrointestinal cancer.

Weight loss is very common after gastric or pancreatic surgery, and may be quite substantial. Some patients wrongly confound this with **recurrence** of their cancer!

Chronic diarrhoea early after food ingestion may also be a consequence of surgery and/or **radiotherapy** of the gastric or pancreatic/biliary tract region. Some patients may require lifelong vitamin B12 supplementation after gastric surgery.

After **colon** surgery, many patients will ultimately regain a “normal” gastrointestinal transit, but this may take months, sometimes years, and some people may find that they never return to their previous function. Patients may suffer from diarrhoea, depending on food intake and other variables. You may have to adapt your diet or take medication. If persistent intestinal or digestion issues are a problem for you, your doctor, a nutritionist or a dietitian should be able to help. The correct amount, timing and ingredients (including vitamins) of your food intake may be crucial to alleviate symptoms and maintain your health as well as stabilise your weight.

Lung problems

Lung problems often manifest through breathing problems and/or cough (with or without blood). It is important to note, however, that even though you may refer to cough and breathing difficulties as lung problems, these symptoms may also be caused by the heart or even by head and neck problems. Your doctor will diagnose the organ responsible for your “lung problems”. In this chapter, we will focus on respiratory problems arising from the lungs.

Certain types of **chemotherapy**, **targeted therapy** and **radiation therapy** to the chest may cause harm to the lungs. Cancer survivors who received both **chemotherapy** and pulmonary **radiation therapy** may have a higher risk of lung damage. Also, people with history of lung disease such as **chronic obstructive pulmonary disease (COPD)** or people who have chronic heart problems may have an increased risk of respiratory problems after chemotherapy or **radiotherapy**.

Similar types of pulmonary problems may be induced by different therapies. To make matters a bit more complicated, these symptoms may also be due to different causes which require specific treatments.

The following categories of pulmonary problems can appear after or during the **chemotherapy** or **radiotherapy**:

- Pulmonary infections: Many anticancer treatments will lower your immunity (“**immunosuppressants**”) and “facilitate” or make you more vulnerable to infection. Infections are commonly treated with antibiotics.
- Medication-induced pneumonitis: Medications, especially newer anticancer agents, such as **targeted agents** (i.e. tyrosine kinase inhibitors which are oral drugs, **monoclonal antibodies**, **immunotherapy**) may cause a condition which strongly resembles pneumonia in its clinical aspects, as well as in laboratory and radiological tests. However, in contrast to infections, treatment is the opposite: **immune suppression**! Therefore, distinction of this disorder is paramount and may require expert opinion. Treatment is based on early detection, corticosteroids and **supportive measures**.
- Radiation-induced pneumonitis: Similar to medication-induced pneumonitis, this condition is often more easily recognised due to its incidence during or shortly after **radiation therapy**, and a radiological image showing that it is limited to the region irradiated. Treatment involves use of corticoids.
- Pulmonary fibrosis: This is a rare disorder that involves excessive scarring of the small lung alveoli (air bubbles, in which the gas exchange takes place) which leads progressively to the lack of oxygen absorption. This is fortunately a rare, but potentially late **side-effect** of some older (but still used) anticancer drugs (e.g. bleomycin) or **radiation therapy**. The condition will show-up on radiological exams and a pulmonary function test. Triggering drugs should be avoided if **radiotherapy** induced corticosteroids are mainly administered and other **immunosuppressive** therapies.
- Haemoptysis (meaning cough with blood) may arise in association with exposure to some antivascular drugs such as bevacizumab, sorafenib, etc. and may require the withdrawal of the drug. Problems should subside once the drug is stopped.
- Likewise, **pulmonary oedema**, interstitial or more common, alveolar, may be drug-induced, but should not be experienced after the responsible drug has been stopped.
- Finally, pulmonary embolism and **cardiac oedema**, are conditions which may arise during or after anticancer treatment, with or without relation to anticancer treatment.

In case of respiratory symptoms, you will need to seek your doctor's diagnosis and advice.

Diagnostic tools include a thorough interrogation and clinical exam by your doctor. Radiological exams, such as an **X-ray** or **CT scan**, may be necessary along with pulmonary function tests and other exams performed by a lung specialist (**pneumologist**). Up to now, there is no role for screening, meaning that specific tests are only requested or performed in the presence of symptoms.

The treatment of these problems has already been discussed above (antibiotics, cortisone, etc.). Other symptoms may require an interventional treatment (e.g. if there is significant bleeding, severe shortness of breath).

2. Prevention and detection of cancer recurrence

One of the main goals of **follow-up care** is to detect a **recurrence** of cancer.

What is a cancer recurrence?

A **recurrence** is when the tumour comes back after treatment. Cancer recurs because small areas of tumour may have remained undetected in the body and/or did not respond to the anti-cancer treatment(s) received. Over time, these cells can increase in number or spread out to other parts of our body until they are detected in the blood or in imaging tests, or cause signs or symptoms.

When can a recurrence occur?

Depending on the type of cancer, the stage of disease at time of diagnosis and the type and success of therapy, this could happen weeks, months or years after the original cancer was treated. Some cancers can be considered cured after a number of years, others not, even though their late relapse is normally quite rare.

A recurrence could appear as **local**, **regional** or **distant**.

A **local recurrence** means that the cancer has come back in the same part of the body, where the original cancer was located.

A **regional recurrence** means that the cancer is present in a part of body near to the original location of tumour.

A **distant recurrence** means that the cancer has revealed itself in another part of the body. This is often called "**distant metastases**".

It is very important to clarify that if the tumour recurs in an organ far from the location of the original cancer and shares the same genetic/cellular characteristics as the original, it is still named after the part of the body where the original cancer began. This can be confusing to many. Should this happen to you, you may believe that you now have a new cancer in this new organ or target of the tumour. For example, if a survivor treated for **colon** cancer now has a **recurrence** in the liver, doctors will call it a liver metastasis from **colon** cancer (**colon** cancer that has spread to another part of the body) and not liver cancer.

Are there means to prevent recurrence? Is there a way to know the likelihood that you will have a cancer recurrence? How will a recurrence be detected? Is it important to detect recurrence early?

While there is no way to specifically prevent **recurrence** of your cancer, there are efficient ways to significantly lower your risk: a healthy lifestyle, stress-management, weight control and regular physical exercise can help you to lower the risk for **recurrence**.



In some cases (e.g. hormone-receptor positive breast cancer) there may be ways to lower risk of **recurrence** through use of medication (e.g. use of an aromatase inhibitor). But there are few chemopreventive agents available to date for most people with cancer.

The probability that the cancer will recur and the time and location of **recurrence** depend on the type of cancer, its stage and the type of treatment you received.

While a likelihood or statistical probability is known for most types of cancer **recurrence**, it is impossible to predict whether a specific cancer will recur.

If you wish to know, your doctor can discuss with you the likelihood of **recurrence** of your type and stage of cancer according to published data.

To help find signs of a potential **recurrence**, your doctor will ask specific questions about your health status, do a careful physical examination and perform **follow-up** tests (blood work, radiologic scans) in specific time interval.

If a **recurrence** is suspected or detected, your doctor will organise further blood and imaging examinations and biopsies in order to learn as much as possible about the **recurrence**. After the integration of tests, the doctor will talk about the results and the next steps with you.

Your doctor will have to weigh and discuss with you the potential benefits and disadvantages for systematic screening examinations.

A specific examination (i.e. a **CT-scan** or a blood analysis or a **colonoscopy**) can be considered beneficial, if detection before the onset of true symptoms will lead to a more efficient treatment. By the same token, an examination which might lead to earlier detection, but without any change in treatment nature or outcome, may not be deemed useful.

A specific examination can be disadvantageous for different reasons:

- If it will stress you because you will be reminded of your (hopefully) past disease. The waiting time for the examination and the time until your doctor will share with you the results may be particularly hard to endure for many patients.

- If it will, even though to a small extent, expose your body to adverse **side-effects** (contrast media, radiation, or simply pain).
- If it may show results which are less clear than anticipated, which may leave you and your doctor with more doubts for a longer time and require additional examinations.

The examinations recommended and their timing will depend on the likelihood of the disease to recur, it's potential to recur fast, and the potential change in treatment options early detection might provide. These tests also depend on the probability of the examination to deliver a reliable answer.

Here is one example to make you understand this complex point a little better: If you have been treated for a cancer with a very low likelihood of **recurrence**, you may have more harm than benefit of repeated **CT-scans**, **endoscopies** or other examinations.

This will be even more the case if the treatment will remain essentially the same and if you can be treated without risks, even if the **recurrence** has not been detected early. This is the reason why systematic **follow-up** for most breast cancer patients does not incorporate **CT scans**, **bone scans** biomarkers or other imaging beyond a yearly **mammogram**. It also explains why **follow-up** intervals are relatively long (proposed are 6 monthly consultations).

Early detection of the primary cancer is very important, since it will determine the stage of disease. The lower the stage of initial disease, the better the chances for cure.

Unfortunately, cancer **recurrence** is mostly metastatic. Chances for true cure in this setting are much less frequent and chances for best long-term survival are often more related to your general condition and location of the metastases than on the exact number of metastases.

Finally, we do not always clearly know whether screening examinations are truly useful! For this we would need comparative studies, and these take time and are not always yet established. Medicine is a fast evolving and busy science. Oh, if we only could know it all already!

In addition to systematic screening, you will be advised to watch out for specific symptoms or signs which could appear in case of a **recurrence** of your specific cancer. These are not the same for different cancer sites. A symptom of **recurrence** may of course occur at any time, independent of screening intervals. You are therefore advised to contact your doctor in case of any doubt, independent of the time since the last consultation.

Please be reminded that all screening examinations can only certify to a certain degree your well-being up to the consultation and cannot (as many believe) guarantee you freedom up to the next scheduled one!

Surveillance for a **recurrence** is stressful and learning relaxation techniques to deal with **anxiety** and/or seeking counselling is helpful, especially if fear becomes preoccupying or immobilising (keeps you from **following-up**). Many find that after several visits, with reassurance that there is no sign of **recurrence**, the **anxiety** levels drop.

3. Prevention and early detection of new primary cancers for patients and their family members

As you have passed through the anticancer treatment many of you are more aware about the prevention of cancer. So now that you enter survivorship, you may ask yourself what could you do to prevent the appearance of another cancer. Based on your own experience, you may want to encourage friends or family members to engage in regular cancer screening tests for early detection.



Cancer prevention and cancer detection in an early stage are very important. The awareness about cancer prevention and of the importance of regular screening for specific cancers has improved in recent years, but there is still a lot of work to do. Let us give you some useful advice about prevention and early detection of cancer!

General cancer prevention measures

There are at least four different situations which may apply to you in terms of cancer prevention:

1. All of us share preventable risk factors which apply to the whole population:

Smoking is a major risk factor for many tumours, such as lung cancer, cancer of the head and neck area, pancreatic cancer, bladder cancer and many others. Everyone should know this by now, and yet smoking continues to be a global challenge.

Alcohol consumption has also been identified as a risk factor for breast, liver, oesophageal, oropharyngeal, laryngeal and rectal cancers.

If you have not yet accomplished smoking cessation, diminished your alcohol consumption or started means for weight control, now is the moment to embrace change!

Excess weight is associated with elevated risk of many cancers. Physical activity is inversely related to risk for **colon** and breast cancer.

Engaging in regular physical activity will not only make you feel better – it will lower both your statistical risk for **recurrence** as well as the risk for a second cancer, whatever your prior fitness level was. These findings have been well proven in large studies.

UV radiation can raise the possibility of having melanoma and other skin cancers. Thus, use of sunscreens and protective clothing along with avoidance of prolonged time in full sunlight are all important preventive health behaviours.

In conclusion, smoking cessation, moderating or avoiding alcohol consumption, maintaining or regaining a normal weight watching sun over-exposure and performing regular physical activity are some measures which can significantly lower the risk of cancer.

2. Depending on your primary cancer you may, unfortunately, have a risk for a second cancer. For instance, if you were treated for a cancer of the head and neck, your risk for a second cancer in this region, the **oesophagus** or lung remains high (particularly if you did not quit smoking and/or drinking). Another example is **colon** cancer: You will remain at higher risk to (re)develop benign tumours ("polyps") which may degenerate into new **colon** cancers. Therefore, your doctor will likely recommend repeat **colonoscopies** more often than the general population. Ask your doctor if in doubt.
3. Some of you may have been diagnosed with a hereditary cancer. This is rather rare in the general population, but there may be hints or proof for a family trait in your case. We will discuss this issue in more detail in one of the following chapters.
4. Even though there may be no proof of a **hereditary cancer** syndrome, we know that the risk for a family member to get cancer may be higher in some cancer types. For example: If you have breast cancer, even being the only one in your family so far, your children have a higher risk to get breast cancer compared with the general population. This is the reason why your doctor may propose screening to be started in your next of kin at an age of 10 years earlier than cancer was detected in your case.

Screening for prevention and early detection in the general population

Unfortunately, at present we do not have reliable methods for early detection in many cancer types. In the following paragraph, we will talk about some important types of cancer for which we can provide efficient early detection in the general population ("screen"), which enhances the chance for cure: Screening as it is provided to a **general population** is a method to try to detect more cancers early on, in an efficient and affordable way and with minimal or absent **side-effects**.

Breast cancer

Experts have different recommendations concerning breast cancer screening in general. Most official screening programmes will start at the age of 50. Your doctor may, however, discuss with you the benefits and disadvantages of screening already from 40 years on. Women aged 40 to 74, and some older women who are healthy, may be offered screening with **mammograms**. This does not mean that you cannot get breast cancer at either a younger or older age. But in these ages, breast cancer is either rare or not considered a general public health issue in the general population. Thus, population-based screening for breast cancer would be too expensive (for insurance or the government who pays for it) and have too many **side-effects** according to the few patients detected to be proposed as a standard screening programme.

Cervical cancer

A very common chronic infection with the genital warts virus (HPV) is a risk factor for cervical cancer; the HPV-test is a prognostic factor for the appearance of cervical cancer. A yearly gynaecological examination including a cervical swab ("Pap-smear") can reduce the risk of cervical cancer. More recently, a vaccine may actually protect women from getting infected with the HPV virus. The HPV vaccination in many European countries is recommended in girls or young women between 9-26 years old, provided that they are not already HPV infected.

Prostate cancer

Digital rectal examination and screening for a blood tumour marker (called PSA) are proposed to detect early prostate cancer in men from 45–50 years old and up. Unfortunately, these examinations are less reliable than the cervical swab for cervical cancer, and there is a risk for both over diagnosis (an examination indicating prostate cancer, when in reality there is none) or under diagnosis (a supposedly normal examination, when there is prostate cancer in reality). Therefore, there is still some controversy among the experts as to its true usefulness, and you may have a different opinion concerning yourself! The best course of action is to discuss with your doctor whether you should undergo this screening procedure, and to discuss both the advantages and disadvantages of this procedure.

Colorectal cancer

Many European countries will provide yearly screening for colorectal cancer testing for occult faecal blood (and **colonoscopy** in case the test result is “positive”). Some countries also directly propose screening **colonoscopy** starting with people 50 years old (repeated every 10 years unless polyps are found when screening interval may be shortened). Since colorectal cancer mostly arises from slow growing, initially benign tumours (polyps), this is a very efficient method to prevent or to detect early colorectal cancer.

People with close family members with **colon** cancer (brothers, parents etc.), people with **hereditary syndromes** (which are associated with high incidence of **colon** cancer) or people with **ulcerous colitis** or **Crohn’s disease** have a significantly higher risk for **colon** cancer compared with the general population. Ideally, screening should begin earlier, and may be also more frequent in these populations. Individual screening recommendations should be discussed, organised and directed in cooperation with your doctor.

Don’t let the array of recommendations confuse you or dissuade you from following through. Get to the point and get the message! With simple things and with appropriate cooperation with your doctor, you can prevent many types of cancer!

Secondary cancers

While being cured for one cancer type, your **chemotherapy** or **radiotherapy** may unfortunately put you at risk to develop a different one, although this is fortunately very rare. **Chemotherapy** and **radiation therapy** can damage the bone marrow stem cells. That can lead to blood disorders such as **myelodysplasia** or **acute leukaemia**. These are malignant diseases of the blood, where the normal parts of the blood either are not produced or are abnormal and uncontrolled/multiplied. Other cancers may arise at the site of **radiotherapy**. In general, risk is low, and there are no specific preventive or screening measure (remark: blood disorders will show on a simple blood test including a general blood count). There is increased knowledge about the statistical risk for secondary cancers induced by anticancer therapies. If in doubt, talk with your doctor about the risk of developing a secondary cancer.

A special category of survivors at risk for secondary cancers are female survivors who had **radiation** to the **mediastinum** as part of treatment for Hodgkin’s lymphoma in childhood or as a young adult. In this particular group of female survivors, yearly examination of the breast and the yearly magnetic resonance imaging (MRI)/mammogram are recommended.

Hereditary cancers

Let's talk a little more about family risk for specific cancers. In general, we distinguish "sporadic" from "**hereditary**" cancers. While a sporadic cancer will arise from an organ tissue at any given time, a **hereditary cancer** arises from altered genetic trait already present at birth. Contrary to common belief, **hereditary cancers** are rare, and make roughly less than 5% of the general cancer population.

When should a **hereditary cancer** be considered? Your doctor may consider this in case of:

Cancers of the same type diagnosed in multiple family members (especially if it is an uncommon or rare type of cancer).

- Cancers occurring at younger ages than usual (such as **colon** or breast cancers in a 20-year-old).
- More than one type of cancer in a single person (such as a woman with both breast and ovarian cancers).
- Cancers occurring in both of a pair of organs (such as both eyes, both kidneys or both breasts).
- More than one childhood cancer in siblings (such as sarcoma in both a brother and sister).
- Cancer occurring in the gender not usually affected (such as breast cancer in a man).
- Cancer occurring in many generations (such as in a grandfather, father and son).

In these cases, there is not yet any certainty, but considerable suspicion of a **hereditary cancer**, which should then be confirmed by specific genetic counselling and analyses (more and more carried out by specialists called oncological geneticists). Examinations may be carried out on tumour tissue, or even blood, in the cancer carrier. Should a hereditary condition be confirmed in this person, it will then have to be looked for in family members (who are not necessarily carriers).

Earlier on, you may have wished, or not, to know about a hereditary risk for a specific cancer, but it did not lead to any better treatment – many patients did not want to know about their risk, feeling "doomed". Nowadays, certain cancers may be detected earlier on (thus providing better chances for cure) or even prevented in specific "high risk" population groups. Examples are breast cancer, ovarian cancer and cervical cancer for women, prostate cancer for men and colorectal and lung cancer for both sexes.

Example: Hereditary breast cancer

Nowadays a very well-defined procedure for a "high risk group" is established in hereditary breast cancer: The screening differs from the general population, and preventive treatment options (such as preventive surgery) apply.

This may be the case if you carry **genes** that increase the risk of breast cancer (or ovarian cancer), such as the BRCA **genes** (which means that you have been tested for this condition by a specific and expensive blood or tissue test). A BRCA **gene mutation** means that you have inherited a specific **mutated gene** which will put you and potentially other family members (provided that they are also **gene** carriers) at a significantly higher risk to develop breast, ovarian and some other cancers. In general, this is a rather rare situation in breast cancer with around 5% of the population in Europe being **gene** carriers.

There is a consensus among specialists that a certain number of criteria should be present to test for this

mutation. You should be recommended testing for a BRCA **mutation** if there are:

- Three or more breast and/or ovarian cancer cases in the family, at least one found in a member age <50 years.
- Two breast cancer cases in women age <40 years in the family.
- One male breast cancer and one ovarian cancer or early onset female breast cancer.
- You are Ashkenazi Jew with breast cancer and age <60 years.
- Young onset bilateral breast cancer.
- Breast and ovarian cancer in the same patient.

Now let's suppose you were considered at risk, tested and confirmed to be a BRCA carrier: this does not mean that you will actually get breast, ovarian or other cancers, but you will have a significantly higher risk for it during your life.

You may be screened starting at a younger age and more often compared with the general population, including specific tools (such as **MRI** of the breast).

Several treatments can be offered to you to significantly lower the risk, including drugs, or prophylactic surgery of the breast and/or ovaries. They need to be individually discussed with you and what you ultimately choose to do will largely depend on your preference and needs and consideration of treatment burden and risk reduction.

It is important to know if a family member has been diagnosed as being a BRCA carrier. However, this does not automatically mean that you, too, are one! You will need to be tested to be identified as a carrier.

Having close relatives (such as a mother, sister, or daughter) who had breast cancer at a young age, gives you a somewhat higher risk for breast cancer even though there may be no **gene** detected, or even no need for a **gene** detection programme. In general, you will be advised to undergo screening starting 10 years before the age at which your relative was initially diagnosed with cancer.

4. Comorbidities and management of comorbidities

Cancer care and treatment does not begin and end at the first cancer treatment. It should be taken in to consideration that many of you may have had other health problems before cancer treatment, some of which may have developed new health conditions as a result of the cancer treatment or from the cancer itself.

Some examples of **comorbidities** which should be taken into consideration are:

- **Diabetes mellitus.**
- Kidney failure with eventual need of **haemodialysis**.
- Heart failure.
- Mobility difficulties; arthritis.
- Sometimes absence/amputation of parts of the body after surgical treatment (for example after removal of breast or testicles).

It is evident that providers caring for cancer survivors should monitor and appropriately manage **comorbid** medical conditions that either were present prior to cancer treatment as well as those that may have developed post-treatment.

Monitoring these **comorbidities** includes not only the medical but also the psychological issues. The psychological aspects of the **comorbidities** may wear you down. Remember that you have already passed through a lot of difficulties and you mastered them!

The management of **comorbidities** often requires the cooperation of different doctors and different specialisations, in order to help you return back to your normal life, for example the cooperation between the family doctor, the **oncologist** and **nephrologists, cardiologists, endocrinologists** or a team of **physiotherapists** or the **psychologists**.

5. Keeping a personal health record / Survivorship care plan

As time passes, it is very difficult to remember every detail of the cancer experience, to remember details about your treatment plan, diagnosis, **side-effects** and problems that you may had to deal with. In parallel, this information is also very important for the doctors, who make the **follow-up**.

To keep a personal health care record may seem difficult and unusual for many of you, it may already be a habit for others. In every circumstance, you should understand that it is a very useful tool in your hands and also for your doctor. If you are not used to keeping a personal health record: this is the time to get started! For those among you who have already made it, just keep on going!



Survivorship check list, care plan and treatment summary

Background information

YES NO

Family history of cancer

☐ ☐

Genetic/hereditary risk factor, predisposing conditions:

Genetic counselling:

☐ ☐

Genetic testing results:

Fertility: cryopreservation

☐ ☐

Diagnosis

Cancer type and location:

Date of diagnosis (year):

Stage:

☐ I ☐ II ☐ III ☐ IV ☐ NOT APPLICABLE

Method of diagnosis:

- Imaging tests
- Laboratory tests
- Biopsy
- Site of biopsy:

☐ ☐
☐ ☐
☐ ☐

Treatment

YES NO

Surgery

☐ ☐

Surgical location, findings:

Surgery date:

Radiation therapy:

☐ ☐

Radiation date:

Radiation area:

☐ Chest ☐ Abdomen ☐ Pelvic area
☐ Head and Neck ☐ Testis ☐ Breast and Axilla
☐ Other area (i.e. extremities)

Systemic therapy (Chemotherapy, hormonal therapy, immunotherapy, targeted therapies)

Type of therapy:

☐ Chemotherapy ☐ Hormonal therapy
☐ Targeted therapies ☐ Immunotherapy
☐ Combination

Name of drug	Therapy start date	Therapy end date

Symptoms and side effects during therapy

Fatigue

☐

Nausea and Vomiting

☐

Pain and peripheral neuropathy

☐

Sleep disorders

☐

Skin and soft tissue problems

☐

Loss of appetite

☐

Heart problems

☐

Change in weight

☐

Change in mood or depression

☐

Lung problems

☐

Difficulties with breathing

☐

Memory or concentration loss

☐

Low red blood cell count (anaemia)

☐

Low white blood cell count

☐

Infections

☐

Pain or bleeding when urinating

☐

Urine incontinence

☐

Digestive problems

☐

Menopausal problems

☐

Sexual problems

☐

Thromboembolic event

☐

Fears and/or anxiety

☐

Other

☐

Symptoms and side effects that have continued after finishing treatment:

Fatigue	<input type="checkbox"/>	Change in mood or depression	<input type="checkbox"/>	Pain or bleeding when urinating	<input type="checkbox"/>
Nausea and vomiting	<input type="checkbox"/>	Fears and/or anxiety	<input type="checkbox"/>	Urine incontinence	<input type="checkbox"/>
Pain and peripheral neuropathy	<input type="checkbox"/>	Lung problems	<input type="checkbox"/>	Digestive problems	<input type="checkbox"/>
Sleep disorders	<input type="checkbox"/>	Difficulties with breathing	<input type="checkbox"/>	Menopausal problems	<input type="checkbox"/>
Skin and soft tissue problems	<input type="checkbox"/>	Memory or concentration loss	<input type="checkbox"/>	Sexual problems	<input type="checkbox"/>
Loss of appetite	<input type="checkbox"/>	Low red blood cell count (anaemia)	<input type="checkbox"/>	Thromboembolic event	<input type="checkbox"/>
Heart problems	<input type="checkbox"/>	Low white blood cell count	<input type="checkbox"/>	Other	<input type="checkbox"/>
Change in weight	<input type="checkbox"/>	Infections	<input type="checkbox"/>		<input type="checkbox"/>

Psychological and social aspects in survivorship

Psychological support:

<input type="checkbox"/> Family	<input type="checkbox"/> Friends	<input type="checkbox"/> Psychologist/psychiatrist	<input type="checkbox"/> Cancer support groups	<input type="checkbox"/> Social workers
<input type="checkbox"/> Health care professionals	<input type="checkbox"/> Other			

Rehabilitation programme	YES	NO	What concerns do you have as you begin your survivorship experience?	
Rehabilitation programme	<input type="checkbox"/>	<input type="checkbox"/>	Emotional and psychological status	<input type="checkbox"/>
Psychological	<input type="checkbox"/>	<input type="checkbox"/>	Cognitive problems	<input type="checkbox"/>
Sexual	<input type="checkbox"/>	<input type="checkbox"/>	Weight changes	<input type="checkbox"/>
Cognitive	<input type="checkbox"/>	<input type="checkbox"/>	Fatigue	<input type="checkbox"/>
Nutritional	<input type="checkbox"/>	<input type="checkbox"/>	Self confidence	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>	Life priorities	<input type="checkbox"/>
Duration of rehabilitation programme:			Body image	<input type="checkbox"/>
			Physical strength	<input type="checkbox"/>
Changes in family relationships:			Going back to work	<input type="checkbox"/>
			Financial advice	<input type="checkbox"/>
Changes or difficulties by returning back to work:			Parenting	<input type="checkbox"/>
			Relationships issues	<input type="checkbox"/>
Wish to extend family:	<input type="checkbox"/>	<input type="checkbox"/>	Sexual health and desire	<input type="checkbox"/>
			Fertility	<input type="checkbox"/>
			Stopping smoking	<input type="checkbox"/>
			Pain	<input type="checkbox"/>
			Other	<input type="checkbox"/>

Follow-up care plan

YES NO

Need for ongoing (adjuvant) treatment for cancer: ☐ ☐

End of main treatment:

Sign or symptoms to tell the doctor about right away:

SCHEDULE OF FOLLOW UP VISITS

Doctor's name	Time of visit

SURVEILLANCE CLINICAL EXAMINATION AND FOLLOW-UP IMAGING AND LABORATORY TESTS

PLAN:

Clinical exam/follow-up visit ☐ ☐ months

Blood tests months ☐ ☐ months

Other (specify):

Radiologic examinations (specify) ☐ ☐ months

Endoscopy (specify) ☐ ☐ months

Test/Examination	When	Results

DICTIONARY**ACTIVE INGREDIENT(S)**

An ingredient in a pharmaceutical drug that is biologically active (in cancer, meaning active in your body against cancer). The similar terms active pharmaceutical ingredient and bulk active are also used in medicine, and the term active substance may be used for natural products. Some medication products may contain more than one active ingredient.

ACUTE LEUKAEMIA

A rapidly progressing cancer that starts in blood-forming tissue such as the bone marrow, and causes large numbers of white blood cells to be produced and enter the blood stream.

ALLOGRAFT

The transplant of an organ, tissue, or cells from one individual to another individual of the same species who is not an identical twin.

ANTIGENS

A substance (sometimes a molecule) capable of inducing an immune response in the host organism (usually by producing antibodies against them).

ANXIETY

An emotion characterised by feelings of tension, worried thoughts and difficulty concentrating. Physical symptoms can include muscle tension, palpitations, trembling, dizziness or difficulty sleeping. Occasional anxiety is a normal part of life, but if the distress interferes with relationships, work or decision-making, professional help is recommended.

B-LYMPHOCYTES

A type of immune system cell. Malignancies that form in B cells are different types of non-Hodgkin's lymphomas; these include Burkitt lymphoma, chronic lymphocytic leukaemia/small lymphocytic lymphoma, diffuse large B-cell lymphoma, follicular lymphoma, and mantle cell lymphoma.

BONE SCAN

A procedure to check for abnormal areas or damage in the bones. A very small amount of radioactive material is injected into a vein and travels through the blood. The radioactive material collects in the bones and is detected by a scanner (a special camera that takes pictures of the inside of the body). A bone scan may be used to diagnose bone tumours or cancer that has spread to the bone. Also called bone scintigraphy. Cardiac oedema: Accumulation of fluids throughout the body caused by heart failure.

CARDIOLOGIST:

Cardiology is a branch of medicine that specialises in diagnosing and treating diseases of the heart, blood vessels, and circulatory system. These diseases include coronary artery disease, heart rhythm problems, and heart failure. It is performed by cardiologists.

CAREGIVER(S)

A person who helps another individual with an impairment with his or her activities of daily living. Caregiving is most commonly used to address impairments related to old age, disability, a disease, or a mental disorder.

CHEMOTHERAPY

The use of drugs to destroy cancer cells, mainly by damaging their DNA during cell division (replication). This is a historical term, since the first substances used in medical cancer treatment were directly derived from the chemical (dye) industry!

CHRONIC OBSTRUCTIVE PULMONARY DISEASE

Commonly known as chronic bronchitis and asthma, it is a disease characterised by air trapping and over inflation of the lungs. The main symptoms include shortness of breath and cough with sputum production. It is a progressive disease, which typically worsens over time. Smoking is a major risk factor for chronic bronchitis.

CIRRHOSIS

A form of liver scarring leading to progressive loss of liver function, usually gradually over many years. Causes are multiple, alcohol abuse being a leading one.

COLON

Part of the large intestine or large bowel.

COLONOSCOPY

Examination of the inside of the colon using a colonoscope, inserted into the rectum. A colonoscope is a thin, tube-like instrument with a light and a lens for viewing. It may also have a tool to remove tissue to be checked under a microscope for signs of disease.

COLOSTOMY

A surgical procedure in which an opening (stoma) is formed by drawing the healthy end of the large intestine or **colon** through an incision in the anterior abdominal wall and suturing it into place. This may be necessary if the faeces cannot be evacuated normally through the rectum/anus (due to tumour obstruction, leakage, etc.). This opening, in conjunction with the attached stoma appliance, provides an alternative channel for faeces to leave the body. It may be reversible or irreversible depending on the circumstances.

COMORBIDITY

Presence of one or more additional diseases or disorders co-occurring with a primary disease or disorder (i.e. **diabetes** as comorbidity in a patient with a primary **colon cancer**).

CROHN'S DISEASE

A condition in which the gastrointestinal tract is inflamed over a long period of time. Crohn's disease usually affects the small intestine and colon. Symptoms include fever, diarrhoea, stomach cramps, vomiting and weight loss. Crohn's disease increases the risk of colorectal cancer and small intestine cancer. It is a type of inflammatory bowel disease. Also called regional enteritis.

CRYOPRESERVATION

A process where cells, tissues, organs or any other biological constructs susceptible to damage are preserved by cooling to very low temperatures (deep frozen). They may thus be protected from harmful medical or therapeutic procedures.

CT SCAN

Computed tomography (CT) is a scan using X-rays and a computer to create detailed images of the inside of your body.

DEPRESSION

A common mental disorder characterised by sadness, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep and appetite, feelings of tiredness and poor concentration. Mild depression can be treated with psychological (talking) therapies, however if moderate or severe, medication may be required in addition to talking therapies.

DERMATOLOGIST

Dermatology is a branch of medicine dealing with the skin, nails, hair and their diseases. It is performed by a doctor called dermatologist.

DIABETES MELLITUS

A medical term that refers to a group of metabolic diseases characterised by high blood sugar level over a prolonged period. Symptoms of high blood sugar include frequent urination, increased thirst, and increased hunger. If left untreated, diabetes can cause many complications.

ENDOCRINOLOGIST

Endocrinology is a branch of medicine that specialises in diagnosing and treating disorders of the endocrine system, which includes the glands and organs that make hormones. These disorders include diabetes, infertility, and thyroid, adrenal and pituitary gland problems. It is performed by a physician called endocrinologist.

ENDOSCOPY (ENDOSCOPIES)

A procedure that uses an endoscope to examine the inside of the body. An endoscope is a thin, tube-like instrument with a light and a lens for viewing. It may also have a tool to remove tissue to be checked under a microscope for signs of disease.

FERTILITY

Ability to produce offspring (=become pregnant or have children).

FOLLOW-UP CARE PLAN

A personalised schedule of examinations and tests that a doctor recommends after the active treatment period.

GASTRIC PROTECTORS

Drugs that protect the stomach from acidity which will produce ulcers and inflammation or other damages caused by the intake of drugs.

GASTRIC FEEDING TUBE

A medical device used to provide nutrition to patients who cannot obtain nutrition by mouth, are unable to swallow safely, or need nutritional supplementation.

GENE

A part of the DNA in the cell that controls the physical development, behaviour, etc. of an individual plant, animal or human and is passed from the parents. An example: A particular gene is responsible for inherited eye colour. Mutant genes cause cancer (see below).

GENETIC MUTATION/GENETIC ALTERATION

A **gene** mutation/alteration is any event that changes genetic structure; any alteration in the inherited nucleic acid sequence of the genotype of an organism.

Mutations result from errors during DNA replication (when cells divide /replicate) or other types of damage to DNA. This may lead to a loss of **gene** function, or amplify its function beyond control. Some mutations of vital **genes** will lead to cell death.

GYNAECOLOGIST

The **physician** specialised in the medical practice dealing with the health of the female reproductive system (vagina, uterus, and ovaries) and the breasts.

GYNAECOLOGICAL OPERATION

Operation of the female reproductive system or the breasts.

HEALTH CARE PROFESSIONAL

An individual who provides preventive, curative, promotional or rehabilitative health care services in a systematic way to people, families or communities. The terms health care professional and health care provider are often used interchangeably. A health care professional could be a doctor, pharmacist, dentist,

nurse, **social worker** or **psychologist**. In some low-middle income countries health care is provided by volunteers or trained non-experts and they could conceivably be referred to as provider, however the term for them is more usually “non-specialist health workers” or “lay health workers”.

HAEMODIALYSIS

A process of purifying/filtering the blood of a person whose kidneys are not functional.

HEREDITARY CANCER SYNDROME

A type of inherited disorder in which there is a higher-than-normal risk of certain types of cancer. Hereditary cancer syndromes are caused by mutations (changes) in certain **genes** passed from parents to children. In a hereditary cancer syndrome, certain patterns of cancer may be seen within families. Hereditary cancers account for 5% of all cancer cases.

(ANTI-)HORMONAL THERAPY (ENDOCRINE THERAPY)

A therapy involving the use of drugs or surgical procedures to suppress the production of, or inhibit the effects of, a hormone (such as oestrogen or testosterone) in order to destroy or slow the growth of cancer cells (e.g. hormone therapy to treat breast or prostate cancers). Only some cancer types are known to respond to hormone blockage.

HOSPITALISATION:

Placing of a patient in a hospital or the period of confinement in a hospital.

IMMUNISATION

The process by which an individual's immune system becomes fortified against an agent (this happens when you receive a vaccine or if you have been exposed to infections like measles: you will acquire immunity).

IMMUNOSUPPRESSION

A reduction of the activation or efficacy of the very complex immune system. It can be the consequence of a disease (i.e. HIV), a **side-effect** of treatment (i.e. **chemotherapy**) or even a therapeutic effect (cortisone in asthma patients). Immunosuppression varies in broadness and severity.

IMMUNOTHERAPY

A type of cancer treatment that stimulates the body's immune system to fight the cancer.

INFERTILITY

Inability of a person to have children by natural means.

LARYNX (VOICE BOX)

An organ in the neck involved in breathing, sound production, and protecting the trachea against food aspiration.

MAGNETIC RESONANCE IMAGING (MRI)

A type of *scan* that uses strong magnetic fields and radio waves to produce detailed images of the inside of the body.

MAMMOGRAM

An X-ray of the breast.

MEDIASTINUM

The area between the lungs. The organs in this area include the heart and its large blood vessels, the trachea, the oesophagus, the thymus and lymph nodes but not the lungs.

MONOCLONAL ANTIBODIES

A type of targeted therapy. Monoclonal antibodies recognise and attach to specific proteins produced by cells. Each monoclonal antibody recognises one particular protein. They work in different ways depending on the protein they are targeting. Myelodysplasia: Abnormal bone marrow cells that may lead to myeloid leukaemia.

NEPHROLOGIST

Nephrology is a medical specialty that concerns the study of normal kidney function and kidney problems, the preservation of kidney health and the treatment of kidney problems. It is performed by physicians called nephrologists.

NUTRIENTS

Component in food that an organism uses to survive and grow.

ŒSOPHAGUS

A tube-shaped organ that connects the throat to the stomach.

ONCOLOGIST

A doctor who is specialised in treating cancer. The main types are medical, surgical, radiation, gynaecological and paediatric oncologists.

ONCOLOGY NURSE

A nurse who is specialised in caring for people with cancer.

OPHTHALMOLOGICAL DISORDERS

Disorders of the function or diseases of the eyeball.

OSTEOPOROSIS

A disease where increased bone weakness increases the risk of a broken bone.

PAIN KILLERS

Group of drugs used to relief from pain. They are also called analgesics.

PELVIC AREA

Either the lower part of the trunk of the human body between the abdomen and the thighs (sometimes also called pelvic region of the trunk) or the skeleton embedded in it.

PERFORMANCE STATUS

An attempt to quantify patients' general well-being and activities of daily life. It is a medical measure which helps to evaluate the fitness of a patient for certain anticancer therapies.

PERIPHERAL NEUROPATHY (POLYNEUROPATHY)

A damage or disease affecting peripheral nerves (peripheral neuropathy) in roughly the same areas on both sides of the body, featuring weakness, numbness, and burning pain (unfortunately a common **side-effect** of some anticancer treatments, it is not exclusive for this setting, but also experienced by diabetic, vascular and other patients).

PHYSICIAN

A professional who practises medicine, which is concerned with promoting, maintaining, or restoring health through the study, diagnosis, and treatment of disease, injury and other physical and mental impairments.

PHYSIOTHERAPY

Physiotherapy is a science-based profession which aims to develop, maintain and restore maximal movement and functional ability. Physiotherapists may assist patients through a variety of techniques including massage, manual treatments such as targeted exercises, ultrasound and electrical-modality treatments. In some countries, the term physical therapist may be used.

PSYCHOLOGIST/PSYCHIATRIST

Mental health professionals who work to address a person's emotional, psychological and behavioural needs.

PSYCHO-ONCOLOGIST

A health professional who specialises in understanding and addressing the psychosocial, behavioural and/or psychiatric aspects of cancer and in meeting the emotional, social and spiritual/existential needs of people at risk for, living with or having survived cancer.

PSYCHOTHERAPEUTIC INTERVENTIONS

Non-pharmacological treatments to help people with psychological concerns (e.g. anxiety, depression, loss of self-esteem) and improve their ability to deal with difficult situations. Interventions can range from face-to-face treatments with a trained health professional to on-line interactive resources.

PULMONARY OEDEMA

Fluid accumulation in the tissue and air spaces of the lungs.

PURIFIED (ANTIGENS)

Purified from large amounts of the pathogenic organism. The vaccinated person produces antibodies to the protein antigen, thus protecting him/her from disease.

RADIOTHERAPY/RADIATION THERAPY (IRRADIATION)

The use of high energy X-rays or other particles to destroy cancer cells.

RECOMBINANT ANTIGENS/VIRUS

A human engineered virus/antigen produced by recombining pieces of DNA using recombinant DNA technology. These may be used for therapeutic means.

RECURRENCE

An event when the tumour comes back after main treatment. Recurrence may be local (at the initial cancer site) or metastatic (present in different organ sites, but composed by the same cancer cells as the initial one).

REHABILITATION

Services and resources that help a person with cancer regain the best physical, social and psychological condition during and after cancer treatment.

SEXOLOGIST

Sexology is a scientific study of human sexuality, including human sexual interests, behaviours and functions. Sexologists may help in case of sexual dysfunction and disorders.

SIDE-EFFECT(S)

Any effect of a drug, or other medical therapeutic procedure (i.e. **radiotherapy**) that is in addition to its intended effect, especially an effect that is harmful or unpleasant (synonym: adverse effect), such as fatigue, incontinence or vomiting.

SOCIAL WORKERS

A professional who helps people cope with everyday problems and challenges before, during and after treatment. Social workers may work for a hospital, social services or local governments.

SUPPORTIVE TREATMENT/SUPPORTIVE MEASURES

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO definition).

Supportive care may be considered a synonym by many, focusing on symptom control.

Many still confound the term of palliative care with *terminal* palliative care or *end of life* care. Historically, these terms were used synonymously. Today, the holistic approach to symptom relief has been recognised throughout a patient's entire **follow-up** starting at the time of diagnosis, and without any notion of (imminent) death.

TARGETED THERAPY

Treatment that targets specific **genes**, proteins or other molecules that contribute to cancer growth and survival. The term applies to several different types of drugs and treatments (and also reflects our current understanding of the complexity of cancer!). While **chemotherapy** hits in a uniform mode, targeted therapies will be directed against cancer cell characteristics (i.e. membrane receptors) which are unique to them, or far more present than in healthy cells. Thus, they are supposed to be far more effective than regular treatment options.

THROMBOEMBOLISM

The formation of a blood clot inside a blood vessel, obstructing the flow of blood through the circulatory system. Deep vein thrombosis (DVT), mainly of the lower limbs, and pulmonary embolisms (PE) are frequently observed in cancer patients. Treatment is mainly by anticoagulant drugs.

TRACHEOSTOMY

A surgical procedure which consists of making an incision on the anterior aspect of the neck and opening a direct airway through an incision in the trachea (windpipe).

ULCEROUS COLITIS

A long-term condition that results in inflammation and ulcers of the colon and rectum. The primary symptom of active disease is abdominal pain and diarrhoea mixed with blood. Weight loss, fever and anaemia may also occur. Often symptoms come on slowly and can range from mild to severe. Symptoms typically occur intermittently with periods of no symptoms between flares. Complications may include colon cancer.

UROLOGIST

Urology is a medical discipline focussing on diseases of the male and female urinary tract and male reproductive organs. It is practiced by a doctor called a urologist.

X-RAY

An imaging test, using a type of radiation that can pass through the body, that allows your doctor to see inside your body.

This guide has been written by Dr. Nikolaos Mitsimponas and Dr. Stefan Rauh representing ESMO, with contribution of ECPC representatives Dr. Francesco De Lorenzo and Kathi Apostolidis.

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The Guide for Patients on Survivorship has been created in order to help you and people like you at this crucial period in life.

Survivorship is a unique experience for each person. What really matters is to find the strength and the way to get through this difficult period of life and to regain as much as possible the aspects of life before cancer. This guide is produced by ESMO and ECPC in collaboration with IPOS.

The ESMO Guides for Patients are designed to assist patients, their relatives and caregivers to understand the nature of different types of cancer and evaluate the best available treatment choices.

For more information please visit **www.esmo.org** and **www.ecpc.org**

