

Coping with cancer

Life during and after treatment



Patient brochure

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We would like to express our heartfelt gratitude to Carolyn Garrat for her free translation of this brochure into English.

This brochure is also available
in French and German.

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Foreword

Dear reader,

For many people, cancer remains a frightening disease even at the start of this third millennium despite of all the medical progresses. It is often quoted as being the illness that people fear the most. Nevertheless, cancer is always on our mind as it occurs frequently and affects everyone. Only how close we are affected by it differs. In the worst case scenario, it is yourself or your loved one who needs to deal with it.

Many questions come to mind after a cancer diagnosis, not only of a medical nature, but also issues on how to adapt psychologically to a life with the disease. The purpose of this brochure is to address these concerns, be it after diagnosis, during treatment or on returning to everyday life and offers possible answers based on psycho-oncological practice. It is therefore aimed at people who are personally affected and their social environment as well at those who would like to tackle this “subject of fear” and want to find out more about facing cancer.

We hope that this brochure will show patients ways of coping with cancer and living a successful life in spite of everything. For those who are not directly affected, this brochure is to provide insight and understanding of what patients are experiencing, and to show ways of helping them.

The Fondation Cancer team

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The first weeks after...

“The diagnosis”

For many the cancer diagnosis comes as a surprise, followed by a period full of uncertainty, anxiety and questions. Here are some of the most common topics and frequent questions patients ask the psychologists of the Fondation Cancer following diagnosis.

Yesterday I learned that I had cancer. Now I'm very frightened about what comes next. You read and hear such terrible things about cancer. How do other people deal with this?

Being diagnosed with cancer is often the most painful news the patient can receive throughout the course of his cancer. Many are in a state of shock after already some difficult weeks of uncertainty, suspicion and extensive medical examinations.

“When the doctor told me yesterday that I had colorectal cancer, it was like a slap in the face. I immediately thought of my neighbour who died of lung cancer last year”, explains Marie (55 years old).

Many patients report that immediately after the diagnosis, they remember friends, family members or colleagues who have died of cancer. Indeed, cancer

remains a life-threatening disease. But it is also true that in recent decades, the prognosis of many cancers has improved dramatically thanks to progress made in early detection and research, as well as a result of improved and targeted therapies. Yes, there are still those who die of cancer, but there are also many patients who overcome their illness, who are cured or who learn to live with their illness on a long-term basis much like other patients with chronic diseases. Nevertheless, at the moment of diagnosis, cancer is often associated with rather painful experiences. This is mainly due to the fact that the most dramatic examples are those which stay in our memory. We remember the neighbour who “died at a young age after a long suffering” rather than the work colleague who returned to full health after breast cancer, or a club teammate who is again clocking up very good performances following his testicular cancer.

Two weeks ago, the doctor told me I had cancer. Since then, nothing's been the same. I'm completely in disarray, sometimes optimistic and at other times pessimistic. I don't recognise myself any more. Is this normal?

We know that many patients experience an emotional rollercoaster ride the first weeks after diagnosis. First there are intense emotions and feelings of incomprehension, anxiety, despair and anger, then come hope and optimism, which in turn give way to confusion and feelings of powerlessness. Even after several days, some are still unable to realize that they themselves are suffering from cancer. Others feel a sensation of bewilderment for some time afterwards. It takes time to understand and accept the diagnosis, and with that often comes a feeling of calm and reassurance.

This already strong emotional burden is exacerbated by the fact that patients must take a lot of decisions at the beginning: "Is this treatment the right one for me? Do I give my consent?" or "How will I organise my children's everyday routine when I'm at the hospital?" "Should I take sick leave during chemotherapy or should I continue to work?" and "What will happen to my job?"

It is often not possible to draw on one's own experiences when dealing with cancer, which can make the problem worse: "How will I tolerate the chemotherapy?" or "How will I cope psychologically with losing my breast?" as well as "Will my marriage stand up to all of this?"

It quickly becomes obvious that it is preferable not to face cancer alone: it is better to look for "allies" right from the start who can help deal with the situation.





“During the first days after my diagnosis, I felt paralysed and powerless. I was drowning and I was afraid that I wouldn’t make it. I wanted to stuck my head in the sand. It’s thanks to my husband and my sister who helped me get out of this hole. With them I was able to speak freely, to think it all through and put some order in my thoughts. We then planned everything together, step by step. What is the most important thing, which is the least important? What information do I need? Where do I get it from?” (Annette, 51 years, lung cancer)

In addition to doctors and care teams, patients can also turn for support and guidance to specialist psychological services either at the hospital or with the psycho-oncologists at the Fondation Cancer. It can also be useful to exchange ideas with others who have experienced a similar situation. There are, for example, supporting groups for patients (led by a psychologist) at the Fondation Cancer (an overview of the various groups is available on request).

I don’t dare ask my doctor all my questions, nor do I tell him when I haven’t understood something. What can I do?

It would be best if the patients think beforehand about the topics they wish to discuss with their doctor. It is extremely helpful to make notes on a sheet of paper

and bring it to the appointment as a reminder. Often patients are so nervous at a consultation that they forget most of their questions. Some patients feel relieved and comforted when a trusted family member or friend comes along. This person can make sure that all the questions written down actually get asked, as well as being on hand afterwards to talk about what has been discussed. On the other hand, some patients feel somewhat constrained if they are accompanied by their partner, their children or their friends. It can be useful to tell the doctor that you are nervous as this can be a way of reducing the level of stress and boosting confidence.

“It was very important to me to tell my doctor that I don’t want too much information about my illness! Currently, I simply don’t want to know everything that could happen to me! And I certainly don’t want to hear any statistics about my chances of recovery.” (Yvonne, 65 years, recurring breast cancer)

People have widely differing needs when it comes to medical information. Some patients need a wealth of information, others just want to know the absolute minimum and this very gradually. It can be useful for the doctor to know the amount of information which the patient requires.

I'm constantly wondering "Why me?" Is it because of my character or my personality that I have cancer?

The question of whether certain character or personality traits can cause cancer has worried many generations of patients and continues to do so.

"I have swallowed so much anger in my life, no wonder that I got stomach cancer", says Nadine (49 years).

Known by the term "cancer-prone personality" or "type C personality", different personality traits have long been suspected of being a contributing factor to cancer. According to the theory of a "cancer-prone personality", some of the characteristics of a person most at risk for developing cancer include "a friendly, warm-hearted facade, socially over-adjusted, diligent and conscientious, who doesn't know his limits, who is inhibited when expressing emotions, unable facing conflict, and possesses low stress management techniques". Certain studies appeared to support the link between these personality traits and cancer; however, they were incorrectly carried out from a methodological perspective. So, from a scientific point of view, the concept of the cancer-prone personality is not proven, and is not taken into account in psycho-oncology. Yet, individual characteristics are considered significant when they lead to certain behaviours known to be a cancer risk factor (e.g. smoking or

alcohol consumption). For example, a person using alcohol and cigarettes because of his depression will have an increased risk of cancer. But the cancer risk is higher as a result of his lifestyle and not of his personality.

Here another example: *"As so often in my life, I don't dare stand up for my rights and point out to my employer that our company is not compliant with the protective measures against carcinogenic substances."* (Jean, 49 years)

Again, it is not the lack of assertiveness which increases the cancer risk, but exposure to the hazardous substances per se.

I've had a lot of stress in my life in recent years, both at work and in my private life. Could this have caused my illness?

"Three years ago, I was the victim of bullying at work. In my opinion, I developed leukaemia at that time because my body could not handle the continuous stress." (Yves, 60 years, leukaemia)

Like Yves, many patients think that stress will have played a role in the development of their cancer. The hypothesis that stress weakens the immune system and that a weakened immune system is more likely to develop cancer is still very widespread. But are there any scientific proofs? It has been proven that stress can influence both the hormonal and immune systems.

But the hypothesis that stress itself causes cancer is currently not confirmed by scientific evidence. However, if stress leads to harmful behaviour (e.g. smoking, alcohol consumption or an unbalanced diet) then the risk of developing cancer is increased.

The field of research known as “psycho-neuro-immunology” will in future examine the complex interactions between the nervous, hormonal and immune systems and will bring about new discoveries. Until then, one cannot come to a simple “cause and effect” conclusion. However, a balance between stress and relaxation in one’s own life is definitely worth it. Stress management will lead to overall health promotion.

My husband died five years ago. The following year I got breast cancer. Surely that cannot be a coincidence?

Patients often associate their own cancer with previous experiences of loss like the death of a loved one or a divorce. Here again, as with stress, some patients assume that a weakened immune system must have triggered the illness. However, the fact that many people do not get cancer after loss or divorce is often not acknowledged when making this connection. Numerous international studies have proved that there is no direct link between cancer and emotional problems. But for some patients, the hypothesis of a



concrete cause for the cancer is more tolerable from a psychological point of view than the absence of one. Once again, if a person in the wake of grief or depression numbs his feelings by consuming alcohol, having an unhealthy diet, being physical inactive or smoking cigarettes, his cancer risk increases due to his behaviour.

“You just have to have a positive attitude in order to beat cancer.” This was my best friend’s advice. Is she right?

Whether on the Internet, in newspapers or books and even in the form of well-meaning advice, patients are called upon to “positive thinking” with the argument that faith and confidence in a positive outcome are the necessary conditions for a cure. Apparent proof for this connection are the many testimonials from patients, such as the following: “I did it, I’m cured! I never doubted that I would defeat cancer as I never allowed myself any negative feelings or thoughts!”

How much pressure such a statement can put on patients shows the following:

“My best friend goes on at me endlessly about the importance of positive thinking, even when I only feel like crying and would much rather be hugged.” (Danielle, 35 years, malignant melanoma)

Jimmie Holland, one of the founders of psycho-oncology, spoke about the “tyranny” of positive thinking. From the perspective of experienced psycho-oncologists, the concept of positive thinking is extremely questionable, because it suggests to the patient that he alone is responsible for the outcome and his chances of healing. Psychological factors are considered to be more essential to the cure than biological factors or ways of treatment. What does psycho-oncological research say about this subject?

Intense emotions such as fear, anger, sadness, despair and discouragement are quite normal reactions to a serious illness like cancer. Virtually prohibiting “normal” emotions caused by a threatening situation can therefore increase the burden on patients. Many experience these emotions and describe them like stages in their journey leading to an improved dealing with the disease. According to the present state of research, we cannot blame these intense emotions for reducing the chances of recovery. Fear does not affect a tumour’s ability to grow, sadness does not open up the way for cancer to spread (metastasize), the different phases of anger as well as the search for meaning



are not the causes of a negative outcome for cancer.

However, it is important to keep the consequences of a depressive or an anxious behaviour in mind. If the depression leads a patient to interrupt his medical treatment, as he cannot see any reason to continue his treatment, his prognosis will probably deteriorate. If a patient with stomach cancer tries to anaesthetise his fear through heavy alcohol consumption, he will also probably reduce his chances. It is therefore rather the behavioural risk rather than the state of mind which will influence the outcome of the illness.

I don't know whether I should tell people about my cancer outside my family circle. How do other patients handle this situation?

Some patients try to hide their illness from their neighbours, members of their choir or other people in their wider circle. The danger here is that this behaviour is open to all sorts of fantasies and rumours, because people will always try to interpret the changes in someone (e.g. his appearance or behaviour). An open approach to one's diagnosis can be an advantage:

"I've thought a lot about what I'm going to say or not to my neighbours. I'm going to tell them honestly that I have colorectal cancer but I won't give them any details. And I'll let them know that I would like to talk about something else

rather than about my illness." (Eliane, 65 years, colorectal cancer)

Patients often have good experiences open up to others while respecting their own limits. They feel that their new-found frankness protect their need for limits whilst at the same time giving others the possibility of compassion and offering practical help.

We wish so much to have another child. Will I be able to fall pregnant after the treatment?

Cancer can also affect young adults before they become parents. "Can I start a family or have more children?" This question will lead to a difficult confrontation with the cancer treatment and its consequences. Cancer treatment can affect fertility. Different treatments hold different risks, chemotherapy and radiotherapy can damage normal cells. That's why it is important to deal with this topic before treatment starts, even when time is of the essence.

"How long after the end of the treatment do I have to wait before I can get pregnant?" "Will my body recover from the treatment and, if so, how long will it take?" There is no universal answer to the question of the perfect time to get pregnant. Each individual is different and timing varies according to many different factors such as the course of the disease, the type of cancer treatment as well as

the risk of recurrence, prognosis and the age of the patient.

Talking with one's doctor can clarify to what extent the chosen treatment can affect fertility and what methods could be used to preserve fertility. Many women and men can have children quite naturally after cancer treatment on condition that their hormonal cycle and reproductive organs are fully functioning. Depending on the treatment and the patient's age, the body needs a shorter or longer recovery time.

The desire to have children should be discussed with the doctor and, if possible, become part of the treatment. There are nowadays methods for couples who can no longer have children after treatment. These measures, which include for example freezing of eggs, sperm or ovarian tissue, must be done before any treatment.

"I always knew that I would like to have two children. My husband and I wanted to wait another year or two before becoming parents. Since I was diagnosed with breast cancer in June, our plans were completely overturned. Now I'm afraid that I'll never have kids." (Julie, 31 years, breast cancer)



Living with cancer

“The treatment”

With the start of medical treatment, surgery, chemotherapy and/or radiotherapy, the cancer patient will face new challenges. Unfortunately, there is no ready-made solution to cope with cancer. Every person is unique and brings his own way of dealing with the illness. Therefore, there is no “right” or “wrong” way of tackling cancer. However, some suggestions as to how limit psychological distress can be useful.

I’m afraid of chemotherapy and its side-effects. What if I can’t tolerate it and I feel ill all the time? Will I still be able to carry on with my everyday life?

Anxiety is one emotion which most patients experience during the treatment and which worries them a lot: fear of invasive procedures or fear of the treatment and its side-effects. Many cancer patients dread chemotherapy, because everyone has read or heard about the unpleasant side-effects that this treatment can have. But chemotherapy is a very important element in modern cancer treatment and can help numerous patients in a significant way. Thanks to appropriate concomitant medication, e.g. against nausea, side-effects can often be relatively well alleviated. Today, fewer patients suffer

from side-effects than some years ago. Likewise, not all cytotoxic drugs have side-effects like nausea or hair loss. In order to be an active participant in the treatment and successfully cope with the cancer, it is essential to speak openly with the doctor about any worries and reservations you may have towards the treatment and to empower yourself with information. In some cases, it is the fear of chemotherapy and its side-effects, like nausea, which causes a patient to be “sick with worry”. Then it’s not the chemotherapy in itself which triggers the nausea, but fear of the chemotherapy. Often, just thinking about the next chemo or even setting foot in the hospital, its typical smell or even certain foods is enough to trigger it. In this case the fear and anticipation of the nausea can make it worse.

"I'm most afraid of the side-effects of chemotherapy. I can still remember the photos of my grandmother when she suffered from cancer when I was eleven. During chemotherapy she just stayed in bed and had to vomit all the time. It would be awful if the same thing happened to me."
(Etienne, 56 years, lymphoma)

The best prevention against "anticipatory nausea" is to treat acute nausea with medication. It can also be treated efficiently with the help of psychology in reducing tension and anxiety using relaxation techniques and clinical hypnosis. Qualified psycho-oncologists at the Fondation Cancer can help you learn useful techniques.

I have just finished my third chemotherapy. When my children are at school and my partner at work, I have a lot of time to think. I have all sorts of dark thoughts and I'm scared. In the evening, I try to hide my fear so as not to affect my loved ones. What can I do to help myself?

Fear is a natural reaction to a threatening situation. It is normal to be concerned about upsetting questions, and that is all part of actively managing cancer and its treatment..

"Since I am on sick leave, I've too much time to think. I often wonder: "Is the treatment going to be effective?" "What will be the outcome of all this?" "Will I get well again?" "What will happen if the chemotherapy doesn't have any effect?"
(Carlo, 48 years, liver cancer)

It is impossible to find an answer to every question, but it can be a relief to voice these questions and give them space. All emotions have their right to exist, even if they are negative or the one we would "rather not have". If a cancer patient repeatedly tries to suppress worries and anxieties, he will maintain and reinforce those troubles. One strategy is to find a person of trust who will listen to these fears. But, when fear restricts the ability to think and act to too great a degree and significantly impairs the quality of life because it dominates everyday life,

then it may be helpful to consult a psycho-oncologist in order to find a solution to the problem together. In the absence of someone to talk to, it can be useful to write down one's thoughts and concerns. Often fear is non-specific and intangible; writing it down helps make it understandable and more real.

When fear is born from uncertainty and a lack of information, it is beneficial to actively seek out information. The first step would be to ask the patient's doctor, who would certainly be the most appropriate source of information. Be careful when researching information on the internet, as the quality of information is not immediately obvious. When searching the web, one has to be absolutely sure whether the source is reliable, because unchecked statements made on the Net can sometimes increase anxiety. The Foundation Cancer supplies information on this subject and gives advice on how and where to find appropriate information.

It can also be helpful to exchange ideas with other people affected by cancer, to learn together (maybe in a sophrology or a yoga group) how to regulate one's own emotions or how to stay calm. The Foundation Cancer informs about the current groups.

Since my diagnosis, I'm watching my body very closely. Every change that I become aware of, makes me panic. Each time that I cough, I'm thinking about lung metastases. What can I do?

Many patients have this problem. Often a cancer diagnosis comes as a complete surprise. You felt healthy and yet a "malignant tumour" has been detected at a routine check-up. In most patients a cancer diagnosis initially triggers fear and a feeling of losing control. They are no longer "in charge" of their own life, others are determining what needs to be done. Excessive worrying about one's own body is a way of taking back control in the short term. Often there is a belief at the bottom of this, along the lines of: "If I check my body closely enough, I will be prepared and can intervene in time."

"Whenever I feel something unpleasant, for example a pain in my neck or pressure in my chest, I think about metastasis immediately and I can't calm down. So I'm tempted to run to my doctor straight away to get another blood test or PET scan done. I just don't trust my body any longer." (Sven, 25years, testicular cancer)

Due to this careful observation and excessive cautiousness, every "normal" physical reaction will be transformed into an alarm signal. The patient forgets that the body is always in motion and it can be quite

normal to feel an occasional twinge, a pull or a creaking sound. Fear often leads us to misinterpret these “normal” physical sensations as a sign of tumour progression. Talking to the doctor about these fears may be sufficient to calm down. But if the patient is listening to his body too closely and it starts to take over his everyday life, he should not be left to deal with it on his own. Anxiety and panic itself can trigger physical reactions such as trembling, sweating, dyspnoea, tachycardia, fainting and digestive problems. These reactions are quite uncomfortable but generally harmless.

If every time you cough you are afraid that it could be lung metastases, and that worrying about your own body and your illness becomes so bad that your quality of life suffers, then outside help may be useful. Psycho-oncologists can help you learn coping strategies to handle your fear.

Are there any ways to reduce the side-effects of chemotherapy? Can a psycho-oncologist help me?

Unfortunately cancer therapies often have side-effects. However, these side-effects do not occur in every patient and not in the same way either. Amongst the most frequent side-effects which affect quality of life are nausea, fatigue and pain. In addition to medical methods, there are ways which patients themselves can use to increase their wellbeing and thus indirectly influence favourably the

side-effects. Adapting diet and behaviour can significantly reduce nausea and vomiting. Nutrition tips are best discussed with the patient’s doctor or an oncology-dietitian (ask at the hospital). Contrary to common belief, there is no such thing as a cancer diet which can simply “starve” the cancer.

Together with the patient, a psycho-oncologist can work out relaxation and breathing techniques as well as coping strategies for nausea and vomiting.

Intense fatigue can also be a very stressful side-effect affecting quality of life. Persistent fatigue can have a number of triggers. On the one hand being diagnosed with cancer and worrying about the outcome can of course weigh heavily on mood and lead to a lack of energy. But the cause can also be the cancer itself, the treatment, the drugs, anaemia, weight loss as well as changes in the metabolism. Whereas previously the patient would





have been told to rest as much as possible, nowadays we know that a balance between activity and rest is very important. On the one hand it has been found that sufficient night-time sleep with fixed times for going to bed and getting up is beneficial for the patient and, on the other hand, the daytime nap should be reduced to short rest and relaxation breaks, as too much sleep can make fatigue worse.

“I have always been a very active and sporty person. That’s why I was determined to continue like that during my treatment. Even my doctor thought it was a good idea. Looking back I have the impression that it was above all this physical activity which helped me manage the changes in my life.” (Patrick, 52 years, skin cancer)

Many studies have shown that adequate physical activity, even a light programme of sport (after consulting one’s doctor) can be an appropriate remedy for reducing fatigue. However, it is recommended that, rather than putting too much pressure on himself, the patient should fix attainable goals, adapted to his state of health. It may be useful to watch the time of day at which an activity seems easier. Another alternative could be to look for entertainment or a pastime to counteract the fatigue. Contact and conversation with friendly people can break the vicious circle of one’s own fatigue and at the same time create stimulation.

I often feel completely demoralized and can hardly motivate myself to continue my radiotherapy sessions. I wonder if it’s all worth it. Am I suffering from “real” depression?

Cancer and its treatment are physically draining for a lot of patients. Brief phases of sadness, as well as feeling low and isolated are considered to be completely normal reactions to a serious diagnosis and are not automatically defined as clinical depression. These symptoms, which can be extremely intense, are often closely related to certain events such as the announcement of bad news. They stay not the same throughout the day and they also fluctuate from day to day: there are better and worse days.

“Sometimes I wonder why I’m putting myself through all this. On other days I know that I will get through the treatment because I still want to spend a lot of time with my family.” (Sandra, 42 years, brain tumour)

Affection, sympathy and support can improve the mood. In clinical practice, we talk about “normal grief” or a so-called adjustment disorder. This expresses the fact that a person after being diagnosed with a serious illness must first adapt to it. Life changes can go hand in hand with violent emotions.



We talk about clinical depression when symptoms persist without interruption for a prolonged period and that they are so intense that the person's life is noticeably impaired. There are certain core symptoms such as despair, apathy and a lack of interest, as well as inertia and increased fatigue, of which at least two must be fulfilled. In addition, depending on severity, there can be at least two more symptoms such as reduced concentration and attention, loss of self-esteem and self-confidence, feelings of guilt and inferiority, a negative outlook for the future, inner restlessness or a slower psychomotor response. There can also be vegetative symptoms such as sleep disorders or loss of appetite. Depending on severity, the patient can also have suicidal ideation or intent. It is important to know that some symptoms of depression such as fatigue, apathy, loss of appetite or concentration problems can also be caused by the cancer and its treatment. Therefore a precise determination of the cause is always mandatory.

Estimates show that about 15% of all cancer patients are affected by a depressive episode. The risk is increased if there were one or several depressive episodes before diagnosis.

Should a patient or a relative notice that several of these symptoms apply, he should contact his doctor to find out what help is available. The psychological service of the Fondation Cancer can also be a source of information. Psychotherapy or a combination of antidepressant

medication and psychotherapy can be an appropriate remedy to reduce symptoms and to provide relief in the case of depression. Especially, if a person's state of mind makes him reluctant to continue the treatment or even leads him to consider stopping it altogether. At this point a psycho-oncologist should be consulted in order to stabilise the patient's mental health.

Sometimes when "everything becomes too much and it would be preferable to stop treatment altogether", apathy can be partially relieved by simple self-help strategies. The recommended method to cope with cancer "day by day" is to focus on just one day at a time. This way of dealing with the illness makes it more bearable for many patients.

My colleague thinks that I can do something myself to feel better. But the chemotherapy is so bad for me! Can I really do something to improve my mood?

Patients wondering whether they can positively influence their mood and their emotions on their own should first reflect on solutions and strategies which had been useful to them in dealing with problems and crises in their life so far. If someone likes speaking openly about his problems with other people, then this should also be the way he should approach things after a cancer diagnosis in order to obtain relief and experience positive feelings like solidarity and



empathy. Joint discussion groups with others patients could be an option. Some patients less keen on talking could turn to other sources of relaxation such as leisure activities, contact with animals, yoga, meditation, spirituality or a creative activity. Experts thus recommend taking one's own needs and wishes into consideration and to use proven strategies to improve one's mood.

"I feel so weak physically that I can't even imagine what would help to improve my mood!" (Christiane, 62 years, breast cancer)

What else can a sick person do to "unlock" positive emotions? Taking time during the treatment to engage in regular pleasurable activities such as a walk in the afternoon, reading an exciting book or listening to an audiobook can have a positive influence on mood. Contact with people who "do you good" should definitely be kept up during the treatment as social isolation can affect mood and lead to a downward spiral. The positive effect on mood of a physical activity and sport (in agreement with the doctor) is also scientifically proven and can influence not only mood and wellbeing, but can also reduce side-effects of the treatment.

I constantly feel really low and sad. You read so much about the fact that it's enough to "think positively" to get well. Does this have an influence whether the treatment has any effect at all?

The time of treatment from the initial disorientation after the diagnosis through to a gradual self-adjustment to a changed life situation is for many a process of intense and often contradictory feelings. Confidence, courage and determination as well as "not letting it get you down" alternate with phases of depression, grieving, anger, despair and sadness. Patience and understanding for one's own emotional roller coaster is needed because experiencing this changes are challenging for the morale. But every type of emotion, whether positive or negative, is legitimate and comprehensible. Expressing these feelings, for example by talking, crying, moving around, making or listening to music, painting, writing or taking up a sport, can bring a sense of relief and liberation.

"My partner keeps saying that all that's needed is to think positive thoughts and all will be well. As if it is that simple! I feel under pressure because I can't bring myself to have positive thoughts. Instead I feel even worse. I don't want to listen to that anymore!" (Michel, 58 years, stomach cancer)



Patients often hear advice such as “You need to think positive and everything will be alright”. Most of the time, they haven’t asked for this “well-meaning” advice which usually reflects the anxiety or helplessness of loved ones who are trying to make themselves feel better. This kind of advice, also very present in the media, can build up additional pressure. They tend to make the patient responsible for the outcome of his illness. Some patients are fearful that their negative thoughts or feelings can be harmful to the course of the disease. This fear is without foundation. It is scientifically proven that a cure cannot be enforced by positive thinking or a fighting spirit. Emotions such as fear, sadness and despair do not cause cancer and have no negative influence on the recovery process. They do not let the cancer grow or spread.

No one can think positively all of the time. One can only find inner balance by accepting every emotion, because they are part of life. However, an active attitude can at least give the feeling of contributing in some degree towards one’s own wellbeing. If fear and despair come to the fore and overtake daily life, maybe even to the point of depression, professional help should be sought.

My husband thinks that I’m depressed, and that it has been caused by the illness. Can depression in cancer be treated by anti-depressants? Does it make sense to take medication to reduce my fear of cancer progression?

The symptoms of depression with tiredness, listlessness and exhaustion are often similar to the side-effects and consequences of the cancer treatment, such as fatigue. Cancer related fatigue is a state of chronic physical, emotional and mental exhaustion which is very common and hardly ever improves with rest. Fatigue is usually caused by the cancer treatment. Whether one has a depression or whether one suffers tiredness and exhaustion from fatigue is therefore important to clarify as treatment will be different. To make the distinction between tiredness and exhaustion due to depression or due to fatigue is mandatory in order to decide the best treatment. Treatment of symptoms always depends on the cause.

Cancer patients often have to take a whole series of medication. Each additional medication, including plant-based preparations with antidepressant activity (e.g. St John’s wort) available in pharmacies without prescription, must be discussed in detail with the doctor to prevent interactions and complications.



Whether a drug treatment is necessary at all depends also on the duration and severity of the symptoms. Patients who suffer from long-term depressive conditions often benefit the most from a combination of psychotherapeutic treatment and psychotropic medication. For other patients, psychotherapeutic counselling or advice will be sufficient. For the cancer patient it is important that the psychologist or psychotherapist has an in-depth knowledge of psycho-oncology.

Good to know: antidepressants are not addictive, but only take effect after a certain length of time (two to three weeks) and have a number of side-effects.

In the short term, the doctor may also plan to treat anxiety and sleeping problems with tranquillizers or sleeping pills. These medications have a mood-stabilising, relaxing as well as a sleep-inducing effect. In the long run however, these drugs are not a solution as they often lead to drug dependency. The intake of preparations belonging to the benzodiazepine group for example can cause a patient suffering from withdrawal symptoms when he stops taking them. Anxieties and sleep problems can also be alleviated long-term with an anti-depressant.

It is good to know that relaxation techniques and other coping strategies, so-called sleep hygiene measures often can help to restore a restful sleep. Psycho-oncology knows a wide range of measures to treat different states of agitation and to positively regulate emotions.

My partner and I actually love each other a lot, but since I started chemotherapy I get the impression that he doesn't understand me very well any more. Is it true that a lot of couples separate when one of the partners has cancer?

Cancer means stress on many levels for the relationship and can put it to a tough test. As a result, a partnership can grow and intensify or break up. The lack of expressing one's feelings after a cancer diagnosis is one of the most frequent problems for couples.

"Since I got diagnosed with cancer, I'm scared of losing my partner. Even though I love her very much, I'm often so irritable and take it out on her, whereupon she withdraws. I often get the feeling that she doesn't understand me. Sometimes I even don't understand myself anymore", says Joao (51 years old, oesophageal cancer).

While facing cancer, partners often feel as helpless as those affected, and they don't always know how to handle it. For fear of saying something stupid and intensifying the pain even more, they sometimes entirely avoid talking about feelings such as fear, sadness and despair. Sometimes their own fears and previous experiences with cancer coupled with their attempts to suppress these, lead to withdrawal and distance in the relationship. If, for example, a man's mother died young



of breast cancer, this life experience will again come to the fore when his own wife is also suffering from breast cancer. He can have the same old reaction pattern he had before, such as withdrawal. The cancer patient will then have the impression of being “left to his own devices” or “misunderstood”.

Often, in retrospect, couples considered showing affection, listening, sharing one another’s fears and worries as well as hugging as the most valuable and helpful things while coping with cancer.

Even normal problem-solving strategies are frequently affected when partners face a cancer diagnosis. Many tasks and roles have to be redistributed and that causes stress: who is going to drive the children to school when mum is in chemotherapy? Who takes care of the tax return, if other worries press? What will happen if the husband loses his job? Looking back, couples say that they have found it useful to create a climate where they could speak openly about their emotions, their thoughts and the tasks to be shared by each member of the family. Respect for the partner’s specific needs and a conciliatory attitude are always quoted as being important factors in resolving problems together. Having pleasant and shared rituals as a couple such as dining out or taking walks together plays an important role in protecting the relationship.

Dealing with cancer can also bring about positive developments for the couple. When it is handled well, a deep feeling

of intimacy occurs and brings the couple even closer together. Having endured hard time together can enhance the quality of the relationship. The ability to speak frankly and without reproach, managing conflicts respectfully, showing each other mutual support and consideration as well as organising the future together can have a favourable impact on the couple’s happiness.

Statistically, we do not know how many couples separate during or after cancer. However, in general the cancer is not the primary reason, but only the trigger for a separation in an already difficult partnership. Sometimes it can be helpful to request psycho-oncological support in the form of couple’s counselling in order to help overcome the challenges posed by the cancer.



Chemotherapy has made me lose my hair and I can no longer hide my cancer. Anyway, I hesitate telling my aging parents. Isn't it better to make something up to spare them from the truth?

At the end of the day, there is actually no right or wrong way to handle a cancer diagnosis. The decision of who you are going to confide in and who is going to be openly involved in your journey remains a personal one. If the diagnosis is confirmed, there are good reasons to tell close family and friends. "False consideration" for them is not a good advice.

Elisabeth (62 years, uterine cancer) worries about telling her parents: *"I can't tell my parents, it would break their hearts. Both are old and in frail health. I don't think they would survive knowing about my diagnosis. But it is strange that for a while now they keep asking me if everything's alright."*

The burden is always greater for the patient if he decides to keep his cancer a secret, since family and friends will nevertheless notice changes in behaviour and emotions and will try to interpret them. This can lead to misunderstandings. When "keeping up appearances", it becomes more and more difficult and exhausting to maintain open and intimate relationships with friends and family. Even aging parents will most likely notice that "some-





thing” is wrong. It can put enormous pressure on a patient for inventing pretexts and excuses all the time, or even lying to parents. This leads to a bad conscience or even a feeling of guilt. In the long run, confidence will suffer and the relationship with one’s parents will get worse. Depending on the circumstances, the patient may risk missing out on an important and useful resource in coping with his cancer, as parents can play a supportive role in it.

In the worst case scenario, parents may accidentally find out that their child has cancer, leading to a significant loss of trust which may undermine their relationship for some time. In principle, it is better to face up to the sad reality of the diagnosis rather than keep it secret and mysterious. Openness creates trust and security. Suitably preparing to announce bad news to parents, who may also be suffering from serious health problems, is possible. In fact, the choice of words has a big influence on how people cope with the news of a serious illness or an imminent operation.

Everyone can see that I have cancer – I feel so ashamed that I’ve lost my hair. Since the operation and the physical changes, I no longer feel attractive and I don’t want to go out. Do others feel the same?

Some people affected by cancer undergo temporary or permanent physical changes.

Sometimes these changes are visible such as a facial scar after surgery, sometimes they are inconspicuous and only the person affected attaches importance to them. He wrongly thinks that other people are always looking at that bit of the body.

“Since the operation, it seems to me that everyone would just stare at my scar. I’ve the impression that no one looks at my face any longer, but only at my neck. I feel so awkward because of it and I think that the scar is awful.” (Caroline, 33 years, thyroid cancer)

Quite a few patients think that they have become less attractive and that makes them lose confidence in themselves. Some measure their self-esteem by their outward appearance and therefore feel ashamed by their new appearance, even to the point of worthlessness. Grieving for their former look and their raving about the changes can seriously affect mood and, possibly, affect other areas of life. Sometimes loss of self-esteem can lead to social withdrawal for fear of rejection or judgement. This is why it is important to openly address these problems, worries and fears.

Most women and also men regard the loss of one’s own hair during chemotherapy as a very visible sign of the illness. Loss of hair may only be temporary and in the meantime there are some very good wigs, but still, this offers little comfort. First of all, what is needed is simply space and understanding for feelings of grief over the loss (albeit temporary) of one’s hair. Adapting to permanent physical changes

in particular requires a lot of time and patience with oneself. It is sometimes difficult to accept the loss of one body part or a physical function you could always rely on. During this time, emotions such as sadness, anger or disappointment can occur. This is completely normal and patients should bring a lot of understanding for themselves and their emotions. It may be useful to unravel these sometimes strong emotions with a trusted friend or family member. Many people also find comfort by participating in a supporting group discussion. They learn that they are not alone and that others are having the same experience.

To restore self-confidence and wellbeing, it is sensible to stay active and to continue to engage in activities or find new ones. Relaxation and physical activity in particular have a positive effect on physical wellbeing and thus boost self-confidence. Some patients report that, by asking good friends, they have discovered what makes them so valuable and lovable in someone else's eyes. Knowing it is their own helpfulness, their loving listening or their kindness that others value can widen the patient's own perspective and increase self-esteem.

The promotion of self-esteem during treatment is a key issue in psycho-oncology. Constantly bemoaning one's look or a depressive reaction after losing a body part or body function can be an opportunity to make contact with a specialist trained in psycho-oncology.

Since I got cancer, others are avoiding me. Good friends have turned their back on me. Does that only happen to me?

One's social environment can offer support and help. However, additional problems may arise under the strain of the illness. It can be painful when friends act differently than expected, or in the worst case turn their backs on you and no longer contact you. Many patients have the impression that their social environment changed with the cancer. There can be multiple reasons why good friends or loved ones suddenly distance themselves. Often it is related to their own experiences and fears about cancer; many people don't know how to handle it or what to say. They therefore withdraw, often unconsciously. But other patients report that brand new friendships have been made or that relationships have been formed which were completely unexpected. Psycho-oncologists often recommend that patients take the initiative themselves when they have the impression that a person who is important to them slips away. If so, openly expressing one's emotions and impressions without reproach can strengthen a relationship or at least provide an explanation.



Since the people around me know that I have cancer, everyone “walks on eggshells”. Everyone constantly tries to take everything off me and I have the impression that they all think that I can’t do anything anymore. Is it written on my forehead that I can’t do anything anymore?

Close family and friends often feel the need to comfort and help the person affected by cancer. Helpfulness is often synonymous with practical support; the person who is helping is happy to be able to do something. But sometimes this goes too far, so that the patient feels too “managed”, and has the impression that people think him incapable of doing anything at all. On the long run, this can lead to a feeling of dependence, powerlessness and at worst depression. People need autonomy and a feeling of control, the satisfaction of being still able to master certain aspects of their life, despite the illness. When a patient gets the feeling that his family spares him too much, he should speak calmly and openly about it. Because it is a new situation for all involved, it is only natural and understandable that new rules must be established as far as mutual relationships are concerned. The patient should set out which tasks he would like to continue to do himself and which activities he would like to delegate. To offer help and to accept it is sometimes difficult and requires discussion.

Since chemotherapy, I feel constantly overwhelmed. I can no longer do my housework and feel bad that I’m no longer managing my everyday life. Am I just a burden for my family?

Cancer is a burden for the patient, as well as for the caregivers. There are times during the illness where you feel overwhelmed. At those moments loved ones can also feel swamped. Difficulties in managing everyday life and the changes involved in the distribution of roles and tasks for the family (the partner and children often undertaking the housework and other everyday duties) can give the patient a bad conscience leading to a strong feeling of long-lasting guilt.

“Since I’m sick, it’s all bad. My husband is totally overwhelmed by the additional tasks and the children have to give up lots of things because of me. It’s my fault that we can’t go on holiday this year. I’m only a burden for my family and without me life would be easier for them.” (Carine, 44 years, breast cancer)

But it doesn’t help to suffer or blame oneself in silence. In the first instance, it can be useful for the patient to recognise that it’s the situation and not her who is the burden. It is better to see the cancer as an uninvited guest who upsets all normal routine and requires new arrangements to be made. Secondly, the patient should



Speak openly to his family about upcoming changes and the manner in which tasks should be redistributed successfully on a temporary basis. This is about bringing up difficult subjects such as “offering help” and “accepting help” and choosing the model which will best suit the couple or the family.

Support can be provided by a psycho-oncologist who will perhaps invite the couple or the whole family to a consultation. In particular, when the patient continues to have strong feelings of guilt, it can be useful to speak with the psycho-oncologist as this could be due to a depressive episode.

I have been on sick leave for four months now. When I occasionally feel better, I feel guilty towards my colleagues and I worry that they are overworked because of my absence. On one hand I feel that, as my chemotherapy is only every three weeks, I could work in between, but on the other hand, I don't want to feel under pressure. Is my uncertainty normal?

At a time when workload is steadily growing, many employees on sick leave feel guilty towards their employer or their colleagues. This is the reason why despite

the sick leave, they go to work, even though they are not up to it. As absence can be fairly long depending on the treatment, it can lead patients to have a bad conscience. Often a guilty conscience is only temporary, but if it persists this can be an opportunity to question it: Where does this guilty conscience come from? What is the cause of it? Is it because of the working conditions? Or maybe of one's own (excessive) demands? Or perhaps too great a work ethic? An outsider can help uncover and question the triggers behind this.

“My colleagues often ask when I'm coming back to work full-time, as I look really well. I find it difficult to justify myself, but actually I am very relieved at working half-time at the moment. This allows me getting back into professional life step by step. Anything else would be too much for me for the moment”, explains Marco (52 years, lymphoma).

Some people may miss work; they long to return to “normality” and a well-structured daily routine. Other patients like to continue working during the treatment because they think of work as a means of helping them. If the body allows it (and with the agreement of their employer), there are various options, such as the so-called progressive return to work for therapeutic reasons, as work can be an important source of self-esteem.

Others use their time-out to completely concentrate on themselves and their treatment. They use those phases of

treatment when they feel better to focus on self-care, in order to regain strength in the long term. The decision to continue to work during the treatment is a personal one and should always be taken together with the doctor.





Returning to everyday life

“After treatment”

Basically everything should now be over, shouldn't it? So why can't I just turn the page? Many patients eagerly await the last chemo or radiotherapy to then find that they are disappointed by the return to daily life, to life before cancer, when it doesn't turn out as easily as expected. Even the experts know that the phase of life after successful completion of cancer treatment can present real challenges as well as moments of crisis. Here some topics that patients have to deal with during the remission phase.

The chemo and radiotherapy are over and the doctors are very satisfied with the results. There is no more trace of a tumour, but I feel so weak and tired. How is this possible?

Usually fatigue is a mechanism which protects one from overload, a warning signal so to speak. In the context of cancer and its treatment, there can be severe fatigue which can become an additional major problem. This fatigue is a state of chronic physical, emotional and mental exhaustion which is very common and can last a long time, even beyond the end of treatment. As opposed to normal tiredness, fatigue in the context of cancer

is described by patients as being much more intense:

“I have never been so tired in my life; it's like nothing I've felt before. The fatigue is flooring me during simple household tasks or even when I'm resting.” (Elisabeth, 49 years, breast cancer)

For some patients this state of exhaustion can persist for months after the treatment finishes. The reasons are many. On the one hand, extreme exhaustion can be attributable to the cancer itself and the side-effects of the treatment. On the other hand, in addition to physical causes, psychological factors play a role. Usually, it is only at the completion of the medical treatment that the psychological process surrounding the patient's experience can

begin. It's actually when everyone thinks "now it's over, it's back to normal" that this process really starts.

Pierre, suffering from colorectal cancer at the age of 58, reports: "*When all the treatments were over and both the doctors and my family were optimistic about my future, I felt like falling into a huge black hole. Only then started I to realize what has actually happened to me over the last few months.*"

Experience shows that to build a "new normalcy", you need up to two years after the end of the treatment. A lot of patience is needed to deal with the fatigue but the good news is that this troubling symptom, though usually very intense, is mostly a temporary one.

I would so love to get back to my routine again after my long illness, but I feel so exhausted. What can I do about this?

At this phase, it's important to look at your own goals and everyday routine and avoid making comparisons with what you were capable of before the cancer.

"It's incredibly frustrating, I was always a well organised person and had loads of energy, but all of a sudden the smallest trifle looks like an invincible mountain. I didn't recognise myself anymore and I felt like I had become dependent on others" explains Roger (55 years, prostate cancer), on his return to work.

It is highly recommended to repeatedly schedule short breaks during the day. It is also very useful to learn a targeted relaxation technique, such as autogenic training or progressive muscle relaxation. However, sleeping during the day should be avoided as this can disturb the day-night rhythm and lead to insomnia at night. Overall, a good night's sleep is important. Too much brooding over traumatic situations as well as fears or depression can affect a good night's sleep. If this happens, it is best to get professional help.

With the doctor's permission, a regular physical activity can be very beneficial. Physical activity (preferably outdoors) has a direct effect on mood, sensitivity to pain and quality of life. Moreover, there is a direct link between muscle mass and fatigue.

Having a healthy and varied diet can be an added way of feeling better as can being more active. For many patients the completion of treatment is an opportunity to re-evaluate their diet.





Is it normal to feel so little relief at the end of treatment? Do other patients also have a problem being really happy when their treatment is successful?

The psychological processing and coping with the emotional burdens since the diagnosis usually start towards the end of the treatment. This kind of work is extremely complex and consumes a lot of energy. It can be accompanied by multiple, often contradictory, emotions. Feelings of shock, insecurity, anger, fear, sadness, injustice, unreality, shame, guilt, joy, loss, gratitude, despair and hope can all come to the fore, each one playing an important role in the process of assimilating the experience. This somewhat hard process nevertheless helps the patient to realise what has happened to him. They mark the process of giving the patient's experience a place in his own biography and adapting to the changed situation over time. Anyone who runs a marathon knows why he is tired at the end of the day. Understanding and categorising events since the moment of diagnosis is just as tiring a process, but it is an invisible one. It is like a computer software programme needing a lot of memory but which runs in the background. Being aware of how many emotions play a role, it is unrealistic to expect that joy alone will be at the forefront of these.

"After my treatment, I was exhausted and at first felt nothing at all. It was only gradually that my joy for living came back."
(Mike, 30 years, testicular cancer)

The end of treatment represents a new stage which requires a lot of energy on a practical and organisational level. During the period of painful and time-consuming treatments, daily tasks and routines often had to be adapted. There are a lot of hospital appointments and the side-effects of the treatment call for more rest than usual. These challenges often result in roles being split differently within the family or even organised with external help. All this needs a lot of energy. After treatment, roles may have to change again. Maybe it will be a return to work. In addition to psychological aspects, a whole series of practical daily necessities needs to be mastered. This can of course curb the sense of joy at the beginning until, step by step, the new challenges are overcome. One of the biggest challenges is obviously dealing with the uncertainty of whether or not the cancer will come back.

Paula (55 years, lymphoma) describes this situation:

"At first I didn't dare be happy about the end of treatment. The fear of a recurrence and having to start all over again was simply too great."

My cancer treatment was successful, but I'm afraid it'll come back. What will my future be like? How can I deal with these fears?

Through their cancer experience, survivors feel the uncertainty and unpredictability of life more vividly. According to many patients, the idea of their own mortality and death often preoccupies them for the first time in their life. This can be frightening. Even after successful treatment, a feeling of insecurity and shock often linger. For example, they are no longer able to make long-term plans in a devil-may-care attitude. Fear of a recurrence is a permanent companion, at least for the first few years. Life no longer seems to be as predictable and controllable as before. Fear of a recurrence is therefore completely understandable.

Communication with an oncologist is essential. The doctor obviously cannot give a hundred percent guarantee, but he can help to guide the patient and give him advice about his fears. Instead of endlessly focusing on dark thoughts, alone at his home, it is recommended that the patient should talk to the doctor. Many patients find it useful to write down their questions in advance and to have this piece of paper at hand when they see the doctor so that they don't forget anything important. Some patients bring someone they trust with them to help out.

"When I felt anxious about the cancer coming back, it was very helpful to know that, no matter what, I wouldn't be alone. I've always tried to keep up contact with friends and to tell them how I was getting on. Even today that still gives me a feeling of support." (Marianne, 65 years, breast cancer)





Fränz (51 years old and suffering from leukaemia) relies on a network of professional help: *“At the start of my illness, I began to create my “own” multidisciplinary support team. Depending on what was worrying me at any particular moment, I always had access to someone I could speak to.”*

Cancer is a complex disease which has an effect on numerous areas of one’s life and thus can perhaps be best managed by a multidisciplinary team. This team may, for example, include a specialist, a general practitioner, a nurse, a psychologist, a physiotherapist, an occupational therapist, a social worker, a chaplain, and a dietician.

A cancer diagnosis not only pulls the rug out from under the patient, it can also undermine confidence in one’s own body. Seeking positive body experiences may be a new source of energy and strength and will help to alleviate fear.

Overall, when one feels that life is out of control, it is useful to look for ways of bringing back that sense of control, e.g. by a change of diet, the reduction of alcohol consumption or attaining important personal goals. It takes time to develop new attitudes and “positive” experiences to help face the diagnosis, regain confidence and make sense of it all. Psycho-oncological support can be very beneficial in helping to handle uncertainty and improve emotional wellbeing.

I do not sleep for weeks before a check-up and I hardly think of anything else except to hope that the cancer hasn’t returned. What can I do?

Just like the fear of a recurrence, stress prior to a check-up is not pathological but a perfectly normal reaction to an exceptional and potentially life threatening situation. Fear and tension indicate that the check-up is important and much depends on its outcome. It is significant for your one life.

However, if fear of a recurrence, or tension and pressure before a check-up is too overwhelming, consulting a psycho-oncologist may bring help and relief. The nervousness will probably not disappear entirely but thanks to targeted techniques and strategies, a sense of control can gradually be reinstated.

“When, on the recommendation of my doctor, I got in touch with the psychosocial department of the Fondation Cancer, I had little hope that it would be of any use to me. But after a couple of sessions, I was feeling better. Even though I still feel somewhat tense, I now have tools I can use to deal with my fear as well as getting a grip on my sleep disorder.” (Michel, 64 years, prostate cancer)

Everyday distractions such as sport, music and relaxation exercises can also help. The pop singer Anastacia, 48 years old, had her first breast cancer in 2003. In



2013, her cancer returned and Anastacia opted for a mastectomy: "At the very time I got my second cancer diagnosis, I was at the studio just about to write new songs. And you know what? I kept on writing them. Of course it was a difficult time, but I tried to put some of this energy into my music. And I think that that comes over in certain songs on the album. To be honest, the second time, I was much bet-

ter prepared. I knew that a cure was going to take longer and that I was putting my career on the line. But I also knew that it was the only option possible for me. I respect the fact that each person must make his own decision. I don't regret anything and I feel more passion and love for my music and for the shows than before".



The illness has made me into a different person. I'm no longer able to reach some of my goals. What can help me to find new goals in life?

Inspiration is something very individual. Some find it in reading, others prefer direct and personal exchanges with persons in the same situation, for example, as part of a discussion group for patients. Yet others find inspiration in music, faith, sports or art.

The Austrian neurologist and psychiatrist Viktor Frankl (1905-1997) wrote a paper based on research showing that the people we admire most are not great politicians or athletes but ordinary people, just like everyone else, who've overcome a difficult destiny in a positive way. He demonstrated three methods as sources of inspiration in the search for meaning in life. First, dedication to a work, a good deed or a project; secondly, devotion to a loved one or the admiration of beauty; thirdly, according to Frankl, is to transform suffering into a human strength. However, this last option can only be considered if the suffering is actually unavoidable. If suffering can be reduced or subsides, this is obviously a priority. But, according to Frankl, if a difficult situation cannot be changed, one always has the option to determine one's own attitude towards the situation. He describes it as the "last human freedom – to choose one's own path". By this he means the very personal choice to choose one's own way of facing up to a situation which cannot be

changed. For Viktor Frankl, each person has to find his own meaning of life, it cannot be given. In the course of this process, it can also be useful to take up old hobbies or try out new activities. One's own intuition can be a sensible guide. "The proof of the pudding is in the eating" being the motto. It is not uncommon for patients to retrain after their illness and change profession:

"After my treatment I could no longer picture going back to my old job. It suddenly became meaningless to me. In my new job, I'll have more contact with people, which I'm very pleased about. In the evening I come home happy."
(Noriane, 44 years, cervical cancer)

However, before being able to set out new goals, it is normal to need time for oneself as well as time to mourn the fact of having to let go of old plans for one's life. This opens up the way to the future.

My priorities have fundamentally changed. My family, my friends and my colleagues all say that I have changed a lot and are not always happy about these changes. Is it the same for other patients after their cancer?

The answer is a clear yes. By confronting a potentially life-threatening disease, perceptions change. New values become important and priorities will shift.

“The first time back in the office was very difficult for me. Suddenly I felt like a stranger in an once so familiar environment. Relationships and interactions with my colleagues also changed. Today I have zero understanding with colleagues who get upset because the machine’s out of coffee, even though I know that I would have reacted just like that before. But, compared to life, how important is coffee?” (Jos, 57 years, colorectal cancer)

At times, a feeling of alienation from others may happen, as circumstances and experiences have suddenly become too divergent. This carries a risk for friendships and relationships in general. Is there a way to bridge the gap between these two different worlds, to find some common ground? Will both worlds align with one

another after some time? It can happen that some relationships reach a point of no-return, as the differences have become so great that they simply cannot continue.

“Some of my old friends are as important for me as before, but there are also people who are no longer part of my life. Our attitudes and interests are just too different. I’m now looking for friendships within groups of patients, people who have had the same experience as me and where I feel understood.” (Marie-France, 73 years, bladder cancer)

Some changes in priorities are temporary, others may be permanent. A few patients even speak about a change of personality after their cancer experience.

During chemotherapy sex was not a topic. Now I notice that my partner is getting interested in sex again, but I’m still not in the mood. Is this normal? What can we do? Before all this, we were both very interested.

During treatment body and soul are focused on survival. It’s therefore understandable that other areas of life such as sexuality are often pushed into the background. After treatment, it is not always easy to find the way back to a fulfilling sexlife. There are some obstacles to overcome and sometimes it is quite



simply a matter of time in adapting to the new situation.

The biggest enemy of a fulfilling sex life is pressure. The more the couple wants it to finally “work again” or attempt too hard to strive for pleasure, the greater chance there is that it will fail. It would be more helpful to have an attitude of curiosity, to rediscover one’s partner during a new stage in one’s life, taking into account and accepting the various changes rather than trying to fight them. Interest, affection and devotion instead of stressing about performance are the keys.

Consequently it could be useful to talk about and define a new “sexual framework” which suits both partners. What did we do before that is still possible and important to both of us and should be maintained no matter what? What familiar habits from before are no longer possible because of the cancer or its effects? What new behaviour could replace those habits? Are there any new methods to try out in mutual respect for one another?

It is essential not to reduce sex to the sole sexual act, whether successful or not. A love life does not just consist of the sexual act; cuddles, familiarity and physical contact are at least as important. These are what give a sense of security and strengthen the relationship.

Sometimes difficulties in a couple’s sexual life are due to other problems. An emotional issue for one or both partners or a conflict in the relationship often reveals

itself as an absence of desire. If so, it might be worth it to take a closer look - as a couple or with the help of a couples counselling.

Last but not least: couples do not always want to bring this subject up at a medical consultation and there is not always a medical solution to every problem but it could be worth talking about it. The doctor may have other recommendations which could help the couple. It’s always worth a try.

I certainly feel healthy again, but my body is completely different from before the treatment. I don’t feel very attractive. My self-confidence is at rock bottom. Is there anything I can do to feel better?

The list of possible physical changes after cancer and its treatment can be long: altered hair structure, loss of body parts by amputation, scars, weight loss or gain, colostomy, changes in skin structure, sweating, movement restrictions, concentration difficulties, water retention, rotten teeth, lesions in nerve endings in the extremities (modified sensation either in the hands or the feet), pain, loss of muscle mass and fitness. Some changes are temporary, others permanent. They



can all have a negative effect on body image and the way a person views his body. Negative changes in body image can jeopardize self-esteem. Self-esteem or self-confidence, together with a positive body image and satisfaction with one's own attractiveness, is directly linked to one's overall sense of wellbeing. Josiane (46 years, breast cancer) confirms this: *"The hot flushes and weight gain have greatly affected my self-esteem. This often puts me in a very bad mood and I am angry and irritable"*.

"When my own negative self-image started to burden our partnership and I realised that I risked losing my husband, I dared to consult a psychologist. She made me draw my body. On her instruction, I drew all the painful and negative physical changes. But the psychologist also asked me what was still working well in my body. This question took me by surprise! I had been concentrating so hard on what I had lost that I had not even noticed the other healthy parts of my body. The simple fact of realising this helped me a lot and I started to feel a bit better straight away", reports Andree. (51 years, lymphoma)

Consciously taking note of healthy body parts and maybe even looking at healthy and reliable "body functions" with gratitude, as Josiane has experienced, gives a more holistic picture and can give strength to handle negative changes in a constructive manner: *"It's marvellous to be able to go jogging again after the breast cancer and to note just how far my legs take me!"*

Regarding perception, it is important to see to whom the patients compare themselves. The beauty ideals of the twenty-first-century as seen in the glossy magazines are unattainable for most people, even the healthy ones. After successfully completing a treatment, it can be beneficial to patients to compare themselves to how they were doing during the treatment, and to consider the improvements since finishing the chemotherapy.

Patients can also listen to their inner voice and reflect on how they handle their own thoughts and what judgements they are making about themselves. What is the result of these inner monologues and are they useful or actually rather painful? What is crucial, apart from handling one's own perception and thoughts, are personal choices in, for example, diet, physical activity, sport, a relaxation course or meditation. For other patients, a course teaching make-up techniques can be useful or getting advice on colours when buying clothes.

After a tiring time full of changes and marked by uncertainty, it is important to be able to get new positive physical experiences once more.

“When the doctor prescribed physiotherapy at the end of chemotherapy, at first I had no desire to drag myself along to even more appointments. I was so tired and I have already had so many medical appointments. However, after some sessions, I started to develop new physical sensations. The massages did me good and for the first time for a long time I had a positive body experience. It was wonderful. My body felt much better.” (Mario, 71 years, lung cancer)

But what we have already pointed out when talking about life goals, applies here too. There is a period of grieving, of exhaustion, of disbelief and/or anger which is perfectly normal and even useful before being able to rebuild one’s life.



My partner says “Now it’s over. Look towards the future!” But for me, it’s not over yet, at least not in my head. If we don’t talk about it, won’t that harm our relationship?

Yes, definitely. If partners cannot communicate openly, there is always a risk that both are going to live in “parallel worlds”. There is a growing danger that the couple will become estranged and end up sooner or later by having nothing more to say to each other because their worlds have drifted apart. Not being honest with each other or not calling things by their name increases the probability that both sides will feel misunderstood and left alone, an ideal breeding ground for misconceptions which probably wouldn’t have existed before. Considerations such as “I want to protect my partner by sparing her from negative feelings or from violent and difficult thoughts” are actually counter-productive. They prevent both partners from thinking about solutions together and making joint decision for the future, whatever those may be. The result: less togetherness and more loneliness on both sides. It is in fact a sham protection which weakens the whole family and implicates that they are not fulfilling their potential.

So what should be done? It would be better to define cancer as a common challenge which should be faced with frankness, honesty and courage. It is important to be able to confide in one’s

partner and to be confident that they will be able to handle their emotions and thoughts. By speaking to a partner in a respectful tone of voice about how they are experiencing the problems in the present situation, they will learn getting to know each other and each other’s reactions better. Thus they will in time learn to support each other instead of isolating one another. The reward for this courage is often an improvement in the quality of the partnership with more satisfaction, intimacy and a stronger bond.

“It was difficult for me to witness that my wife’s worries really started once the chemotherapy was over. During the chemo she carried on courageously without complaining. For me, the time of her depression came as a surprise, and I would have preferred to ignore her problems. I was frightened of her reaction but, to be honest, even more frightened about my own reaction. A friend of mine who had experienced something similar encouraged me to try to talk openly with Lisa. Looking back, it was the best advice I have received in a long time. Today we are even stronger than before. Our marriage has acquired a depth which I would never have dared to have imagined before.” (Jean-Luc, 34 years)

Psycho-oncological practice shows that many patients and some couples experience a crisis just after the end of chemo or radiotherapy. The timing is not surprising. Sometimes, during the treatment, there is little time to exchange thoughts and emotions; it is more about



concentrating on everyday life and survival. Not only that, but the protective surroundings of the hospital are no longer there after the last chemo appointment and that can give the feeling of no longer being “looked after”. In addition one must confront the reality of returning to everyday life, which can be difficult. Psycho-oncological help can be very useful, also in the form of couple’s counselling. If the couple wasn’t already in a crisis before the cancer diagnosis, this crisis could be turned into an opportunity to make things better and avoid any future threat hanging over the partnership.

My treatment was successful and finished a few weeks ago but I’m sleeping very badly and am often irritable. I’ve got constant negative images and thoughts running through my head which are difficult to control. Is this a normal reaction?

Irritability, difficulty sleeping, nightmares, stressful thoughts or pictures, unpleasant physical experiences, memory loss, apathy, indifference, being emotional and overreacting as well as avoiding activities, people or places can all be part of a normal reaction to the difficult and extreme life situation, insofar as these symptoms subside fairly quickly. But if they continue

for a prolonged period of time, it is in any case recommended that the patient seeks professional help in order to avoid the chronicity of the symptoms.

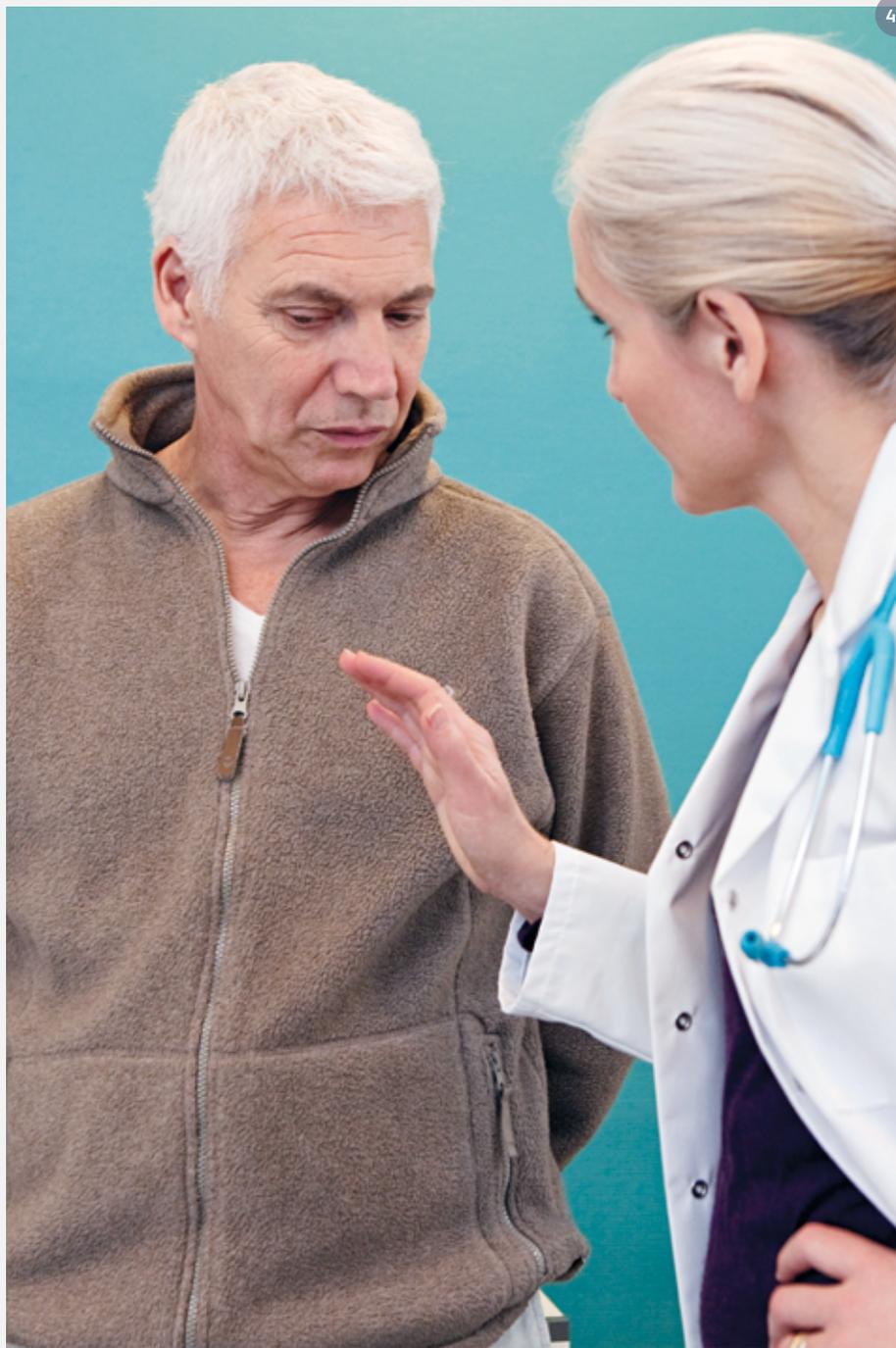
Post-traumatic stress disorder (PTSD), which is characterised by one or several of the abovementioned symptoms, can be a possible follow-up reaction to one or several traumatic events. According to the World Health Organisation's International Classification of Diseases (ICD-10) this disorder "arises as a delayed or protracted response to a stressful event or situation (either short or long lasting) of an exceptionally threatening or catastrophic nature, which is likely to cause pervasive distress in almost anyone". By threat it is meant an exposure to danger of one's physical and mental integrity, or threat to one's own life or that of someone else. The vast majority of cancer patients experience the diagnosis and/or treatment as traumatic. The frequency of post-traumatic stress disorder in the course of a

serious illness is about 10%. Patients can be affected but their loved ones can also develop this disorder.

There are effective psychotherapy treatments to help reduce these symptoms or to eliminate them.

"For a long time I suffered from haunting nightmares which left me drenched with sweat when I woke up. During the day I was obsessed with thoughts about what had happened and sometimes even about dying. I wasn't interested in my family, often felt overwhelmed and reacted aggressively. Until my doctor sent me to the Fondation Cancer where, with the help of a therapist specialised in trauma and with EMDR (Eye movement desensitization and reprocessing), I was able to free myself relatively quickly from the troubling symptoms." (Tom, 60 years, pancreatic cancer)





Psychological and social support

A cancer diagnosis often hits the patient and his loved ones without warning and can cause many fears and anxieties. In addition cancer treatment involves frequent hospitalisations, numerous examinations and waiting for results. That is why, many cancer patients have difficulties assimilating the psychological demands and life changes without support. Professional psychological and psychotherapeutic support can ease the burden and open up new paths. Information about daily life with cancer can be an additional help for the patient and their family.

The psychosocial department of the Fondation Cancer offers **free** psychological advice and psychotherapeutic support for patients and their families. Advice on social, practical and administrative problems due to the illness is also given. The team consists of six qualified psychologists with additional psychotherapeutic qualifications (for example cognitive behavioral therapy, systemic family therapy and advice, trauma therapy and EMDR, clinical hypnosis, personal counselling and psychosocial oncology). Staff is at the disposal of patients and their families to answer questions and address problems and is active in looking for personalized solutions together. The whole team possesses in-depth knowledge in psycho-oncology (see below: Definition of psycho-oncology).

Counselling and psychotherapy support consist in:

- **Psychological support from the time of diagnosis, during and after treatment**
- **Assistance in coping with cancer and therapy-related restrictions**
- **Support in emotional stress situations**
- **Psychotherapy for psychic comorbidities such as depression, adjustment, anxiety, post-traumatic stress disorders, etc.**
- **Relaxation techniques and stress management**
- **Parental counselling and, if needed, support for children of parents with cancer**
- **Group therapy**
- **Cognitive rehabilitation**
- **Onco-sexological counselling**
- **Onco-cosmetic counselling and care**
- **Oncological nutrition counselling**
- **Advice on practical, social and administrative issues**
- **Information and brochures**
- **Support and counselling for relatives**
- **Financial support in the event of hardship**
- **Family support**



The support offers are available in Luxembourgish, French, German, English, Greek, Spanish and Portuguese.

Fixing an appointment

To make an appointment for a free advisory consultation, please contact the secretariat of the Fondation Cancer:

T. 45 30 331 or **E. patients@cancer.lu**.

What actually is psycho-oncology?

Psycho-oncology is a fairly young discipline in oncology dealing with the psychological and social aspects of cancer. It deals with the effects of cancer on the experience of the patient and their family as well as the many questions pertaining to the quality of life of those affected.

In psycho-oncology one also studies whether psychological factors play a role in causing (or co-causing) cancer. From a scientific point of view, assumptions about the various hypotheses on “Psyche and Cancer” can only be verified with the help of prospective studies. In these long-term studies, large samples from the general population are evaluated over several years both psychologically and medically. So far, no convincing evidence for a “cancer personality” has been found.” The psyche only seems to have an influence on the development of a cancer by way of one’s health behaviour. If someone is stressed, worn out or depressed he may smoke more under some circumstances, he may try to drown his sorrows in alcohol, not paying attention to a healthy diet or doing little

physical exercise. There is no direct link between cancer and personality: a certain personality, under pressure and with a high stress level does not lead to cancer.

Other main research topics are “Psyche and disease progression”. Here, too, data is collected. Current data confirms that simple cause and effect relationships are false. Based on this knowledge gained from a constantly updated database, we are able to formulate recommendations for improving our support offers.

What in fact are the aims of professional psycho-oncological support?

Supportive counselling or psychotherapy for cancer patients and/or their families always aims at maintaining or improving their quality of life. That can include reducing disease or treatment-related symptoms such as, sleep disorders, depressive moods, nausea, despair and helplessness or pain. Learning a new way of dealing with anxiety rather than giving in to fear can be an important goal.

Regarding couples or family counselling one aim may be to facilitate and support communication between the patient and his/her partner/children. This is about maintaining or improving the family’s quality of life.

After treatment, the objective is often to support the patient whilst he copes with the after-effects of the illness or treatment. Adapting to changes in everyday

life after cancer is the focus of attention which can include reinforcing the patient's self-esteem or encouraging personal responsibility for one's own life. Steps to promote health are also part of this (for example supporting someone whilst they try to stop smoking or whilst they are losing weight for medical reasons).

In every stage of the illness, professional psycho-oncological support is always directed towards the specific life situation of those affected and is therefore focused on the personal objectives of the person requesting help. In practice, what has the patient or his family asked for or what issues do they have? The first hour is often taken up with this discussion. It can be useful when patients reflect in advance on the objectives they wish to pursue during the consultation or psychotherapy. Sometimes patients may specifically say "I would like get over my fear", "I would like to sleep better and stop mulling it all over during the night" or "I would like to get on with life again with greater self-confidence and be optimistic when my treatment's finally over". Sometimes their request is formulated in a more general way; simply "I would like to be better." After the counsellor/psychotherapist and the patient/family member have discussed the hopes and wishes of the patient, they can both look for possible solutions together. Cooperation and motivation on the part of those asking for help are always necessary in order to attain the objectives. Psychotherapy is not a magic trick which can simply make anxiety or despair disappear.

Which patients or family members can benefit from professional psycho-oncological support?

Sound estimates exist whereby between 30 and 45 % of cancer patients could benefit from psycho-oncological support, during the course of their illness, in order to improve their quality of life. According to scientific studies, psychotherapy is the tool of choice for certain patients, particularly with problems as anxiety, depression, psychosomatic disorders or post-traumatic illness. In these cases additional treatment with medication could perhaps be advisable.

The authors of this brochure have no estimates of the percentage of family members for whom supervision may be helpful. However, this figure is probably high, as it is obvious that family members are certainly under pressure indirectly and in different ways, but just as much as the patients themselves.

Unfortunately, there are still many patients (or family members) who are obviously under tremendous pressure but who avoid seeking professional advice because they fear that others will consider them "mad" or "too weak" to be able to resolve their own problems. However, a lot has changed in Luxembourg during the last few years. Today, resorting to psycho-oncological support, whether through the psychological services at the hospital, at the Centre François Baclesse or through specific organisations such

as the Fondation Cancer for example, is an integral and appropriate part of the treatment.

Experience shows that it can often be appropriate to request help ahead of time in order to avoid stress getting worse.



What should be taken into account by the patient or family member in choosing a psychotherapist or counsellor?

Over the course of the last few years, a vast amount of support for cancer patients has been developed in Luxembourg. It is not always easy for patients or their close family or friends to find a qualified specialist with whom a relationship of trust can be established. It can take some time before one finds a suitable psychotherapist or counsellor, who is both sufficiently qualified and “with the right chemistry”.

When looking it is important to make sure that these “support and assistance providers” have enough knowledge of the problems encountered by cancer patients, meaning that they will have sufficiently studied the latest findings and research in the field of psycho-oncology and avail themselves of ongoing training. In particular, patients must be sceptical when they are promised that cancer can be “cured” by “so-called” psychotherapy, or that life can be extended by psychological intervention.

If a patient needs psychic or psychosomatic treatment (for behavioural problems or disorders) he can, when choosing a therapist, enquire as to whether if he or she has official recognition as a psychotherapist by the Ministry of Health. Psychotherapy is a regulated profession since 2015, meaning that the person must have various qualifications in order to obtain this certificate.

The Fondation Cancer as well as the psychology services in the hospitals or at the Centre François Baclesse can also help to look for an appropriate counsellor/psychotherapist. Lists of names cannot be given, but knowing the criteria to look for, can help with the selection.

The Fondation Cancer

For you, with you, thanks to you.

Fondation Cancer was founded in 1994. Many years of involvement and a proud record of achievement have earned Fondation Cancer widespread recognition as a prime leader in the fight against cancer. Fondation Cancer aims to reduce cancer mortality and morbidity rates by waging an encompassing fight - by promoting research, prevention and early detection, improved methods of treatment and rehabilitation and quality of life. Fondation Cancer supports cancer patients and their family throughout their journey and strives to ensure their rights. Fondation Cancer works in collaboration with the health authorities but is financially independent.

Most of Fondation Cancer's funding comes from private donations, with only 8% of its budget contributed by government.



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