



The involuntary
TRAVELLER
a book about your cancer journey

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The involuntary **TRAVELLER**

“I had an image of a bolting train and I didn’t know where I was headed. As the journey went on I filled the train up with the people that stood by and got close to me: family, friends, neighbors, health professionals, colleagues, kindergarten staff ...”

Cancer survivor



Foreword

More than 50 000 people in Sweden every year start their often unexpected and unwanted cancer journey. A journey that can cover many years regardless of if you are cured or end up with a chronic illness. For you who get cancer, and for you who are close to someone who gets cancer, the journey will bring with it all kinds of challenges: physical and mental, practical and existential. Evaluation and treatment in Sweden is exceptionally good but within areas such as care, continuity, cooperation between healthcare centers, and rehabilitation, we need to become a lot better. Waiting times need to be reduced and unnecessary waiting removed.

A national cancer strategy exists and a comprehensive improvement project is underway since a couple of years back. Six regional cancer centers have been founded and nationally there is cooperation for equal and better cancer care. National guidelines within cancer rehabilitation has been published in May 2014 as a knowledge base for everyone working within healthcare. The need for rehabilitation is there during the entire cancer journey and should be present in planning of all the aspects of care. Region Halland has been operating a pilot project with the support of Swedish Association of Local Authorities and Regions with the aim of providing all patients with appropriate rehabilitation, regardless of cancer diagnosis or in which clinic treatment is provided.

This book is a result of this pilot project. The content of this book has emerged from the close encounters and exchanges between those affected by cancer and the pilot project. I hope that you as a cancer patient or significant other will find help during the journey through the advice and suggestions of “The involuntary traveller”. Together we can make cancer care even better!

Swedish municipalities and county councils, January 2014
Gunilla Gunnarsson, cancer coordinator

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INTRODUCTION

This book is for you who are an involuntary traveller on a periodically tough and turbulent journey – the cancer journey.

The cancer journey is a journey that you have not chosen to embark on, but that you now will have to take on. In other words, you are not looking forward to, or saving up for, a holiday, even if travelling in itself does have certain metaphorical similarities to the cancer journey. Common to all forms of travel is that the journey in itself affects us and can present tough challenges but also pleasant surprises. During the simplest everyday trip unforeseen events can unfold and that can scar you for life. On the other hand, that same trip can also present you with events and meetings that will enrich you and give rise to new opportunities.

Where are you going? What do you dream of and what do you long for? It's from your perspective that you will experience your cancer journey, and manage it. That's why it is also important that healthcare providers and society listens to you, you're the expert of yourself and the needs you have.

From the day that cancer entered your life, whether it invaded your body or that of someone close to you, you are a cancer survivor and the cancer may become a lifelong companion. It affects the entire person, the family and friends around. Maybe not all the time and every day, but to and from during everyday events and life's different stages.

To be a cancer survivor also means that you and your significant others could need support during the challenges you are faced with along the way, and not only during the time the actual cancer illness is being treated. The support is there so that you can feel as good as possible during your journey, but also so that you can move on and live the life you want.

Some challenges are those that most cancer survivors face, whilst others are associated with a specific type of cancer. This “travel guide” will not provide you with any finished recipes for how to react and feel, and what you will have to face during your journey. Our hope, however, is that you will get an introduction to some of the challenges that cancer survivors can face, and what support there is along the way.

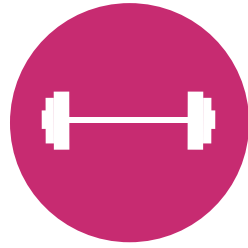
Much like a travel guide we briefly describe the actual journey and some destinations, and we offer some suggestions and advice based on experience and knowledge. What then “speaks” to you is once again a result of your perspective – where on the journey you are and where you are heading – just as a journey would be completely different if you were a lone backpacker, family with kids, or in a group of retirees.

This book is based on a close cooperation between cancer care and those affected by cancer in conjunction with Region Halland’s pilot project with hospital-overreaching cancer rehabilitation. A project with the support of Swedish Municipalities and County council that was conducted at Halland’s hospital Halmstad 2010-2013. The content of this book has emerged from the close encounters and exchanges between those affected by cancer and the pilot project.

We hope that “the involuntary traveller”, together with the individual treatment plan you and your treatment team will establish, will help you along the way and work as a compass to find direction during your journey.

The content of this book has emerged from close encounters and exchanges with people affected by cancer.

Symptoms
don't have
to be life
threatening
to affect the
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your life.



PHYSICAL CHALLENGES

Cancer often leads to physical problems. It can be nausea, vomiting, pain, constant fatigue, troubles conceiving and lymphedema (swelling in an area of the body). If you are receiving chemotherapy you can also experience trouble concentrating or thinking clearly during the course of your treatment.

Symptoms don't have to be life threatening to affect the quality of your life. Dry mouth, altered taste perception and difficulties eating warm food are experienced by some after receiving cancer treatment. Symptoms like these can affect your social life quite a bit.

Many of these symptoms will disappear after the treatment is completed, but talk to your treatment team about the physical symptoms or how the side effects will affect the quality of your life. Within both cancer care and through your health care center there is the opportunity to get support and treatment from an occupational therapist, dietician, speech therapist or physiotherapist.

You could also notice that the cancer illness has a greater effect on certain aspects and roles in your life than others. You might not be able to do all the household chores and still be able to work, or vice versa. Some people don't experience a big change at home, but they have to be away from work for extended periods of time or maybe even stop working. How the cancer affects your different roles can also change during different parts of the cancer journey.

Even you as a significant other can be physically affected by changes. You may have to take on new chores at home, or step into the role of caregiver for the person that is close to you.

In addition, the cancer journey, and the stress it brings, means that you change your daily habits in a way that affects the quality of your life. You may develop worse food habits, become less physically active, sleep poorly or become tense which can result in dullness and ache.



EMOTIONAL CHALLENGES

Living with, or close to, cancer can affect how you feel emotionally and change your feelings towards yourself and relationships to other people.

You might notice:

- Tensions in relationships, perhaps particularly with your partner.
- That it's harder to establish new relationships. You might find that it is hard to know how, when and how much you should tell about cancer to a new person in your surroundings.
- That your feelings for your own body, or your loved one's body, have changed. This could be due to scarring, changes in the body after surgery or side effects of treatment, such as weight gain and loss of hair.
- That you feel differently about sexuality and intimacy. This is deeply connected to self-image, self-esteem, state of mind, and how you are feeling.
- That you feel scared and anxious about planning the future, taking a step in a certain direction or making changes in your life.

When receiving a cancer diagnosis you can feel anger, shock, anxiety, fear or sense of unreality about the future, or you can feel sorrow, hopelessness and a sense of loss. The reactions can be strong, which can lead to anxiety and sometimes depression.

Sometimes the emotions don't hit you in full until the treatment is over and there is time left to reflect on what has happened.

You have experienced a range of emotions during your life, obviously, but when the feelings are associated with cancer you can find them even stronger and lasting for longer periods of time.

Many experience that these feelings subside a bit with time, and don't dominate to the same extent as before, but it is good to remind ourselves that the emotional aspect is just as important as the physical aspect throughout the entire cancer journey.

Guilt and anger

In the roller coaster of life we will experience many emotions. Love, happiness, sorrow, anger and guilt are just a few of them.

When we are faced with a life crisis our emotions often become stronger than usual and they can also take up quite a bit of your strength, which you might already have felt during your cancer journey.

Maybe you feel angry about being affected so badly or maybe you're mad about the fact that someone close to you got cancer early in life. Angry about everything you can no longer do, and things you can't affect.

You can also feel guilt for not having the energy or strength to do what you want for those you love. Feeling guilty for being a burden to your loved ones and for things you have said, or not said. There are also more existential feelings of guilt, such as feeling guilty for neglecting things you wanted to achieve, but never took the time to do. That's when it's easy to feel like you have let yourself down.

If you feel guilt or anger about the fact that you or a loved one has been affected by cancer that is completely ok. Those are both strong emotions and part of sorrow and coping with grief. You may need to cry but also "get a grip" of guilt feelings so that you don't get stuck in blaming yourself.

You, those who are close to you and your treatment team need to be vigilant so that these emotions don't take over in a way where pronounced sadness and anxiety hinders you from living the life you want for yourself.

Anxiety

If you always feel upset or angry or if you have troubles with sleeping, focusing or making decisions, you might have anxiety. Other symptoms of anxiety could be that you avoid things or situations that worry you and that you constantly feel the need to be calmed down. These feelings of anxiety can affect the quality of your life and people around you.

If you feel that these feelings of anxiety become pronounced and emerges more than a few times, you need to get in touch with someone within cancer care or at your health care center. They can help you and also assess if you need further help. If needed, you can get help with getting in touch with a counselor or psychologist who can offer psychological treatment.

Depression

Depression is a common problem in society and it's even more common among those who have been thrown on a cancer journey. This applies both to you as a cancer patient and you as a significant other or loved one. Some of the most important signs of depression are a constant feeling of sadness and a loss of interest for things that you used to like to do. Trouble sleeping and poor appetite can also be signs of depression or side effects of a cancer treatment.

Depression can make it harder to deal with, and mentally cope with, the cancer illness and everyday life.

You might avoid talking about your feelings or seeking help, since you feel you should be able to deal with it yourself or that you don't want to be a burden to the people around you. You might feel pressure from yourself or your surroundings to be strong and positive, which can make it harder to ask for help. If you are feeling sad or even depressed you need to talk with a doctor or nurse, either if you have contact with someone within cancer care or at your health care center. They can help you and also assess if you need further assistance. If needed, you can get help with getting in touch with a counselor or psychologist who can offer psychological treatment.

It is important to know that there are effective treatments that can help you deal with many of the challenges you may face.

There
are effective
treatments
that can help
you deal
with several
challenges.



SOCIAL CHALLENGES

A cancer journey also brings some practical things to consider, such as treatments, support services, trips, accommodation, childcare and special items such as wigs and prostheses. You also have to think about your finances, as sometimes it's hard to work during and after a cancer treatment. Your financial situation can get worse if you as a cancer patient or significant other need to be on sick leave for some periods of time. Worrying about practical questions can affect how you feel, especially if it means disruptions of your daily activities.

The cancer journey also affects your family and social network. You might have a bad conscience about what your cancer treatment entails, or that you are spending all your time and energy on a loved one so that the rest of the family have to change their routines.

You might not be in a relationship and it could be that, for one reason or another, you have few or none you consider to be close. If you are alone it's a good idea to notify your treatment team of this so that you can get the best possible support.

Remember that the mental aspect and social support are just as important as the physical aspects. There is support connected to healthcare, municipality based care, work life, school, religious organizations, and associations that can help you through tough times. You don't have to go through it all-alone. Information about financial, practical and social support can be obtained through your treatment team. There is also information available on several websites, including those of your municipality, Försäkringskassan, or on www.1177.se. If things get difficult or complicated you can get help from the counselor in your treatment team or at your health care center.

A periodically turbulent journey

There are moments during your cancer journey when there is a greater risk that you will experience high levels of stress or anxiety, for example, when receiving the cancer diagnosis or before surgery. You can also feel more anxiety when hormonal- or chemotherapy starts or when the treatment ends.

It's completely normal that you feel fear or anxiety over the cancer returning for several years after completed treatment. Some find it particularly hard when it's time for a new post-treatment checkup.

A relapse can mean a range of new challenges. Many think that being told the cancer has come back is harder to handle than the initial cancer diagnosis. If you are faced with handling a relapse, you can experience more anxiety and uncertainty.

As we mentioned previously, your cancer journey is to a large extent affected by who you are and where you are in life. You can have a harder time dealing with the cancer illness due to your age, family situation, or other reasons.

- **If you are young**, you might worry more about how the cancer illness is affecting a partner, child, or others close to you, and they in turn may feel isolated.
- If you have **problems with your partner or within the family**, you may feel that they are not getting enough support.
- **If you are alone**, you may feel isolated or scared to start a new relationship.

*If you are alone you may feel
isolated or scared to start a new
relationship*

- **You who have kids** can have a bad conscience about how the illness is affecting the kids, and you may also worry about finances and childcare.
- **If you have experienced stressful events earlier in life**, you can feel additional pressure during the period of illness.
- **If you have financial problems** you can be burdened even more by the additional costs associated with treatment and absence from work.
- **If you have been previously affected by depression or anxiety**, you are at a greater risk of being affected again.
- If you have had **problems with alcohol or drugs**, you may experience more emotional stress.
- **As a woman** you run a greater risk than a man of having anxiety or depression and have problems with sexuality or your body image.

The list can go on longer and it's obvious that the cancer journey is experienced differently depending on personal circumstance. If you on top of this come from a different cultural background and mother tongue, you can feel isolated or think that your personal and cultural convictions clash with Swedish health-care.

If you are aware that the points mentioned above make you more vulnerable then you, people around you and your treatment team, better deal with certain challenges proactively. If you feel that you have some kind of 'baggage' that makes you more vulnerable it is good if you bring it to attention in your contact with doctors or nurses.

How do you know if what you are experiencing is normal?

You don't, that's the short answer. If you were able to get rid of the thoughts and doubts surrounding what you are experiencing, feeling and thinking is different, and that everyone else seems to handle their ordeals much better, your eyes would most likely never have rested on this text.

Sometimes you will struggle to assign words to your feelings, you might even feel like you are the only one in the world that can feel that this is weird. If we can afford ourselves a small joke, we can say that it's normal to feel abnormal. There are simple tools and support that can help you disentangle your thoughts and express your needs. One example is the checklist in the chapter "Your Baggage" further on in the book. It helps you explain what your feeling; to yourself, to your surroundings and in your contact with healthcare.

A well worn expression is that you should talk about how things are going, preferably about everything and with everyone. There's actually a very good point here. You are a human being, and thus a social being, that through the interaction with others also gets a better understanding of yourself.

Taking part in a discussion about what concerns you can therefore be a great help along the way. It does not matter if it is with someone close to you, a stranger, healthcare professional, or a member of an association. It also does not matter if you are mostly speaking or listening, if it's in a group of people or online, anonymous or personal - find the channel that suits you best.

***There are simple tools and support that
can help you disentangle your thoughts
and express your needs.***



EXISTENTIAL CHALLENGES

You know what it's like to live, you have been doing it ever since you were born. You have a fundamental outlook on your life and you have certainly, more or less consciously, reflected over who you are and what you want the meaning of your life to be. Dreams, longing and aspiration for goals and meaning.

Then came cancer, properly upsetting the fundamental building blocks that your life has so far rested on. During your cancer journey you will be faced with tough life decisions and reflect on them in a way you haven't done earlier.

Death – How does one relate to the concept of no longer existing? All people die although no one knows what happens afterwards.

Loneliness – You can discover that there are parts of you and your innermost self that you don't share with anyone, and there you are completely alone.

Meaning – What is the meaning of your life? Does it differ now from what it was before cancer? Every human being must find his or her meaning.

Identity – Who are you? If you change due to illness or lose abilities you used to have, what is then left of you as a person?

It is important to meet and process reflections on and thoughts about meaning and existence. What we choose to do can be different from person to person, the important thing is to not forget the questions. You can, among other things, get help from a psychologist or spiritual counselor, for example, the hospital church.

About crashing once in a while

You might have heard “it’s ok to feel” before, and you should know that it really is. It’s also ok to fall apart once in a while and think that most things, or everything, are hopeless. If we count the period of time that a cancer journey covers, it is often more than a brief parenthesis in a life. The cancer ghost can whisper of relapse and death, and continue to be an unwelcome companion throughout life. If it hasn’t already happened that you have felt like everything came tumbling down and you completely lost your composure and control, it could be good to keep an open mind to the prospect that these moments can come. You who have been thrown on this cancer journey will also find that you have a lot of resources and strategies to deal with the journey’s challenges. There is also help and support to get from your own network and from the healthcare and the society.

People who have ended up in addictions often use the word setback rather than relapse. They do that to keep the mantra: “sure it’s one or a couple of steps back, but at least I am not back at square one”.

All challenges you have faced so far in life and those associated with cancer illness are never a waste, even if it may feel like this once in a while.

If it hasn't already happened that you felt like everything came tumbling down and you completely lost your composure and control, it could be good to keep an open mind to the prospect that these moments can come.

When the journey becomes lifelong

Several forms of cancer are chronic, which means that the cancer cannot be cured. You who have chronic cancer, or you who are close to someone with lifelong cancer, live with the illness next to you every day for the rest of your life. Practically, it means regular contact with doctors, healthcare professionals and medication, but also relates to the fact that life has taken on a new turn. It's tough to "just" get a cancer diagnosis and to, on top of this, find out that cancer is here to stay; this turns your life upside down. A lot of people feel great uncertainty about the future and additional anxiety for how life will be together with the illness.

One way to gather strength, and to find a way to keep living when the cancer journey becomes lifelong, is to meet others with chronic cancer. It can be both inspiring and healing, for both you who has cancer and you as a significant other.

Let what's most important to you be your compass

What do you think matters in life, what things are meaningful and what do you want your life to stand for?

These are big questions that are always important even if they are more or less present in everyday life. They have been your compass to get directions and goals in life; like when you chose your education, career, fell in love or ended relationships, chose to become a parent or not, planned your life as a retiree and so on...

Having been thrust on the cancer journey many of the big questions will be put on a fine point, which is why we want you to know that your life questions will continue to be just as important even on this journey.

Right now it might be mostly about thinking about yourself, or someone close to you, getting better, living on, avoiding pain and these goals, of course, take up a lot of room. At the same time you might be more dependent on your life compass than ever before.

What mattered to you before cancer entered your life is most likely still just as meaningful. During your cancer journey you will face decisions regarding treatment and other things associated with the illness. Decisions where you need to get a clear sense of direction.



CHALLENGES ASSOCIATED WITH SEX AND INTIMACY

Whether you are young or old, straight or gay, man or woman, healthy or ill, with partner or without, sexuality is a part of your life. With cancer your sexuality will be affected, at least periodically. The illness changes your lust and function both for you who have cancer and you as a partner. Some treatments affects lust and ability directly physically, and so also does the stress that a cancer journey represents. Side effects, changed self-image, disdain, stamina and fear of making your partner hurt or sad are examples of physical, mental, social and existential challenges associated with sexuality.

If you, before you got ill, found it hard to speak about your sexuality, it won't automatically get easier during a cancer journey. Since sex is a source of pleasure, intimacy and good health, it's important not to push problems with sexuality to the side.

If you experience problems associated with sexuality and intimacy, bring it up with a doctor or nurse in your treatment team or at your health care center. They can give you information and advice but also connect you with others that can help, for example, a sexologist.

The Swedish Cancer Society (Cancerfonden) put together good information about sex and cancer. The information is available as a brochure on their website. RFSU has information about sexual-technological aids that can be of help during and after cancer treatments.



THE FELLOW TRAVELLER – being related

In this book we want to talk to you as the cancer affected, meaning both to you as a cancer patient and to you who are close to someone who has or have had cancer. Sure, the perspectives are in some ways different if the cancer has invaded your body or that of someone close to you. At the same time both are involuntary travellers on a journey that no one wishes to take. As a partner, friend, child, parent or colleague, you can struggle to deal with the situation you have found yourself in and maybe also need support. It can even be that you sometimes experience more stress than the person who has cancer and you can have different needs for information. For you who are the child of someone who has cancer it is particularly important that your needs are brought to attention. You can become particularly stressed if you are not able to talk about both cancer and thus need support on your journey.

Both as a cancer patient and significant other, you may notice that friends and colleagues don't know how to talk to you about cancer and that they may even withdraw themselves. At the same time others may turn out to be surprisingly good support.

On www.1177.se/cancer you can find good information for you as a significant other.

Children and adolescents

You who are a child or adolescent will also be affected if someone who is close to you has cancer. You may have to help out more at home? Maybe you feel as if you are brushed to the side? Maybe you are angry or have feelings of guilt? All of this can make it hard for you to focus on school and extracurricular activities and you might experience that your relationships with friends change. Just like adults, you as a child can experience physical, mental, social and existential challenges during your cancer journey. Your friends can be fantastic support but it can also be important to find an adult you can talk to about how you feel and what you need.

Healthcare has a particular responsibility for you who are a child or adolescent - to make sure that you get information about what is happening and that your needs are met. Healthcare counselors, doctors and nurses are also there for you, and you can also get support and help from your school's student health section.

Näracancer.se is a website for you who are an adolescent and is close to someone who has cancer. There you will meet other adolescents in similar situations and can get answers to your questions from healthcare professionals. On top of that, there is the Children's helpline at BRIS on telephone number 116 111 and the Red Cross on-call chat buddy.

You who are adolescent may have to help out more at home? Maybe you are angry and have feelings of guilt?

Living on

Someone you care about has maybe recently died from cancer and as a significant other your cancer journey has come to a tough stop – about living on even though the other person is no longer there.

It is a huge stress when someone close to you dies. You may feel that stress mentally, in the form of loneliness and hopelessness, and you may become restless and anxious.

Stress can also find its way into the physical body – you may get stomach pains and aches in muscles and bones.

We all grieve differently and there is no right or wrong way, but most of us go through the four phases of sorrow. These phases don't have to happen consecutively, but often shift back and forth.

1. Shock phase

It is hard to understand that the person you care about is gone. You can walk around in a bubble and struggle to accept what is happening around you. The shock phase often lasts for a shorter period.

2. Reaction phase

When the shock lets go feelings such as despair, anxiety, anger, longing, and abandonment arise. You can be completely preoccupied with sorrow and have no energy to do anything else. This period can last from weeks to months.

3. Processing phase

You are still thinking about what has just happened but you are starting to get a perspective on your loss and understand how it will affect the rest of your life.

4. Reorientation phase

After a while most feel that they both can and want to move on with life. It doesn't mean that you are forgetting the person who died. The feelings of loneliness and longing are still there, but they no longer dominate your everyday life.

You can get support in your grieving process in many ways and not only from family and friends. It's important to remember that also children need help to process what has happened, which can be hard if you are in shock or dealing with your own grief.

Healthcare offers professional help for you to move on with life. The Church of Sweden and other associations often offer support calls. For children and adolescents there are, among other things, the Children's helpline at BRIS on telephone number 116 111 and the Red Cross on-call chat buddy.

Suggestions and advice from a significant other

- Show that you care. Being close to someone who is ill is about letting go of your own focus and sharing yourself with another person. It's about showing that you care without taking up too much room. Letting go of your own priorities and simply being there when someone else needs you will get you a long way. Taking time off to go with on hospital visits could be invaluable.
- Listen. If a person needs to ventilate his or her thoughts then let the person finish. The last thing one needs is to be interrupted when it is important to speak out about thoughts and feelings.
- Be open about how you feel. Talk to friends and family. Ventilate. It's a part of the process to deal with the situation yourself. You are no superhero. It's easy that you start overthinking things and eventually end up in some kind of state of depression. Then you are really not doing any good, for yourself or for the person with the illness that needs support.
- Never forget yourself. You are also affected by what has happened. Don't have a guilty conscience for needing time on your own. Are you feeling bad and need time for yourself? Take it. There is no right or wrong in that, what matters is how you are feeling. We all need our time to breathe.
- Change environments once in a while. Especially if you are really close to someone who is ill. It's natural that your entire life starts circling around cancer (which isn't wrong), and that's when it can feel good to change environment and have a chance to breathe sometimes. Spend time with friends, go swimming or go on a holiday. It doesn't have to be complicated, as long as you do it.
- Get help if you need it. If the entire situation becomes too much to handle then don't be afraid to get the help for significant others that healthcare offers. There is nothing strange about it, you are only human and sometimes things simply become too much to handle and process on your own...

(Source: www.patrikjarl.se)



SUPPORT ALONG THE WAY – a practical guide for the involuntary traveller

It is very important that you get support during your cancer journey. With good support from family, friends, healthcare professionals and other support from society, the cancer journey can be made easier.

The cancer journey seldom follows a clear-cut path and you can't always predict what will happen along the way. To talk about feelings, anxieties and challenges can make the journey a lot easier. It can also help you come to understand the problems that you are confronted with. It is important that you know that there is help and different treatments that can improve the quality of your life dramatically.

You might be helped by talking to your partner, a friend or family member who makes you feel safe. You may prefer to seek help within healthcare or from someone who has been through a similar experience. If you experience physical, mental, social or existential problems there are different supports, tools and treatments that can help you move on.

Apart from your social network there are several members of your treatment team and at your health care center that can support you through your cancer journey.

Within cancer care the psychological care, the practical support, the physiotherapeutic treatments, dietary advice and more are referred to as cancer rehabilitation. Cancer rehabilitation focuses on the entirety – it takes into account social situation, spiritual convictions and individual affairs.

Practical suggestions along the way

– **Ask to** receive all the information you need about your, or your loved ones, cancer illness. It can reduce feelings of anxiety and hopelessness. Writing a list of questions to bring with to the doctors appointment can be a good idea. Another idea could be to ask your doctor if you can record the oral information given to remember it better after the meeting.

– **Bring a** family member or friend who can help you remember what is said and who can be a support.

– **If you** are close to someone with a cancer illness, dare to express what kind of information and support you need. It helps both you and the person you are close to if you have enough information and can handle the cancer journey.

– **It's ok** to ask for a second opinion if you feel that you need more information or if you don't think that your concerns are being addressed.

– **It can** often help to acknowledge the challenges you face and deal with them as they arise. Avoiding discussing physical needs, emotions and thoughts can increase anxiety.

– **It can** help if you are flexible when it comes to handling your own or your loved ones illness. During the cancer journey there can be some sharp turns and it is hard to get and feel like you have control of the situation.

– **Exercise and** eat healthy and balanced, a lot of fresh fruits and vegetables. It is important for your well-being.

– **If you** use tobacco it could be a good idea to stop and improve your health.

– **Do things** you like to do!

What can help?

Certain treatments can help you handle the physical, mental, social, and existential challenges that the cancer journey represents.

If you worry a lot, a psychologist or psychiatrist can help you with certain psychological and medical treatments that can improve the quality of life, reduce anxiety and depression and some physical ailments.

Being able to talk about your cancer illness and about how you feel can help

you deal with anxiety. Support groups give you the opportunity to meet and talk to people who have been through, or are going through, a similar experience to yours.

Support groups are not for everyone, so don't feel forced to join one. If you are not comfortable in groups you may prefer to talk to someone privately. The meetings don't have to be done face to face, but can also be held via telephone or online. For you, who are not living in any of Sweden's major cities, this will be perhaps the only option, since support group activities are not found all over the country.

Some hospitals and health care centers also offer programs where you and people close to you can get information in groups about cancer and discuss it together.

Family or couples counseling can help you and your partner talk about what is happening and the challenges you face.

A physiotherapist can design a tailored program. In addition, exercise in groups or in swimming pools help you with several physical challenges. On top of that, physical activity produces a better general condition and counteracts mental problems.

Occupational therapy efforts help you to continue being part of everyday life, at work and during your spare time.

Dietary advice, special diets, and nutritional drinks can be of great help in conjunction with treatment.

Who can help?

Occupational therapists offer practical support to help you conquer physical problems and obstacles at home or at work.

Dieticians help you with eating and nutrition problems, and also to maintain a healthy diet.

The contact nurse is a key person of your cancer rehabilitation. The contact nurse is responsible for that you as a cancer patient get an individual treatment plan that identifies your rehabilitation needs.

Counselors can offer advice about finances, offer practical support and counseling. In addition, some can perform psychological treatments for anxiety

and depression. They can also offer emotional support when needed, which can include supporting family members.

Speech therapists help you when you have trouble speaking, eating or swallowing.

Doctors also assess and treat you during cancer rehabilitation and are a link to a range of competencies that can offer support and treatment during the cancer journey. The doctor is responsible for sick leave and can, when needed, prescribe medication.

Psychiatrists are doctors that specialize in mental health and how the brain works. They can, in addition to offering counseling, also treat conditions such as depression and anxiety and, if needed, prescribe medications.

Psychologists offer advice and psychological treatments to help you with, for example, depression, anxiety, and existential challenges.

Physiotherapists offer advice and treatments to allow you to retain your mobility and feel less pain. Physiotherapists with special training can also solve physical problems, such as lymphedema.

Nurses can provide support during the entire cancer journey. Nurses in general have a lot of experience helping people deal with physical challenges and know the psychological challenges that cancer patients are faced with.

Spiritual counselors are people from the church and other faith communities that can help you with questions that concern belief and existential challenges. They can also help you to be included in the support that is organized through faith communities, for example, support groups, and financial and social support.

Tangible help from society

Support for significant others: All municipalities have significant other consultants so that significant others can get relief and practical assistance.

Occupational rehabilitation: To be able to continue working even after you have gotten cancer is important in order to feel as good as possible. You have the right to get support to get back into working life in a way that suits your current situation. If you have employment then it is the responsibility of your employer to make sure that you get a proper rehabilitation. If you are not employed it is the responsibility of Arbetsförmedlingen together with Försäkringskassan.

Accommodation: From your local municipality you can get help with, among other things, adapting your accommodation, domestic help services, and access to various aids.

Financial: Becoming ill is often a strain on your finances. Information and compensation in connection to illness is available at Försäkringskassan. To be able to keep your costs down in relation to care, there are certain high-cost protections you can get via your county council or region. The municipality also offers financial support for you who have been affected by the illness.

Transportation: Illness can make it hard for you to move around on your own by bike, car, bus or train. You need to be able to move around freely without depending on your family and friends. County councils and regions are responsible for trips to and from care providers. To get transportation service you need to contact your municipality. The municipality is also responsible for providing you with the special permit you can get to be able to park your car on the marked parking spots for the disabled. Should you have lasting difficulties moving around there is a special car support that you can apply for at Försäkringskassan.

Personal assistant: If you are under 65 years old and have severe disabilities and in a great need of help in everyday life, you can get help from a personal assistant.

Support groups: Healthcare offers both you as a patient and you as a significant other to participate in education and support groups. Patient organizations along with different faith communities can also offer support group activities. The purpose is to raise your self-esteem and manage anxiety.

Meetings
don't have to
be done face
to face, but
can also be
held via
telephone or
online.

How do I ask for help?

It can be hard to talk about how you are coping with the situation you are in. You may feel that you can't put your feelings into words. You may feel troubled, that you don't want to be a burden, or that the doctor is too busy.

Here are some suggestions of how you can make people aware and talk about your physical, mental, social and existential needs. They are for both you with cancer and you as a significant other:

"Lately I've had troubles sleeping/felt rather down/ felt that I don't have the energy and I've heard that there are treatments that can help. Can I talk to you about this?"

"I am in pain/feel weak/can't handle things physically to the extent I wish. What support is there to get?"

"I haven't been dealing with this as well as I wanted to and I feel that I could use some help. Do you know if there is support to get?"

"I am struggling to get everyday life to work and need help with examining what support I can get."

"I read something about psychological care for cancer survivors, where can I get that?"

"I've realized that I sometimes struggle to keep up with things and would like to talk to someone about that."

"I feel like I have lost my meaning and direction in life since cancer. I need help!"

"I don't know how my children are coping with this and how I should talk to them. I think we need help."

"This sex thing isn't working at all right now and it makes me anxious and creates frustration. What can I do?"

You can struggle to ask for help. Just remember that a lot of people seek different forms of support on their paths through life, for many different reasons, and that you are also worthy of good support.

You can talk to anyone on the treatment team or at the health care center about any physical, mental, social or existential questions you can have. Choose someone you trust and feel safe with; maybe a nurse, doctor or counselor. They can make sure that you can get in contact with the person that is most appropriate to help you.

You may also feel that you struggle to keep up with things but don't want to seek professional help. You may feel that you are fine on your own with the help of the advice you receive from your doctor. It is good to seek help if you need it, but it is also good to manage things on your own with support from family and friends. The important thing is that you continue to be aware of how you feel physically, mentally, socially and existentially. Also, be alert to how you react to stressful events and to changes in your state of mind, feelings and level of energy.

You can also get support with how to proceed with your problem, what type of help that may be good for you and where to turn to.

If you decide to seek help from your GP or someone on your treatment team, make sure that you get in touch with the people that are most suited to help you. It could be a specialist such as, for example, a social worker, advisor or psychologist, or maybe a support group. If you are recommended to see a specialist within healthcare you can call them directly to book an appointment.

To be able to talk to someone who is interested in your problems and can help you with expressing yourself can be of great help. It can also help you to better understand your problems and your anxiety, and explore new ways in which you can handle your situation. Many experience this as quite calming and feel relieved and hopeful. Read more in the previous chapter "Who can help?".



NATIONAL CONTACTS

Where can you turn if you need more support or information? In case you are in contact with a treatment team within cancer care, with a contact nurse, in contact with a health care center or in contact with a patient association, you should always feel welcome to raise the questions that are important to you in these contexts.

On www.thecancerjourney.se there is also a form where you can compile and update the contacts that are important to you personally. Below is a list of websites and telephone numbers that can be good starting points for the planning of your onward journey.

1177 Care guide – you can, at any time of the day, call the phone number 1177 and get answers to your questions surrounding illness and care. On the website www.1177.se you can also ask questions anonymously.

www.1177.se/cancer – here you will find information about cancer and can share experiences of other people in reports, chronicles, and films. Here is also up to date contact information of the following associations. www.1177.se/cancer

- Barncancerfonden (Childrens cancer)
- Blodcancerförbundet (Blood cancer)
- Bröstcancerföreningarnas riksorganisation (Brest cancer)
- CARPA (NET cancer)
- Gynsam (Gynecological cancer)
- ILCO (Stoma and reservoir operated)
- Lungcancerförbundet Stödet (Lung cancer)
- Mag- och tarmförbundet (Gastro and colon)
- Melanomföreningen (Melanoma)
- Mun- och Halscancerförbundet (Head and neck cancer)
- Nätverket mot gynekologisk cancer (Gynecological cancer)
- Prostatacancerförbundet (Prostate cancer)
- Svenska hjärntumörföreningen (Brain cancer)

The Swedish Cancer Society – you can reach the Swedish Cancer Society’s information and support line by phone 020-59 59 59. On their website there is good information available regarding cancer illness, treatments and living with cancer. There you can also get in touch with others and share your experiences. www.cancerfonden.se

The National Helpline (Nationella hjälplinjen) – The helplines on-call telephone service offers psychological help for people in mental crisis and difficult living situations. Call 020-22 00 60.

The Network Against Cancer – cooperation between cancer-profiled patients and NGOs at national level. Works to highlight important common questions that apply to cancer care in Sweden. www.natverketmotcancer.se

Especially for you as an adolescent

Näracancer.se – a website addressed to adolescents aged 15-25 years old and those who are close to someone who has cancer. Here you can meet other adolescents in similar situations and get answers to your questions from hospital staff. www.naracancer.se

Ung Cancer – an association for those who are between the ages of 16-35 years old and affected by cancer, regardless of if you are a patient or significant other. www.ungcancer.se

Especially for you as a significant other

Anhörigfonden – an independent foundation that works to provide support to the significant others of cancer patients. www.anhorigfonden.se

Cancerkompisar – a not-for-profit organization that operates a mediation service where significant others of those affected by cancer can get in touch with other people in the same situation. www.cancerkompisar.se

More about cancer rehabilitation

CancerRehabFonden – a not-for-profit organization that contributes with resources to those affected by cancer illness. www.cancerrehabfonden.se

Regional Cancer Centers in cooperation – conducts development of Swedish cancer care according to the national cancer strategy. www.cancercentrum.se

Regional Cancer Center south – supporting RCC for the national guidelines for cancer rehabilitation. www.rccsyd.se

SWEDPOS – association of psychosocial oncology and rehabilitation, that offers multi-professional factual knowledge within cancer rehabilitation www.swedpos.se



PRACTICAL TOOLS

– finding your way home

Here we present some simple tools that can help you:

Your Baggage: A checklist and simple estimation to draw attention to your needs during cancer rehabilitation. You can use it as a basis when talking to doctors and other healthcare professionals. In your contact with cancer care you will probably encounter an assessment tool called the Distress thermometer, which is used within cancer care in Sweden and abroad.

Your Travel Itinerary: within healthcare it is called an individualized care plan. It should help you to identify what is important to you, what challenges need attention, what goals and actions can help you further on, and finally follow-ups on your progress. You can use your plan as a basis when you talk to your doctor and other healthcare professionals.

Your Checklist: Here you can compile important questions and topics that you want to bring up when you are visiting your treatment team, your health care center, and in your contact with authorities such as Försäkringskassan.

Your Important Contacts: A comprehensible list of where to turn for more information and support. In the previous chapter you will find a brief national contact list. In addition, at the back of the book there is the possibility of inserting a personal contact list where you can put local and regional contact information. You can also download the contact list directly from www.thecancerjourney.se. Here there is also a version for you as a significant other. Update your contact list as you get new contacts.

The
checklist
helps you
see your
needs for
support and
treatment.



YOUR BAGGAGE – assessing your needs

You might know of the pain scale, where you are asked to describe your degree of pain on a scale from zero to ten. Anything above five indicates significant pain. Just like with the pain scale you can use the checklist, see next page, to specify the extent of stress or strain you feel on a scale from zero to ten, on both physical, mental, social, and existential challenges. You can fill out the checklist while you wait for a treatment or meeting with your doctor, and it then forms the basis of your “Travel Itinerary”.

When you are using the checklist you are asked to estimate the degree of stress/strain you have experienced during the past week. The scale ranges from “no stress/strain” (zero) to “extreme stress/strain” (ten). A higher value might be a signal that you need some form of professional help. See the scale only as a simple guide where your own feelings and your own assessments of which support and help you need are the most important.

To help you with this, there is a list of areas where you can feel stress/strain, a list of problems others are faced with, and a list of available support. Please select the problem you have noticed during the past week and what kind of support you think you need. If you are missing an alternative you can write it down on an empty line.

The purpose of the checklist is to help you and your treatment team to draw attention to your needs for support and treatment. Simply put: your rehabilitation needs! If you want to use the checklist several times it is available at www.thecancerjourney.se.

What specific problem/problems have contributed to an increase in stress and strain in the past two weeks?

Put an X on the specific problems that feel relevant.

<input type="checkbox"/>	Breathing
<input type="checkbox"/>	Work
<input type="checkbox"/>	Troubles with balance
<input type="checkbox"/>	Childcare
<input type="checkbox"/>	Decisions about treatment
<input type="checkbox"/>	Accommodation
<input type="checkbox"/>	Depression
<input type="checkbox"/>	Diarrhea
<input type="checkbox"/>	Finances
<input type="checkbox"/>	Loneliness
<input type="checkbox"/>	Fever
<input type="checkbox"/>	Constipation
<input type="checkbox"/>	Hygiene
<input type="checkbox"/>	Health problems in the family
<input type="checkbox"/>	Identity/who am I?
<input type="checkbox"/>	Nausea
<input type="checkbox"/>	Anger
<input type="checkbox"/>	Itching
<input type="checkbox"/>	Concentration
<input type="checkbox"/>	Feeling bloated/swollen
<input type="checkbox"/>	Digestion
<input type="checkbox"/>	Weakness
<input type="checkbox"/>	Meaning and context
<input type="checkbox"/>	Memory
<input type="checkbox"/>	Addictions
<input type="checkbox"/>	Mouth sores
<input type="checkbox"/>	Muscle weakness
<input type="checkbox"/>	Possibility of having kids
<input type="checkbox"/>	Sadness

<input type="checkbox"/>	Nervousness
<input type="checkbox"/>	Stamina
<input type="checkbox"/>	Problems urinating
<input type="checkbox"/>	Relation to children or family
<input type="checkbox"/>	Relation to partner
<input type="checkbox"/>	Fear
<input type="checkbox"/>	Mobility
<input type="checkbox"/>	Sexual problems
<input type="checkbox"/>	Healthcare insurance
<input type="checkbox"/>	Pain
<input type="checkbox"/>	Language and speech
<input type="checkbox"/>	Tingling in hands and feet
<input type="checkbox"/>	Studies
<input type="checkbox"/>	Troubles swallowing
<input type="checkbox"/>	Sleeping
<input type="checkbox"/>	Thoughts about death
<input type="checkbox"/>	Lost interest and desire
<input type="checkbox"/>	Dry skin
<input type="checkbox"/>	Dry mucous membranes
<input type="checkbox"/>	Transportation
<input type="checkbox"/>	Fatigue
<input type="checkbox"/>	Appearance
<input type="checkbox"/>	Troubles eating
<input type="checkbox"/>	Other problem:
<input type="checkbox"/>	Other problem:

Put an X next to the color that describes you best. Mark how you are feeling with the help of the colors below. Red is high stress/strain and green is low.



Put an X on the specific problems that feel relevant.

Within which area/areas do you experience an increased stress and strain now?

<input type="checkbox"/>	Existential challenges
<input type="checkbox"/>	Physical challenges
<input type="checkbox"/>	Social challenges
<input type="checkbox"/>	Challenges related to sex and intimacy
<input type="checkbox"/>	Physical challenges

Based on the stress and strain I experience I think that I would need to get in contact with the following people:

<input type="checkbox"/>	Occupational therapist
<input type="checkbox"/>	Dietician
<input type="checkbox"/>	Counselor
<input type="checkbox"/>	Speech therapist
<input type="checkbox"/>	Doctor
<input type="checkbox"/>	Support person (organization/association)
<input type="checkbox"/>	Psychiatrist

<input type="checkbox"/>	Psychologist
<input type="checkbox"/>	Sexologist
<input type="checkbox"/>	Physiotherapist
<input type="checkbox"/>	Nurse
<input type="checkbox"/>	Spiritual counselor
<input type="checkbox"/>	Other contact:

Rehabilitation
is also about
how you feel
inside. To
see the whole
you.



YOUR TRAVEL ITINERARY – making an individual plan

In order for you to feel as good as possible during your cancer journey it is really important to consider rehabilitation already from the start. That way you can prevent and reduce problems that can come with cancer illness. Rehabilitation concerns not only the physical body but also how you feel on the inside and your relationships to other people. To see the entire you as a human being. In conjunction with you, as a patient, get in contact with cancer care, you will get an individual treatment plan established. In it, you and your treatment team will write down rehabilitation needs, goals and what actions need to be taken. You as a significant other also need a “travel itinerary”, which is why it is important that you talk about how you feel and what needs you have. Your health care center can help you with this.


On the next page you will find a simple plan where you can, using different circles, fill in:

Direction: What is important to you? Please read the chapter “Let what matters to you become your compass”.


Challenges: What kind of challenges do you encounter? Please read the chapters “Physical challenges”, “Mental challenges”, “Social challenges” and “Existential challenges”.

Steps: What can help and who can help? Please read the chapter “Support along the way”.

Hindsight: What steps have I taken and where did they get me? Please use the checklist “Your baggage” to check that you have accounted for everything. In preparation for your contact with healthcare it can be good to write down a brief checklist of things you want to know and that you want healthcare to pay particular attention to.



DIRECTION
What is important to you?



CHALLENGES
What kind of challenges
do you encounter?

STEPS

What can help and who can help?

HINDSIGHT

What steps have I taken and where did they get me?

Remember
that it is
about your
cancer jour-
ney and your
life – so
there are no
stupid
questions!



YOUR CHECKLIST

– communicating your needs

Healthcare that provides good information is very important, but most importantly is that you get answers to the questions that matter to you. Only you know what questions you need to have answered, which is why we don't offer any examples in the checklist on the next page. Remember that it is about YOUR cancer journey and YOUR life – so there are no stupid questions! On top of that, it is incredibly important that healthcare gets information about you.

It could, for example, be about drawing attention to:

- That you are facing important life events or milestones in your life. It can be possible to adapt treatments so that they interfere as little as possible with your plans.
- That you are planning to become a parent and need to know how your cancer journey affects that.
- That you, for one reason or another, lack or have a limited network of significant others.
- That you have elderly parents that are affected by your cancer journey.
- That you have with you vulnerability from earlier in life that can affect your cancer journey.
- That you have children near you that will also be affected by your cancer journey.
- At www.1177.se/cancer there are lists with suggestions of questions to ask when visiting doctors and nurses.



I feel that I need to know about this:

These functions are important to me to maintain and fight for:

I feel that you within healthcare need to know about me the following:

Important contacts for me during my cancer journey:

Name	Role	Contact details



TOGETHER WE CAN MAKE THE CANCER JOURNEY MORE EASILY NAVIGATED

– www.thecancerjourney.se

During our work with “The involuntary traveller” we have encountered the commitment and ingenuity of those affected by cancer. That also led to thoughts regarding what genuine patient and significant others’ influence is about:

As a person affected by cancer you are a specialist in yourself and the needs you have. You also have the “travellers” perspective and thus a unique competence for what can improve the journey that those affected by cancer must undertake. It really should be you who tell healthcare and society how things should be and function. At the same time, it is our experience that this is rarely the case, and that this competence is not properly harnessed within research, healthcare development and societal planning.

Together we can change that!

We believe that there is an abundance of good ideas “out there” – ideas that can shape projects – projects that can make the cancer journey more easily navigated for everyone involved. “The involuntary traveller” is the beginning of a project to actively harness your, and others affected by cancer, experiences, ideas and commitment.

The website www.thecancerjourney.se constitutes the bud of this project and there you can:

- Find forms and other material pertaining to the book.
- Reconnect with what you think about the book, good and bad, and discuss and give suggestions for support, services and functions.
- Support and participate in projects that is pushing development of the cancer journey from the perspective of those affected by cancer.

We warmly welcome you to influence and work together with us!

SECTION FOR YOUR STUFF

Here you can gather information and material that is important to you. It can be one of the forms that are available at www.thecancerjourney.se or information you have received from your treatment team, Försäkringskassan, or someone else.

At www.thecancerjourney.se you will find the following material that is appropriate to have in this section:

Your important contacts – a form for collecting important contact details. One version for you as a patient and one for you as a significant other.

Your baggage – a checklist that you can use as a basis for assessment and discussion, either for yourself or together with your treatment team.

Your travel itinerary – a form for planning what steps you can take and what support you need.

Your checklist – a form for collecting what is important to you.

Bring this with you when you meet your treatment team, your contact person at Försäkringskassan etc...

the involuntary TRAVELLER

This is a book for you who have been forced on an involuntary journey – the cancer journey. Whether it is you who have a cancer diagnosis or you are a significant other of someone with cancer, this is your book.

- Here you can find and recognize yourself in challenges you may face during your cancer journey – physical, mental, social or existential challenges.
- You will get help in defining and talking about what needs for support you have.
- The book contains tangible tools, good contact lists and examples of support offered by society.

“The involuntary traveller” has emerged from the close conversations and exchanges with those affected by cancer. The aim is that we, together, can make the cancer journey more easily navigated. This project continues at www.thecancerjourney.se

You are more than welcome to participate and influence!

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