Danish Cancer Society



# Help and Information

- If you or someone you care about has been diagnosed with cancer



# Dear reader

This booklet covers some of the topics that may become relevant to you when you have cancer. Depending on your personal situation, not everything in the booklet may be relevant. The booklet also outlines your options for counselling with the Danish Cancer Society. If there is anything you do not understand or if you need any more information, please do not hesitate to contact us.

The Danish Cancer Society is a patient association devoted to cancer-related research, prevention and patient support. We provide free counselling for all cancer patients and their relatives. If you do not speak Danish or English, we can book an interpreter. This service is free of charge. You can contact us in either Danish or English to book a session with an interpreter. If you cannot express yourself adequately in Danish or English, you are welcome to have somebody else book the session for you.

With warm wishes, The Danish Cancer Society



Cancer Helpline +45 80 30 10 30

# Just after being diagnosed with cancer

For most people, being diagnosed with cancer is a severe and life-changing event. It can totally disturb your everyday life and you have to come to terms with a new reality.

There is no one particular reaction to a cancer diagnosis – either as a patient or a relative. Some people really need to talk about it, while others feel better keeping it to themselves. Your reaction is the right one for you. If you and your relatives have different ways of tackling the situation, try to accept that and accommodate each other.

It may take some time before the final diagnosis and treatment plan are settled, and the vast majority of people find this period of waiting tough. Many people find themselves on an emotional rollercoaster ride – shifting from worry and anxiety to a belief that everything will turn out fine. Bear in mind that the term 'cancer' applies to many different diseases, and that not one case of cancer is exactly the same as another.

# 3 tips for you



While waiting for the diagnosis or the result of tests and scans, it can be frightening to hear and read about cancer and other people's cases. Try to concentrate on what you know about your situation at that moment. Every case of cancer is different, even though the diagnosis is the same.



Do not expect to accomplish everything you usually do. It is normal to spend a lot of time and energy worrying, until you know exactly what you are up against. Many people find it easier to cope with the situation once they know their diagnosis and what their treatment plan will be.



If you need advice, call the Cancer Helpline on +45 80 30 10 30. If you do not speak Danish or English, you have the option of booking a counselling session with an interpreter. Counselling and interpretation at the Danish Cancer Society are both free of charge, and both services are available to all cancer patients and relatives.

# Cancer and treatment

Cancer is a disease of the cells that occurs if, somewhere in the body, the cells start to grow without control or purpose. Even though we refer to cancer as a single disease, the word 'cancer' applies to many different types of cancer. The stage of the cancer and if it has spread to other parts of the body also make a difference.

Your cancer treatment will be planned to treat you and your specific cancer. The three most common methods of treatment are surgery, chemotherapy and radiotherapy – and sometimes a combination. For hormonesensitive cancers, antihormone treatment is also common. In recent years, a number of other therapies have also emerged. These include immunotherapy and a special form of particle therapy (radiation therapy).



# Consultations with the doctor

Prepare for any consultation and write down your questions, so you will remember them. If at all possible, bring a family member or friend to the consultation. It can be useful for two people to hear all the information, ask questions and keep track of the process. It may also be a good idea to ask the doctor if you can record the conversation so you can listen to it again later.



# Ask questions

If you are in any doubt about your disease or treatment, ask the doctor who is treating you. You can always ask to talk to the doctor. You do not have to wait for the next ward round or appointment. There is no such thing as a stupid question!

Before you give your consent, you have the right to know how the treatment is expected to work and what side effects it may have. This is known as 'informed consent'. If, on the other hand, you do not want to know everything about your disease and treatment, you also have the right not to know. All you have to do is state explicitly that you do not wish to be informed



# Ask at the hospital

Refer to the hospital's patient counsellor if you have any questions about treatment, waiting times, patient rights etc. The patient counsellor can advise you about issues concerning the hospital you are referred to.





## Primary attending physician

Cancer patients must have a 'primary attending physician'. The primary attending physician is a named doctor at the hospital, who has overall responsibility for the patient's course of treatment. The primary attending physician does not necessarily perform the individual examinations and treatments you have to undergo. But he/she is responsible for ensuring that your course of treatment is safe and coherent.

### Maximum waiting times

There are rules governing how much waiting time there may be for examinations, treatment and aftercare. The region is responsible for ensuring that the maximum waiting times are complied with.





# Your medical records

If you wish to view your medical records, you can ask the healthcare staff for a printout. This is known as 'right of access to documents'. As a rule, you should get the documents within 7 days. If you have a NemID, you can also view some information from your medical records on www.sundhed.dk

# Cancer patient pathway

For the majority of cancers, your diagnosis, treatment and follow-up conform to an overall standard procedure, which is referred to as a 'cancer patient pathway'. The treatment is tailored to your specific case, based on an overall assessment of your needs and your disease.





### **Transport**

If you receive treatment in a hospital, you may be entitled to have your expenses for transport to the hospital paid. Ask at the hospital.

### Patient hotel

If you live far away from your place of treatment, you may have the option of an overnight stay at a patient hotel. Ask at the hospital.



# Side effects and late adverse effects (late side effects)

A number of people experience side effects and late adverse effects after their cancer treatment. Side effects are discomforts that usually disappear once the cancer treatment is completed. Late adverse effects are more prolonged discomforts that may occur during cancer treatment or after. If you experience side effects or late adverse effects, it is vital to talk to your doctor in order to receive the appropriate help.



# Get your teeth checked

If you are going to receive chemotherapy or radiotherapy, it is a good idea to have a check-up at your dentist's before starting treatment. If the therapy causes dental problems, you can only get financial support for the necessary dental help if you can prove that any damage was caused by the treatment.

# Looking after yourself

This chapter features topics such as food and exercise, and other issues that can help strengthen the body and mind when you have cancer. Do not expect to be able to do everything. Select what makes sense for you. When you have cancer, many things deplete your energy. Examinations, treatments, concerns and things you feel you should do because it is supposed to be good for you. When you cannot cope with everything, do not be hard on yourself. Permit yourself to do things you like – things that boost your energy.







### Keeping active

Physical activity — to the degree that you can handle in your current state — will help strengthen your body and prepare you for your treatment. It will also put you in a better mood, boost your energy and give you a better night's sleep. If you sit very still during the day, occasional movement can also make a big difference for your body and well-being. It does not have to be very much — maybe just walking around in your home or getting up and stretching your body.

If you want to start working out you may need to be careful with the activities you choose. This depends on your cancer and treatment. Your doctor or nurse can give you advice on this.

Many cancer treatment centres provide 'Body and Cancer' – a workout programme for cancer patients undergoing chemotherapy. If you would like to find out more, ask the staff. All municipalities also have exercise programmes for cancer patients.

### **Fatigue**

It is common to experience intense fatigue when you have cancer. Fatigue is quite different from ordinary tiredness. Fatigue is not caused by inadequate sleep, and sleeping more does not help. Nor can you beat fatigue by pushing yourself. Everyday chores such as emptying the dishwasher can be very exhausting. Try to accept the fact that, in your current situation, you will not have as much energy as usual, and organise your everyday life accordingly. Divide your activities into manageable chunks to prevent yourself from getting exhausted. Take note of your energy level from day to day. Use your energy on things that make sense to you. Exercise, mindfulness, relaxation and yoga can help with fatigue.



## Sleep

Sleeping problems are common. Thoughts and worries may take over, or pain that makes it difficult to relax. Sleeping badly for a period of time will not make your illness worse. However, if you have problems sleeping for a longer period of time, this may affect your mood and energy levels. One of the best things to do is to exercise and get some fresh air during the day. This will make you naturally tired and help you sleep better. Relaxation exercises and breathing techniques are also excellent tools for a good night's sleep. It is all about finding the solutions that work for you and help your body unwind.



#### Food

You can help strengthen your body and cope with your treatment by eating foods that will help you maintain your normal weight. You will probably hear a lot in the media or from your friends and acquaintances about what you should and should not eat. When you have cancer and are undergoing treatment, never forget that it does not necessarily apply to you. Your appetite and weight will determine what is healthy for you to eat. See which of the three options on the next page that suits you best.



1

### IF YOU CAN EAT AS USUAL AND ARE NOT LOSING WEIGHT

The same dietary guidelines apply to you as to everyone else. In other words, it is a good idea to eat wholegrains, fruits and vegetables, and fish and poultry rather than beef, veal, pork or lamb.

2

### IF YOU HAVE LITTLE APPETITE AND ARE LOSING WEIGHT

It is important to eat high-calorie, high-protein foods to prevent you from losing further weight and hopefully restore your normal weight. You should therefore ignore normal dietary guidelines for now. Talk to your doctor or nurse about what you can do.

3

## IF YOU HAVE DISCOM-FORTS THAT CAUSE EATING PROBLEMS

If, for example, you are nauseous or have difficulty swallowing, pain in your mouth or stomach and intestinal problems, you may need to consider carefully what you eat. Talk to your doctor or nurse about what you can do.



# Smoking and smoke

As far as possible, avoid smoking tobacco and exposure to second-hand smoke. If you are a smoker, it is a good idea to stop, even though that may seem very demanding in your present situation. It will create the best conditions for your treatment and reduce the risk of developing other diseases.



## Thoughts and emotions

Maybe you have heard about the importance of positive thinking for cancer patients. Forget it. It is both impossible and inappropriate to suppress negative thoughts and emotions such as anger, frustration and anxiety, all of which naturally accompany a serious illness. Conversely, it may be a good idea to talk to other people about your thoughts: friends or family – or anyone else with whom you can talk freely, and who is a good listener.



Having cancer is a stressful situation that often last a long time. Studies show that mindfulness has a positive effect on stress, anxiety and depression, even when you have cancer. You may also benefit from other exercises and techniques that will help calm you down and tackle your worries: for example, breathing and relaxation exercises or yoga.

The Danish Cancer Society's professional counsellors can help you cope with thoughts and concerns. We provide counselling in both Danish and English. If you need a session with an interpreter, remember to make an appointment for the session so we can book an interpreter for you – it is free of charge.

See the addresses of our cancer counselling centres on page 26-29. You can call the Cancer Helpline on +45 80 30 10 30.

# Cancer and everyday life

Cancer can affect your everyday life in different ways. This chapter touches on topics such as family, work and sick pay.







## Work and sick pay

Illness and treatment can both make it difficult to work, so many people are off sick for a period of time. Your workplace may need information about cancer and how to support you along the way. The Danish Cancer Society can help both you and your employer with information and advice on your situation.

### Insurance and pension

When you have cancer, it is a good idea to check your insurance and pension policy terms. Through their workplace or trade union, many people have a pension or life insurance scheme that gives them the option of a lump-sum payment in the event of critical illness. Most cancers are covered by such schemes. In some cases, the children of the policyholder may also be entitled to benefits.

If you travel abroad, it is vital to check whether your travel insurance covers you when you have cancer. If you have any doubt about your coverage, it may be a good idea to seek pre-approval from your insurance company.

On www.pensionsinfo.dk you will find a comprehensive overview of your pension savings, pay-outs and coverage. You will need to login with your 'nemID' og 'MitID' to gain access.



### DO WHAT FEELS RIGHT FOR YOU

Cancer is a disease that everyone knows about. Some people will, with the best of intentions, tell you stories about what it was like when their family members or friends had cancer. You may also find that other people have an opinion on how you should deal with your situation, what you should eat etc. Sometimes it can be helpful to hear about other people's experiences and get some tips. But it can also be overwhelming.

It is okay to speak up, when you do not feel like hearing about other people's experience of cancer. Follow your intuition and do what feels right for you. A counselling session at the Danish Cancer Society may help you to prioritise all the tips and information.



### Relatives

Just like you, your relatives are facing a new, highly demanding life situation. Some people find that they get closer to their family because of the cancer diagnosis. For other people, the opposite is the case. Either way, the majority have tough periods. Both you and your relatives may find yourselves feeling both hopefulness and uncertainty, optimism and anxiety. Occasionally, you will have different feelings and find it difficult to understand each other. You may also have different needs or desires in relation to what is happening.



# Children in the family

If you have children living at home, it is important to tell them that you are ill, and involve them in what happens along the way – on their terms. If you need counselling and information, the Danish Cancer Society can help you. The Danish Cancer Society's cancer counsellors provide group counselling for families. We can also book an interpreter for the session, if you need one.





# Relationship and sex life

Cancer can affect your relationship and sex life. If you and your partner are having problems with your sex life, talk to our counsellors, your doctor or a nurse. It may also be helpful to talk to a sexologist or to draw on the experiences of others who are or have been in the same situation. You can meet others with the same type of cancer as you via a relevant patient association. For contact information for individual cancer patient associations, visit:

www.cancer.dk/patientforeninger



### Rehabilitation

It is normal to experience physical or emotional problems after your cancer treatment. If they are likely to affect your ability to return to a normal everyday life you can get help. If you experience physical discomfort from the disease or the treatment. physical rehabilitation is available. Every municipality also provides a variety of health schemes to boost your possibility of returning to a normal everyday life: for example group counselling, dietary advice, psychological help etc. If you are hospitalised, it is up to your attending physician to assess whether you need physical rehabilitation or anything else, and to devise a follow-up plan with you. Feel free to take the initiative and talk to your doctor about it, since the plan must be devised before you are discharged. If you are not hospitalised, or if you need recurrent training or other health services, talk to your municipality or general practitioner.



# Someone to talk to – support and counselling

If you or your relatives need to talk to someone about your situation, the Danish Cancer Society is always here for you. You can talk to professional counsellors at our nationwide cancer counselling centres and on the Cancer Helpline. All our counselling services are free of charge. See the addresses of our cancer counselling centres on pages 26-29 or call the Cancer Helpline on +45 80 30 10 30.

If you need an interpreter for the session, remember to make an appointment for the session so we can book an interpreter for you.







If you do not have close relatives to support you and find it difficult to cope with all the appointments, examinations and treatments, the Danish Cancer Society's Navigator scheme may be something for you. This scheme assigns you a volunteer navigator who can support you in your contact with the hospital and help you cope with cancer. If you need an interpreter, we will book one.

Contact your nearest Cancer Counselling Centre if you want to know more about the Navigator scheme. See pages 26-29.



# Complementary and alternative medicine

Many people use complementary and alternative medicine to supplement treatment at the hospital. 'Complementary and alternative medicine' is a broad term and refers to many different kinds of treatment: for example, reflexology, acupuncture, dietary supplements and herbal remedies.

If you are considering taking dietary supplements or herbal remedies during your course of treatment, you should always talk to your attending physician first, since some supplements may adversely affect your cancer treatment.



Call the Cancer Helpline on

+45 80 30 10 30

or visit one of our cancer counselling centres.
 Go to pages 26-29 for contact information.



# Where to get help

The Danish Cancer Society provides counselling, information and support for you and/or your family.

All counselling services are free of charge. If you do not speak Danish or English, we can book an interpreter for the conversation.

You need to contact us in either Danish or English to book a session with an interpreter. If you cannot do this yourself, you are welcome to have somebody else book the session for you.



# The Cancer Helpline Call (+45) 80 30 10 30



Call the Cancer Helpline's professional counsellors if you have questions about cancer or need support and guidance.

We do not offer specific advice on treatment, but our counsellors can help you gain a sense of perspective regarding your situation, and answer general questions on cancer and treatment, symptoms, side effects, psychological issues, social rights, family life, exercise, diet and alternative treatment.

### Opening hours:

Weekdays 9.00-21.00 Saturday and sunday 12.00-17.00 Public holidays closed Chat: www.cancer.dk/chat Letterbox: www.cancer.dk/brevkasse Online counselling: www.cancer.dk/onlineraadgivning

# Nationwide cancer counselling centres

The Danish Cancer Society's cancer counselling centres are often located near cancer treatment hospitals. Feel free to drop by for a cup of coffee – maybe just for a short break when you are at the hospital. Our cancer counsellors provide professional advice for you and/or your relatives. If you do not speak Danish or English, we can book an interpreter for your session.

In addition we offer counselling by appointment in a number of towns (see the map on page 25). We also offer online and telephone counselling. If you need an interpreter for your session it is important to book the appointment ahead.

# Where to find us:





- Opposite the proposition of the
- Counselling services by appointment
- Ounselling services in cooperation with the municipality by appointment
- Ocunselling services provided by volunteers drop-in on certain days



All cancer counselling centres are on Facebook. Find them by searching for 'Kræftrådgivning', followed by the name of the town/city.

# Where to find the Danish Cancer Society:

To find the addresses of your local counselling services, contact the nearest counselling centre (listed on the following pages) or visit www.cancer.dk/raadgivning



# Counselling Centre Aalborg



# Counselling Centre Herning



## Counselling Centre Aarhus



## Counselling Centre Esbjerg



## Counselling Centre Vejle



# Counselling Centre Aabenraa



# Counselling Centre Odense



### Counselling Centre Næstved



## Counselling Centre Roskilde

Gormsvej 15 4000 Roskilde 870 20 26 48 □ roskilde@cancer.dk www.cancer.dk/roskilde



# Counselling Centre Copenhagen



# Counselling Centre Herlev

Borgmester Ib Juuls vej 2 2730 Herlev 70 20 26 55 herlev@cancer.dk www.cancer.dk/herlev



# Counselling Centre Hillerød

Østergade 14, 1. sal 3400 Hillerød 50 20 26 58 Hillerod@cancer.dk www.cancer.dk/hillerod



# Cancer Counselling on Bornholm

We offer counselling at the hospital in Rønne on certain days. Contact us to book an appointment:

# Cancer Counselling in Rønne (Bornholm)

Bornholms Hospital
Ullasvej 8
Opgang D, etage 0
3700 Rønne

38 67 10 31

roenne@cancer.dk
www.cancer.dk/roenne

## Other activities and services

### Cancerforum.dk

On the Danish Cancer Society's online meeting site, Cancerforum. dk, you can meet other people living with cancer. It is a place to share thoughts and experiences with people who have been through the same as you. Cancerforum.dk is for both patients and relatives, and there are different groups for different diagnoses and topics.

To find out more, visit:

www.cancerforum.dk

### Letterbox

In the Letterbox you can ask questions about cancer and life with cancer. You can also read previous questions and answers from the letterbox. To find out more, visit:

www.cancer.dk/brevkasse

### **Grants**

If you have limited income and economic resources, you can apply for a Danish Cancer Society grant for cancer patients and their relatives. To find out more and submit an online application, visit:

www.cancer.dk/legat

# App: 'Sammenholdet' (Solidarity)

This app makes it easy to communicate with, and coordinate help from family, friends and acquaintances when you have cancer. Download the app 'Sammenholdet' for free from the App Store or Google Play.

#### Patient associations

There are a number of patient associations that organise activities, where you can meet other people with the same type of cancer. To find out more, visit:

www.cancer.dk/patientforeninger

### Local associations

The Danish Cancer Society's local associations are run by volunteers who organise activities, raise funds and provide information etc. There is also a local association in your municipality. You can follow your local association on Facebook. Search for the Danish Cancer Society, followed by the name of the municipality.

Find contact information for all local associations here: www.cancer.dk/lokalforeninger

# Ung Kræft (Young Cancer)

Ung Kræft sets up meeting places throughout the country for young cancer patients between the ages of 15 and 39. To find out more, visit: www.ungkraeft.dk

### **OmSorg**

OmSorg provides support and inspiration on how adults can help children who have a sick parent or who have lost a parent. To find out more and for an overview of grief support groups for children and young people, visit:

www.cancer.dk/omsorg

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### Your support is important

Like the Danish Cancer Society's other counselling services for patients and relatives, this booklet is free of charge. You do not need to be a member in order to benefit from the Danish Cancer Society's services. However, if you wish to support us, we would be very grateful. The work of the Danish Cancer Society in the fields of research, cancer prevention and patient support depends almost exclusively on private contributions. Only 3% of our revenue comes from public funding

To find out more about how to support the Danish Cancer Society and what our funds go to, visit: www.cancer.dk/stoet-os

You are also welcome to call our membership service on (+45) 35 25 75 40 - from Monday to Friday between 9.00 am and 3.00 pm



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> The Cancer Helpline + 45 80 30 10 30 www.cancer.dk

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