

FOR THE NEXT-OF-KIN



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- 3 Introduction
- 4 Being next-of-kin – what does it mean?
- 8 Communicating with health care providers
- 10 The interaction between you and the one who's ill
- 12 When children and young people are next-of-kin
- 16 People's reactions
- 18 If you are a friend, colleague or employer
- 22 For more information
- 25 Five areas of importance in our work
- 26 Services across the country
- 28 Our offices across the country
- 29 The Cancer Helpline – someone to talk to
- 30 Patient associations that we cooperate with

**For the next-of-kin
- family, friend or colleague**
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Professional consultants have been hospital chaplain Hilde Marie Aarflot and cancer nurse Anbjørg Thingnæs.

Relatives Hanne Ludvigsen, former general manager of the Norwegian Breast Cancer Society Lise Høie, and oncologist Bjørn Erikstein have provided useful input.

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Fuel Reklamebyrå as
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Introduction

We have made this brochure for those of you who experience that somebody close to you is being diagnosed with cancer. Together with him or her you are about to face new everyday challenges. Some people are very young when this happens, and this brochure is also for you. You are, as next-of-kin, the most important support someone can have when being seriously ill. As next-of-kin you're also an important partner for health care providers.

In health care, focus has traditionally been on the patient, leaving the next-of-kin less visible. The efforts of family and friends have not always been fully seen or appreciated. We hope this brochure will give you some support.

You need information and knowledge in order to handle an unfamiliar situation, and to facilitate interaction between yourself, the one who's ill and the health care providers.

We hope you'll find this brochure useful. If you need someone to talk to, you're welcome to call the Cancer Helpline at 800 57 338. One third of all people who contact us are next-of-kin. See page 29 for more information.

The Norwegian Cancer Society is currently cooperating with twelve patient associations representing people with different cancer diagnosis and their next-of-kin. See page 30 for more information.

Oslo, April 2012

Best regards
The Norwegian Cancer Society

Being next-of-kin – what does it mean?

When someone is diagnosed with cancer, the people close to them are affected as well. The family's life is likely to change on all levels – emotional, practical and social.

Being close to someone and yet being sidelined is a challenging and manifold task. It can be a scary and unfamiliar situation for most of us. Most next-of-kin will have a need for follow-up and information; still many don't expect health care providers to meet this need.

Nowadays, more treatments and follow-up take place as out-patient services (the patient is not admitted to the hospital). Next-of-kin are often left with a responsibility of coordinating and keeping an overview of the situation. With so much at hand, the next-of-kin will need to cooperate closely with health care personnel.

NEXT-OF-KIN

Traditionally, family members such as spouse, mother, father and children have been considered next-of-kin. But many feel close to people outside of their family. It's therefore important that the person who's ill is the one who defines who their closest next-of-kin are.

NEXT-OF-KIN'S RIGHTS

In the Norwegian Patients' Rights Act

of 2 July 1999, section 1-3, the next-of-kin is defined as: "the person whom the patient names as his or her kin or next-of-kin. If the patient is incapable of naming his or her next-of-kin, the next-of-kin shall be the person who, to the greatest extent, has had a lasting and continuous contact with the patient, however in the following order: spouse, registered partner, persons who live with the patient in a relationship resembling a marriage or partnership, children of full legal age and legal capacity, parents or other persons with parental responsibility, siblings of full legal age and legal capacity, grandparents, other family members who are close to the patient, guardian or provisional guardian."

This law only defines children as next-of-kin when they have attained the full legal age because of legal responsibilities that may occur. However, all experience indicates that it's important that children and young people are involved when someone in their family has been diagnosed with cancer.

Amendments to the Health Personnel and Special Health Services Acts aimed at strengthening the legal status of patients' children became effective from 1 January 2010.

The purpose of the changes is to ensure that children as next-of-kin are

looked after in a better and more systematic way than before. Children and their parents are to be provided with information and guidance. In the specialist health services, the amendments imply that staff members with a particular responsibility for informing children are to be nominated.

The Norwegian Patients' Rights Act of 2 July 1999, Section 3-3 reads: "If the patient consents thereto or circumstances justify it, the patient's next-of-kin shall receive information concerning the patient's health condition and the health care that is being provided." The formulation and presentation of the information is mentioned in section 3-5: "Information shall be adapted to the qualifications of the individual recipient, such as age, maturity, experience and cultural and linguistic background. The information shall be provided in a considerate manner. As far as possible, health personnel shall ensure that the patient has understood the contents and significance of the information."

In the Norwegian Ministry of Health and Care Services' National Cancer Strategy from 2006-2009, the situation of those who are next-of-kin is described as follows: "The carer/ family of the cancer patient, whether they be spouse, partners, parents, brothers and sisters, children or close friends can be a significant resource both with respect to care and practical aspects. It is important that the carer/ family is able

to provide these support functions.

However, the carer/family can also constitute a vulnerable group. Young children in a family affected by cancer must be given the utmost consideration when mother, father, or sibling become ill or die. An increasing number of cancer patients live alone with no close relatives. The situation of the carer/family, or of those who have no carer/family, must therefore be mapped and used as the basis for provision of help by public bodies."

It's only natural that you as next-of-kin may feel a need for talking with the doctor and/or nurse without the one who's ill present. Norwegian law obligates health care personnel to give medical information only to those the patient has nominated, but regardless of this you can ask for a conversation based on your own needs. Good communication with health care personnel is important in your efforts to support the one who's ill.

"While I found strength and energy through my role as caretaker, and by shielding myself from other things, it became important for my husband to continue doing his daily chores, like going to work." (Ellen)

CHANGES IN EVERYDAY LIFE

Even though the disease takes up a lot of time, everyday life and chores must be taken care of. The disease will entail practical alterations. Roles may change

and your burden increase. At the same time, the future is uncertain, and a lot of things can seem frightening. Many patients get sick from the treatment and its side effects. You wish to support him or her at the same time as you have to deal with your own emotional reactions.

“I spent a lot of energy on not falling apart, since Tormod could react negatively if he saw me crying.” (Hanne)

FINANCES, RIGHTS AND OPPORTUNITIES

Long-term disease often involves reduced income and increased expenses. Talk openly with each other, and discuss different options. It's important that you get an overview of your finances and think about what consequences the disease might have financially. Ask for advice about what you can do to improve your situation, both short term and long term. For most people, your own bank would be a good place to start. Go through your insurances. Your local public welfare agency (NAV in Norway) will have information about arrangements for financial support. Most hospitals have social workers that can be of good help. The Norwegian Cancer Society's social workers and lawyers will gladly assist you with advice and guidance. See page 29.

LEAVE OF ABSENCE FOR NEXT-OF-KIN

You may find that going to work is a way of gathering strength and energy by shifting your focus onto other tasks. It can make you feel safe and grounded during a difficult time.

“School became a necessary sanctuary for me. I could be myself and talk about other things than Tormod's disease.” (Hanne)

Only you can decide what is right for you. What gives you strength? What deprives you of strength? Do you need to take time off work? Talk to your doctor. He or she can give you necessary help and support during this time.

The Norwegian Cancer Society has published a brochure called “Rettigheter for pasienter og pårørende” (Patients' and their next-of-kin's rights), in which you'll find more information. The brochure can be downloaded at www.kreftforeningen.no (as per 2012 in Norwegian only). Also see page 27.

MANY DIFFERENT EMOTIONS

“After Mari was diagnosed, everything felt shocking and unreal. I felt powerless and weak. I cried and I cried. It felt like I would never be able to laugh again. In between all the tears, I also felt this intense anger, without being able to direct it towards anyone.” (Ellen)

The statement above describes the emotional chaos most people experience. It's impossible to anticipate how you're going to react in a crisis like this, but there's no right or wrong. Many experience new and unfamiliar sides to themselves and the one who's ill. Familiar patterns change – the strong one might become the weak. But breaking old patterns can be painful; it may take some time to regain the balance in your daily life.

“To me, it became important to find some peacefulness in the situation. I actually found strength in spending a lot of time with Mari. Sometimes I had to put my own feelings aside to accomplish all the tasks – when I look back now, it doesn't seem to have done me any harm. The expression “support to be supported” became sort of a motto for me – I helped myself by helping someone else.” (Ellen)

The next-of-kin might experience a greater deal of anxiety than the one who's ill. Many find that the level of anxiety decreases once they actively participate in what's going on, and avoid being sidelined. It's also important to have someone to talk to. Support groups, where you can meet others in similar situations, are helpful and inspiring to many. To find out if there are any groups or meeting places available near you, ask your local community, the hospital, and the Norwegian Cancer Society.

Many people feel insufficient when they can't live up to their own high expectations. They don't feel patient enough, good enough or strong enough. As it turns out, they usually demand more from themselves than others do. Some people feel sad when their lives turn out differently than what they had expected. You might have to put aside your own plans, desires and ambitions. Perhaps you feel ashamed or have a bad conscience for what you perceive as selfish thoughts. All of this combined causes many people to wear themselves out. They try so hard to perform their tasks the best way possible, and forget their own needs in the process.

HELP AND RELIEF

Sometimes the disease can last very long, for months or years. It's therefore important to ask for help and relief to prevent exhaustion. Think about the many different people in your social network that you can ask for help. Who can relieve you in practical matters? Who do you want to talk to about personal things? Who's a good listener? Who can give you information about the disease, your rights and options? It's important to have the names and telephone numbers of the people who are responsible for the one who is ill when he or she is at home in between treatments, or after treatment is finished.

Communicating with health care providers

No one can teach you how to be a next-of-kin. When you see how busy the health care workers are, it might feel difficult to approach them. That's why it's so easy to end up on the sideline like a spectator. But in order to cooperate well, it's extremely important to communicate with them. The patient will be spending a lot of time at home if treatments and check-ups are provided in out-patient units. In that case, knowledge about what you can and must do is crucial.

“When Mari came home from the hospital, it became my job to take care of the wound from her surgery. This allowed Mari to stay at home and receive out-patient radiation treatment.” (Ellen)

Be firm, active and expect to be seen and heard. This approach will benefit your friend or family member, yourself and the health care providers. You have a right by law to be informed about the condition of the patient and the treatment and care he or she is receiving, if the patient has consented to this. The health care providers will know where you can get help. Don't hesitate to ask!

Many patients express concern for those closest to them. It's comforting for the patient to know that you too are being looked after. It can relieve the patient of concern and responsibility.

It's easier for health care providers to help you if you're open and honest about how you feel and how you experience the situation. Openness can prevent misunderstandings between health care providers, yourself and the one who's ill.

THE IMPORTANCE OF YOUR PARTICIPATION

Although the hospital doesn't invite you explicitly to come along to a consultation, it's necessary, useful and positive for everyone involved that you do. Receiving information together will contribute to openness, intimacy, and make it easier for you to discuss the situation with your ill friend or family member. First hand information is important for you to understand, and participating will give you the opportunity to ask questions yourself.

Agree in advance what you want to ask about, and what you want to know. Different people perceive information differently, and you will probably remember and emphasize different things. It's important to respect each other's different ways of handling the situation. It might be hard to capture everything you're being told when you're experiencing a crisis. To clarify any uncertainties and ask questions, request another consultation with the doctor later on. questions, ask for another consultation with the doctor later on.



The interaction between you and the person who is sick

“You must open up to the healing powers that exist within a family. Next-of-kin represent life giving resources because they are caring human beings whom the one who is ill has confidence in. Love from the closest ones builds resilience and is a source of survival.”

(Mads Gilbert)

It can be difficult to share your feelings with others, especially when it comes to fear of death. It's normal to want to protect each other from these feelings and thoughts. But silence can be a misunderstood way of showing consideration; it can result in all concerned being left alone with their own difficult thoughts.

OPENNESS

We often tend to believe that the other person doesn't want to talk about the situation. We might think that he or she is too fragile or simply not willing to talk. If we dare to ask each other, we might find that this is not the case. If you're open about your feelings, it can make it easier for the other person to start talking as well. Being open and honest can help bring you closer together.

LOOK AHEAD

It might feel difficult to make plans, but it's important to have something to look forward to. If you don't, the disease can end up controlling your life. Perhaps by making a few adjustments, you can both do the things that give you joy and inspiration, power and strength.

A NEW DAILY LIFE

Many types of cancer and cancer treatment involve physical changes and impairments that make every day life unpredictable. This is a challenge, both for the one who is ill and their close ones. It helps to be open and discuss how the challenges can be overcome. The need for help, and what she or he wants to do, will vary. It may be difficult to find the right balance between helping and taking over. Talk to each other; trying to figure out what's right on your own will quickly become tough and exhausting.

“The openness between Mari and myself– the fact that she wanted my participation and care – meant a great deal to me. I mobilized all my strength to help and support her.” (Ellen)

FOR YOU WHO ARE NEXT-OF-KIN

- get involved as quickly as possible
- seek knowledge and information
- be there when information is given
- include children and young people
- ask for follow-up conversation and prepare questions in advance
- clarify who's responsible and who you may contact
- gather information on what is to happen next
- find out where you can receive help
- find out how you can find strength
- be open and honest with each other
- keep making plans
- ask for help and relief



When children and young people are next-of-kin

Research and experience show that children and young people need to be included when someone close becomes seriously ill. Excluding them will not shield them. Involving them in conversations and giving them information is crucial. This way, the family can cooperate and support each other. Including children and young people early spares them being alone with their thoughts and fantasies. They get a sense of being part of the family-group. Always let health care personnel know when there are children and young people in the picture. When someone in the child's family has been diagnosed with cancer, inform the school and kindergarten and find out what routines and experiences they have that could be helpful

FOR YOU WHO ARE YOUNG AND NEXT-OF-KIN

"Mum's disease has given me life experience that few people my age have. Sometimes it makes me feel much older than the other kids. A lot of things that are important to them are not very important to me." (Girl, 17)

You'll have a lot of questions, and experience unfamiliar feelings when

someone you love becomes seriously ill. Many experience the situation as a complete chaos. You may alternate between feeling scared, sad, angry and guilty. Perhaps you're worried that the one who's ill is in pain or is going through a hard time, and at the same time you're scared that the disease will change your own life and future. These feelings and reactions are normal and completely natural. What can help is to speak with someone about your thoughts and have your questions answered.

You have a right to know about the disease and what's being done to help the one who's ill. Sometimes it's best to come to the hospital when the doctor is explaining what's going on, other times it's better if the grownups tell you. Don't be afraid to ask about anything you want to know – there are no stupid questions. You can read more about your rights on page 4 and 5.

Perhaps you want to come to the hospital when he or she is being treated. Cancer treatment can make him or her lose their hair, feel nauseous and tired. If you have been there and seen what's going on, it might be easier to understand how treatment sometimes makes people sicker than the disease itself.

When someone in their family becomes ill, many young people experience that their parents act a bit differently. Perhaps they are sad and quiet, worried, less patient and less present. It's easy to feel overlooked and forgotten. When you're a teenager, it's completely normal to be angry and argue with your parents from time to time. When one of your parents become seriously ill, you may feel regret and perhaps have a bad conscience about the arguments. When the grownups become sad and remote, it can feel like you're being punished, and this can make you feel even worse. Remember that it's not your fault that he or she is ill.

Don't be afraid to talk to him or her, your family or your friends about how you feel. If you find it hard to talk to your parents about everything, you can contact another grownup you trust, for example a teacher or the school nurse. They have a duty of confidentiality. This means that they cannot tell anyone else about what you talk about. Not even your parents, if you don't want them to know. Maybe there are some things you only want to talk to your friends about. Other times, it might feel better to talk to a grownup you know, like an aunt, an uncle, or your friend's parents.

Many people find it hard to talk to others about how they feel. Sometimes it feels good to be able to just cry with someone instead. Or do nice things together. It's ok to keep doing the activities you usually do and spend time with

your friends, even though you and your family are going through a hard time. It's important that you keep doing this. You're the only one who can decide what's best for you.

Sometimes you'll only want to stay home with the one who's ill and the other members of your family. Other times it can be nice to "forget everything" and be with your friends. This might feel difficult, because when you are at home you wonder what your friends are doing, and when you're with your friends you feel restless and worry about your family.

You might find that your friends care about things that seem unimportant to you. Maybe you've become more serious, or feel more mature than your friends. This can make you feel lonely, because they don't understand what it's like being you. Some people find it helpful to draw, write poems or express themselves in other ways.

Even though you might feel lonely, you're not the only one who feels this way. There are conversation and support groups for young people many places in the country, where you can meet others who share your situation. The Norwegian Cancer Society's youth group (UG, Ungdomsgruppen) tries to expand the alternatives available to young people who are next-of-kin. You'll find more information about the youth group on their webpage: www.ug.no

IF YOU HAVE A YOUNG PERSON AS NEXT-OF-KIN

Families with teenagers face great challenges when they are affected by a serious disease. In the middle of the chaos around the disease and treatment, you are engaging with a child who is about to grow up. This is a very important stage in the teenager's life.

The teenage years, or puberty, represents one of life's crises. This is the time when we develop our personal identity, and young people prepare themselves for independence. This time is characterized by big changes – both for the young one and for the family as a whole. The teenager switches between the need for independence and the need for intimacy, which requires a great deal of patience and a willingness to adapt from everyone. Social life outside of the family is important to a teenager. After a while, friends will begin to take over some the parents' functions, and they play a part that parents can't. Being with their friends helps teenagers deal with their problems and emotions. Teenagers sometimes look and act like adults, therefore people around them might perceive them as such. But in a crisis, many teenagers actually react as if they were younger, and might need extra support. Some react by being quiet and keeping to themselves, while others may become anxious. A very common reaction is loss of concentration.

Teenagers are mature enough to realize that the serious disease of a mother or father can entail big changes in their own life. This can subconsciously disturb the natural secession from their parents – it's not easy to revolt against someone who is seriously ill.

What matters most to the young person is to be acknowledged and included in the family. By sharing information and knowledge about the situation, disease and treatment, you establish a trusting relationship. It's important to be honest about your own feelings, as well as all the unanswered questions. Young people often expect parents to know everything. By being honest, you create trust. The young person will know that they can talk to you whenever they need or want to.

Include him or her when tasks are being delegated. To the young person, it's important to be able to help and support. It's necessary for a teenager's development and health to spend time with kids their own age. You should express this and be understanding. If you manage to balance chores, responsibility and freedom, you'll meet the teenager's needs.



CHILDREN AND YOUTH AS NEXT-OF-KIN – WHAT KIND OF HELP IS OFFERED?

The Norwegian Cancer Society hosts gatherings for families with a mother or father who suffers from cancer and others for families where a parent has died. Several places around the country you can find support groups, groups for bereaved and grieving, meeting arenas and theme nights for children and young people. Children, young people and parents can all contact the Cancer Helpline (see page 29) or other people from the Norwegian Cancer Society (see page 26) for advice and support.

People's reactions

"It provokes me when people say this kind of experience makes you stronger. It's hard to be next-of-kin, and you become weak and very vulnerable." (Hanne)

When someone is diagnosed with cancer, their whole family is affected. The disease also affects relatives, friends, neighbours, colleagues, and others. Many people want to know what's going on, and often the closest next-of-kin have to answer all the questions. It's mainly a good thing that people get in touch, but it can end up being too much, and become a burden.

PEOPLE'S NEED FOR ANSWERS

Health care workers share information about the disease and treatment only with the patient's designated next-of-kin because of their duty of confidentiality. People will be referred to the next-of-kin for information if the patient doesn't want to, or isn't able to talk to everyone who makes contact. If all the inquiries get exhausting, it's ok to let people know. It can be done in a polite way, for example by saying: "It's nice of you to call, but right now I can't bear to talk about this." For some people, smart use of the answering machine can be helpful.

"I became really good at rejecting people over the phone. I even had to reject my own sister when she

invited herself over for the weekend." (Ellen)

Most people ask about the patient, which may cause you as a next-of-kin to feel overlooked. Let them know that you're having a difficult time as well.

PEOPLE'S WISH TO HELP

Many people wish to help. You might need some time to get used to the idea of receiving help. Think of how help from other people is good for you in many different ways. You'll have more time on your hands, and it feels good to contribute for those who want to be supportive. They might not know how they should proceed, make it clear what you want them to help you with. Don't hesitate to ask!

PEOPLE'S NEED FOR COMFORT

When a close friend or acquaintance is diagnosed with cancer, it can cause anxiety, grief and despair among people other than their closest family. Some find it difficult to speak directly to the patient, so they contact the next-of-kin instead. It's not unusual that people tell you their own stories about illness. Some experience this as an additional burden. You don't have to accept this. It's demanding to be the closest next-of-kin, the one who answers all the questions, informs, comforts, and at the same time look after oneself.



"20 QUESTIONS"

How are things at home?
What? Why didn't you say anything?
It can't be easy...
Is there anything we can do?
Have you gotten past it yet?
Would you like to come to a party?
How are you handling things?
Have you sought help?
How can you stand it?
There must be something...
Would you like to talk about it?
What does the doctor say?
Is there nothing they can do?
Would you say hello from us and say

that we're thinking about you all?
When did it happen?
Isn't this the same thing as three years ago?
Anything serious?
You don't say?
Will it be open then?
What will you do now?
Is it serious?
Is she at home?
How long will she stay there?

Hallo
(Eivind Karlsson)

If you are a friend, colleague or employer

What can I do to help? Will it seem intrusive if I get in touch? The family probably needs some peace and quiet right now? Who should I address: the one who's ill or the next-of-kin?

Someone you know being diagnosed with cancer may cause a lot of uncertainty. Many people hesitate to get in touch because they face the dilemma of wishing to help while at the same time being afraid to intrude. This way of showing consideration can be misinterpreted by those affected as being let down – it may feel like friends are turning their backs on the situation, that they're afraid to get in touch, or that they don't care.

HOW YOU CAN CONTRIBUTE

The best thing you can do is show that you care. Get in touch, and trust that those affected by the disease set boundaries for what and how much he or she can respond to. The need to share will often vary; he or she will sometimes wish to discuss the situation, other times not. Respect this, but have the courage to ask again later.

Both patients and next-of-kin find comfort in knowing that they have people around them who they can trust, and who are willing to help. Yet, it can be difficult to know what to say

to the patient and how. Statements like "It will be ok, the doctors are clever now a days" or "But you look fine!" may be perceived as not taking the patient seriously, and can create distance. Don't give advice unless it's asked for. Try to be considerate, open-minded, and listen to the one who's ill.

Help and care is not necessarily given through concrete action. Just being present and listening can be of great help. This may help the other person see things clearer and find solutions. Open-ended questions enable sharing, and give the patient the opportunity to choose whether or not to answer. Examples of open-ended questions are "What do you want me to do for you now?" or "How are you?"

Next-of-kin need to be seen, understood and helped too. The needs of the patient and the next-of-kin are different, and are expressed in different ways. If you're uncertain about what's helpful and what's not, ask.

It's better to make specific suggestions on what you can do to help, than saying things like "Just let me know if there's anything I can do". It's not easy to ask for help – let alone know what to ask for.

- get in touch
- ask open-ended questions
- take the situation seriously
- show respect if people don't want to talk
- have the courage to try again later
- write a postcard or letter
- call or send a text message
- the people close to the person who is ill need your attention too

WHEN A COLLEAGUE GETS CANCER

Despite cancer being a common disease, it's often a shock when someone at work is diagnosed. As a colleague you may be affected both emotionally and practically, and a lot of questions arise.

Many people go on sick leave after they get diagnosed and during their treatments. Others continue to go to work. More than ever before, your colleague will need to be surrounded by thoughtful and tolerant people. Don't distance yourself, but listen, and be open. Avoid giving good advice without being asked, or talking about other people you know who have cancer. Each patient's experience of cancer is different.

It's important to make room for the

healthy side of your colleague as well. Your workplace must be a sanctuary, a place to escape the disease, if he or she wants it to be. Openness will make the situation easier for everyone. One person's illness can result in more work for everyone else, something most people will be tolerant of. Yet, it's best to discuss this openly with your colleagues first, and divide the work between you before you get tired and maybe annoyed from the increased burden. The management has an important responsibility to facilitate the best possible solutions.

When treatment is finished, people often expect everything to return to normal. But things might never be the same as they were before the disease. Many struggle with long term effects of the disease and the treatments. Respect that this may take time.

FOR YOU WHO ARE IN CHARGE

Many managers experience that one of their staff members are diagnosed with cancer. This will affect the whole work place and place specific demands on you as a leader. You must look after both the one who's ill, and the other employees.

Find out what the patient would like the colleagues to know, and not know. It's best to ask them about this your-

self. That way, you'll have the opportunity to find out what would constitute the best support. Remember to ask if he or she wants their colleagues to contact them, or if one person should be in charge of all communication.

A good way of helping would be to suggest a meeting a few weeks after the diagnosis, where you have the chance to talk about the situation. It will give both of you the opportunity to exchange information. You might focus on questions about rights, financial circumstances and insurance, as well as mutual expectations. Keep in touch; this will create a fruitful dialogue. Corporate health services, your company's HR-department and workplace health and safety arrangements, can all play an important role, and be helpful to you as a leader.

As a leader it might be a good idea to talk to your staff about reactions they might have.

- Clarify the situation with the one who's ill
- Aim towards cooperation and openness, and try to create the best situation possible for everyone involved, both for the ill staff member and the other employees.

See www.kreftforeningen.no for more information.



For more information

On the Norwegian Cancer Society's website, www.kreftforeningen.no, you'll find current information about different treatments, how to live with cancer, and much more. You can order or download brochures from our website (as per 2012, primarily in Norwegian). Call 07877 if you need assistance.

The Cancer Helpline answers any question you might have. We have Norwegian, English and Sami speaking staff members. For more information visit our website. Don't hesitate to ask health care personnel about available services!

MEETINGPLACES FOR NEXT-OF-KIN

- The Norwegian Cancer Society's local offices (workshops, groups and conversations).
- Patient associations representing people with cancer and their next-of-kin.
- The Montebello Centre (Montebello-senteret), in Mesnali Lillehammer. www.montebello-senteret.no (in Norwegian)
- The Varde Centre in Oslo. www.vardesenteret.no (in Norwegian)
- Røros Rehabilitation Centre (Røros Rehabiliteringssenter)

DVD ABOUT CHILDREN AND YOUNG PEOPLE AS NEXT-OF-KIN

- *"Jeg har ikke gjort leksene i dag, min mor fikk kreft i går."* ("I didn't do my homework today, my mother got cancer yesterday.") The movie is about three different families' experiences from the time after the diagnosis.
- *"Han vil alltid være i hjertet mitt"* ("He'll always be in my heart.") Children and adults talk about losing a father.
- *"Min far er på video."* ("My father is on tape.") Children who have filmed their own and their family's everyday life. What happens when a father, brother or sister is diagnosed with cancer?

The movies are available on webtv.kreftforeningen.no (Norwegian)

SUGGESTIONS FOR LITERATURE

- Lian, Torunn: "Bare skyer beveger Stjernene". Aschehoug & Co. 1997 (also available as film and audio book. Film is available with English subtitles).
- "Idas dans". The story of a mother. Corwin, Gunhild. Dinamo Forlag 2005 (in Norwegian)
- Magnus, Jon: "Veien til Karlsvogna". A diary about cancer and love. Forum Aschehoug 1999 (in Norwegian)
- Ranheim, Unni: "Vær der for meg". About youth, death and grief. Tell forlag 2002 (in Norwegian)





Five areas of importance in our work

Forskning

Research makes a difference. Thanks to research two out of three people now survive. The Norwegian Cancer Society is one of the largest sponsors of cancer research in Norway. We allocate approximately half our budget for mission-related activities to research. Research generates knowledge that makes improvements in diagnostics, treatment and care possible. The end result is increased survival rates and better health for those who live with the disease. Research gives us hope for the future!

Care

Providing help and support for people affected by cancer across Norway is a priority for us. We are available for everyone who needs our services. Based on our extensive experience, we know what challenges and problems cancer patients and the people close to them are facing. Mastering everyday life can be a challenge – we are there for people affected by cancer.

Prevention

Cancer prevention is another priority for us. The incidence of cancer is increasing and at least one in three cancer cases is related to lifestyle factors. Unfortunately there is no such thing as a guarantee against cancer, but it is possible to reduce the risk. We can stay away from tobacco, avoid being overweight, engage in physical

activity, choose a healthy diet and low alcohol consumption, and adopt healthy sun habits.

The foundations for good health are laid in childhood and adolescence. This is why many of our preventative efforts are directed at children and young people.

Influencing policy

Our goal is to ensure the best possible treatment, living conditions and quality of life for cancer patients and the people close to them. We also want to strengthen the rights of people affected by cancer. We, as a non-government organisation, are active health policy advocates who initiate change through our dialogue with relevant authorities.

International work

We are active in a range of arenas where we highlight cancer as a global challenge. Tobacco is the single most important cause of cancer, and tobacco prevention is therefore important in our international work. We support tobacco prevention projects in Africa and Northwest Russia.

Read more about our work and key priorities on
www.kreftforeningen.no and
www.kreftforeningen.no/english

Services across the country

We cover topics within cancer care, living conditions, rights and public health. Our services are provided by way of conversations with cancer patients and their next-of-kin, courses, group sessions, theme meetings, and as training for health and social services professionals.

MASTERY COURSE: 'LIVSLYST'

This course is for people who have or have had cancer, their next-of-kin as well as for those who have lost someone to the disease. Our goal is to help the participants help themselves through challenging times.

The course offers:

- an opportunity to learn more about how to cope with stress and capture ones enthusiasm for life.
- practical tips and useful tools for meeting everyday challenges
- the opportunity to share experiences, good and bad, with others affected by cancer.

The course is based on cognitive learning and the interplay between thoughts and emotions is emphasized. It is lead by professionals with broad experience in group activities and cancer counselling. The course is free.

FOR CHILDREN AND YOUNG PEOPLE: 'TREFFPUNKT'

This is a meeting place for children and

young people between the ages of 6 and 16, who are affected by cancer or other serious diseases in their family. 'Treffpunkt' is also for those who have lost a loved one. Here, the participants get to meet kids their own age who are going through similar experiences as well as grown-ups who understand their situation. 'Treffpunkt' is led by professionals from our staff and can be found many places across the country.

Visit www.kreftforeningen.no/tilbud for our services or call us on 07877. All our services are available free of charge.

THE VARDE CENTRES

The Varde Centres offer comprehensive care and services to cancer patients and the people close to them. They provide a place to meet and a venue for activities that promote quality of life and well being. The aim is to instil a sense of mastery that can help people live an active life with or after cancer and treatment. The Varde Centres are open to everyone who is or has been affected by cancer, no matter where in the country they live. All services are free of charge.

The Varde Centre
Oslo University Hospital
The Norwegian Radium Hospital
Building J, 5. Floor (patient hotel
building)
Ullernchausseen 70, 0310 Oslo
In 2012 and 2013, centres will be

established in Trondheim, Tromsø and Stavanger. www.vardesenteret.no – as per 2012 in Norwegian only.

BROCHURES AND INFORMATION

The Norwegian Cancer Society publishes a wide range of brochures, facts sheets and other information. An up-to-date overview is available at www.kreftforeningen.no/brosjyrer. All information is available free of charge.

INTERNET FORUM

Here, patients and next-of-kin meet to exchange experiences and advice for support and help. The forum can be found at www.kreftforeningen.no

THE CANCER HELPLINE 800 57338 (800 KREFT)

How may cancer affect emotions and family life? What may the practical, economic and legal implications be? What happens after treatment or what if it doesn't work? How should I proceed in my dealings with NAV?

No matter what questions arise when affected by cancer, talking to someone who listens, understands and provides answers may be helpful. At the Helpline you can get in touch with nurses, social workers, lawyers and other professionals who have a duty of confidentiality, who know a lot about cancer, but also what it means to be a

next-of-kin or to lose someone to the disease. We may also offer financial support.

THE CANCER HELPLINE 800 57338 (800 KREFT) is open to all and the service is free of charge from home phones.

IN ADDITION TO CALLING, YOU CAN REACH US BY: e-mail to the nurses kreftlinjen@kreftforeningen.no

e-mail to the social workers and lawyers: rettigheter@kreftforeningen.no

sms: brief questions can be sent to 1980. Start the message with the word Kreftlinjen

online chat on-line dialogue with a nurse available at www.kreftforeningen.no

THE HELPLINE'S OPENING HOURS: Monday, Tuesday and Wednesday: 0900-2000 Thursday and Friday: 0900-1500 Closed all weekends and public holidays

April 2012

Our offices across the country

- Grønnegata 86–88, 9008 **Tromsø**
(covering Finnmark, Troms and Nordland)
- Prinsens gate 32, 7011 **Trondheim**
(covering Nord-Trøndelag, Sør-Trøndelag and Møre og Romsdal)
- Strandgaten 62, 5004 **Bergen**
(covering Sogn og Fjordane, Hordaland and Rogaland north of Boknafjorden)
- Dronningensgate 2A, 4610 **Kristiansand**
(covering Aust-Agder, Vest-Agder and Rogaland south of Boknafjorden)
- Strandgata 65, 2317 **Hamar**
(covering Oppland and Hedmark)
- Øvre Langgate 42, 3110 **Tønsberg**
- Regional Offices **Oslo** and **Tønsberg**
(covering Telemark, Vestfold, Buskerud, Oslo, Akershus and Østfold)
- Oslo University Hospital, the Norwegian Radium Hospital, Building F, Ullernchausséen 70, 0310 **Oslo**
(covering same counties as the office in Tønsberg)

Head office
Tullins gate 2, 0166 **Oslo**

e-mail: servicetorget@kreftforeningen.no
Telephone, all offices **07877**

The Cancer Helpline – someone to talk to

The Cancer Helpline is the Norwegian Cancer Society's information and support service. Here, you can receive guidance to help you feel safer and more able to cope with changes in life, whether you have cancer or someone close to you does. What, for example, may happen to the family life and emotions of those affected?

At the Helpline you will meet specialist nurses, lawyers and social workers who in addition to answering medical questions, can help you with health related legal problems, social security issues, and any questions you may have regarding probate and inheritance law. What practical, financial and legal implications may arise if the disease strikes? What happens after treatment or what if it doesn't work? What can I do to prevent cancer?

There is no problem too big or too small and at the Cancer Helpline you will talk to people who have extensive experience in working with cancer related issues. They all have a duty of confidentiality, and you can choose to remain anonymous if you wish. You don't need to have a specific question either. Maybe you just need someone to talk to? Or perhaps you prefer our anonymous online chat option? The choice is yours!

Navigating the public system can be difficult enough when healthy, and becomes even more challenging when someone is seriously ill, both for patients themselves and for their next-of-kin. When calling the Helpline, you can also receive assistance from professionals experienced in meeting people in crisis. They know what rights you have, and if they are unable to answer a particular question, they can advise you where to find more help.



We are here to help with problems big and small.
Bodil Husby,
social worker



To those affected by cancer, we can help with all legal matters that may arise.
Camilla Fosse,
lawyer



You can ask us about anything and remain anonymous if you prefer.
Trine Skorpen,
cancer nurse

Call the Helpline: 800 57338

Opening hours: Mon - Wed: 09.00-20.00, Thu - Fri: 09.00-15.00, except on public holidays. The service is free of charge when calling from a home phone. If you don't feel like talking you can use our online chat. You can also contact us by e-mail. Se kreftlinjen.no for more information.

Patient associations that we cooperate with

As per 2012, we cooperate closely with twelve associations representing people with cancer and their next-of-kin. The associations offer peer-to-peer support across the country, along with membership meetings, information, workshops and recreational activities. Throughout the years they have won important rights for the benefit of cancer patients. They have worked to stop the purchase of necessary aids and appliances being an additional financial burden. The associations promote openness and a greater understanding about the disease and the situation of patients and their next-of-kin.

The associations are independent organisations and associated members of the Norwegian Cancer Society. They have per 2012 a combined membership of approximately 30,000.

The Norwegian Cancer Society cooperates with the associations to

- reach out to more people with cancer and their loved ones
- stand stronger in our battle for important causes

Read more about the associations and their activities (in Norwegian)

- Breast cancer: Foreningen for bryst kreftopererte (FFB) ph. 02066, www.ffb.no

- Mouth and throat cancer: Munn- og halskreftforeningen ph. 22 20 03 90, www.munnoghalskreft.no
- Young people aged 15-35 Ungdomsgruppen i Kreftforeningen (UG) ph. 469 68 033, www.ug.no
- Families of children with cancer: Støtteforeningen for Kreftsyrke Barn (SKB) ph. 02099, www.kreftsyrke-barn.no
- Stoma/ostomy and pouch/reservoir: Norsk Forening for Stomi- and Reservoaropererte (NORILCO) ph 02013, www.norilco.no
- Stem cell transplant and leukaemia: Margen – Foreningen for stamcelle transplanterte og leukemipasienter ph. 22 20 03 90, www.margen.no
- Prostate cancer: Prostatakreftforeningen (PROFO) ph. 22 20 03 90, www.prostatakreft.no
- Neuroendocrine cancer: CarciNor ph. 22 20 03 90, www.carcinor.no
- Lymph cancer: Lymfekreftforeningen ph. 22 20 03 90, www.lymfekreft.no
- Gynecological cancer: Foreningen for gynekologisk kreftrammede (FGK) ph. 22 20 03 90, www.gynkreftforeningen.no
- Lung cancer: Lungekreftforeningen ph. 934 70 121, www.lungekreftforeningen.no
- Brain tumor: Hjernesvulstforeningen Ph. 22 20 03 90, www.hjernesvulst.no

You may also call **07877** or visit our website for more information.



HOW CAN YOU SUPPORT OUR WORK?

The Norwegian Cancer Society receives minimal financial support from the government. Donations from members, individual and business supporters make our work possible. Thanks to this support we are able to play a major role in cancer research, prevention, care and advocacy. By supporting the Norwegian Cancer

Society, each and every one of us can make a difference. Our vision is: Together we create hope!

Would you like to support our work?
Make a donation to bank account 5005 05 11011, visit our website (www.kreftforeningen.no) or call 07877.

WOULD YOU LIKE MORE INFORMATION?

An up-to-date overview of brochures, fact sheets and other information is available at www.kreftforeningen.no/brosjyrer. All information is available free of charge.

ABOUT US

We are a nation-wide, non-government organisation addressing the challenges of cancer. Our work is made possible by gifts, collected donations, bequests and gaming pool funds from Norsk Tipping. We have several hundred thousand members, individual and business supporters. This broad support makes us the leading cancer organisation in Norway and allows us to target the fields of research, care, prevention and information.

Our main goals are to

- reduce the incidence of cancer
- increase cancer survival rates
- ensure the best possible quality of life for cancer patients and their loved ones

The Norwegian Cancer Society is one of the largest sponsors of cancer research in Norway. As per 2012 we cooperate with 12 patient organisations.

Our vision is *Together we create hope*. Read more on www.kreftforeningen.no

Become a member! Together we create hope
– Call us on 07877.

The Norwegian Cancer Society,
Tullingsgate 2, 0166, Oslo.
Ph: 07877
www.kreftforeningen.no



Kreft
foreningen



The Norwegian Control Committee for Fundraising in Norway

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