

*WHAT DO I DO?*



*WHEN YOU  
HAVE BEEN  
DIAGNOSED  
WITH CANCER*

A handbook for **young  
relatives** to young  
people with cancer

“ As a relative, it is so important that there’s also room for the raw emotions, and that you have a place where you can talk about all the things that are difficult. Especially because you struggle to keep yourself together in front of the sick person.

Kristine

“ The most important thing is that others dare to ask us what’s going on. Remember the relatives. I have felt forgotten, and that it’s me who is left with everything.

Sofie



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Ung Kræft is a community within the Danish Cancer Society for young current and former cancer patients, relatives, and young people who have lost a loved one between 18 and 39 years old.

Read more at [ungkraeft.dk](https://ungkraeft.dk)



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#### Notes on the translation

Throughout the book we link to external sources. Some of them are only available in Danish. Information in English can be found on the Danish Cancer Society's English website [cancer.dk/faa\\_raadgivning/english/](https://cancer.dk/faa_raadgivning/english/). You can also call the Cancer Helpline on **80 30 10 30**

In this book we use the term relatives to refer to young people who are close to a young person who has cancer – friends, siblings, partners etc.

The quotes in this book have been translated from Danish to English with a focus on maintaining the meaning of the quote rather than translating it word for word.

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☞ You feel so different, as if you are moving in a parallel universe. Everyone else seems to have a life different from mine. Friends can do things that I no longer can. They can be happy, party, and plan their future, perhaps even start a family. It's as if everything's been taken away.


Line B.

☞ As a young person, you're in a stage of your life where you're figuring out who you are and what you want to do with your life. Suddenly, you need to be more grown-up than you actually are.

Lise



# ***PREFACE:*** ***YOU ARE NOT*** ***ALONE***



This book is written specifically for you, who are a young relative to a young person with cancer. Perhaps you are a partner or spouse of a young person who has been diagnosed with cancer, or it's your sibling or close friend who has fallen ill. You are not alone.

We understand that it's particularly vulnerable to be confronted with a serious illness at a time in life when you're just beginning to explore and shape your life. Suddenly, like the one who is ill, you must navigate through a healthcare system and a daily life marked by illness, difficult conversations, and fear of death.

Your role as support for your loved one is unique. It can be rewarding and meaningful, but also a huge responsibility. You may feel alone, especially because your life is so different from that of your friends. You may also experience changes in the person who has cancer, which are intense and difficult to share with others.

This book is written to support you in the emotions you're experiencing right now and to make your daily life a little easier. It lends a hand to you in the new situation you find yourself in where you want to do everything you can to help and support the one you love and care for. And at the same time, you need to take care of yourself.

All cancer treatment pathways are different. But we hope you can find one or more sections that provide useful knowledge, inspiration, comfort, or hope.

If you have experienced loss, you are in a very intense and frightening situation. Therefore, the last part of the book is written lovingly for you as a person who has lost.

Ung Kræft 



You should know that you are not alone. We have gathered three personal narratives about being a young relative to a young person with cancer.

# *THREE YOUNG RELATIVES SHARE THEIR STORIES*

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Read more stories from young relatives on [ungkraeft.dk](http://ungkraeft.dk) or on Instagram [@ungkraeft](https://www.instagram.com/ungkraeft)



## JULIE, SISTER TO EMILIE

“ I alternated between being there for my parents, for my sister, and for myself – probably least of all for myself.



Julie is a sociologist working in the eldercare sector in the Municipality of Copenhagen. Julie's sister Emilie, who is two years younger, was diagnosed with lymphoma in 2015. Her treatment took place in Iceland, where Emilie has been living since 2012. It was difficult, and the family was scared

#### **HOW WAS IT FOR YOU BACK THEN?**

The entire first month after the diagnosis is just a big, black blur that I have difficulty remembering. I imagined how our parents would feel if they had to live through losing a child. I also have a younger brother. What would it be like if we had to live with Emilie not being here anymore? At that time, I was working on my thesis and had installed myself in a summer house to finish it. My father came to pick me up, and on the way home in the car, he tells me that Emilie has cancer. It was hard for him. He beat around the bush for a long time before he could say it. He also mentioned that they had considered not telling me so I could finish the thesis. I just remember thinking, "how could you even consider that?".

#### **WERE YOU INVOLVED IN DOCTOR'S APPOINTMENTS AND TREATMENT?**

The entire treatment took place in Iceland, and sometimes I travelled up there to be with her. It was so awful seeing my little sister lying in such a machine (scanner red.). I think I shed some tears on the first day, and then it passed, but when I saw her lying there, I realized how serious it was. She looked so small and vulnerable with her arms above her head. Our mother couldn't bear to go for scans. When she had to travel to Iceland right after the diagnosis, she couldn't figure out how to pack her suitcase. It was February, and she packed strange things, so I had to go and repack and swap out a summer dress for a pair of woolen socks.

#### **WHAT WAS YOUR ROLE?**

I alternated between being there for my parents, for my sister, and for myself – probably least of all for myself. Our father and mother were not together, but they had partners. They had someone. I didn't have a partner at the time and felt very alone. I remember being disappointed that my parents didn't visit me more often in the apartment, where I lived, and took care of me.

#### **WHAT WAS YOUR DAILY LIFE LIKE AT THAT TIME? DID YOU CONTINUE TO STUDY?**

I postponed my thesis for six months but continued with my student job and was really grateful for that. And then I tried to keep up with my workout routine. I've always been able to use exercise to get back on track – or go out and have a few beers with friends and feel happy and uplifted, but it didn't work. All my methods of feeling good were useless. I felt so homeless. I remember watching all seasons of "Dexter" and "The Big Bang Theory" on Netflix. I can see on my bank statement that I just sat and watched TV and ate take-out. But that's what I needed.

#### **HOW DID YOU MOVE FORWARD?**

We were quickly informed that Emilie would recover, which was a huge relief, but it didn't make the grief go away. Or the fear. After about a month, I decided to do something about my thesis. It ended up being really poor, but that's just how it is sometimes. It was all about Emilie and my parents. And there was still a lot to consider, which affected us as a family, such as whether she would have her eggs harvested and frozen.

#### **DID YOU TALK TO YOUR YOUNGER SISTER ABOUT IT?**

We talked about fertility and children. She chose not to postpone her treatment. She just wanted to get started and get it over with. Emilie is very private, and she was 26 at the time, and I also think she was protecting us. She didn't want to share her thoughts and her grief, and I think that's very common in a family. We shield each other from the darkest thoughts. I didn't tell her

either that I was afraid she might die, or that I've imagined her funeral a hundred times in my head.

**WHAT WAS THE HARDEST PART?**

One of the hardest things was probably what I perceived as a betrayal from my group of friends. We were very close and confiding, and I didn't feel that way during that period. It's lonely to be sick, but it's also lonely to be a relative. I have accepted that now, but at that time, I had very high expectations of what my friends should help me with. I felt very alone and was not at all prepared for how much it affected me afterwards. It had been an ongoing process of tests and treatments. You knew what you were dealing with, but when the last treatment was over, it was like being let go. Also as a relative.

**WHAT DID YOU DO THEN?**

I traveled to Iceland and lived with Emilie for three months after the treatment was over and I had submitted my thesis. It was great, and I finally felt like I could be a sister to her. I was a little worried that she thought I was just an annoying, clingy older sister: "Get out of my life", and stuff like that. But she wanted me to visit. When I got home, I was completely closed off, and I think it took about a year before I could really function again. I threw myself into volunteering for Relay for Life at the Danish Cancer Society, and it helped me a lot. It made sense that I could do something.

**DID THE PROCESS CHANGE ANYTHING IN YOUR RELATIONSHIP WITH EACH OTHER?**

I see her more as an equal now. I am very proud of how she fought through the process up there in another country and in a language, she didn't speak so well. I really gained a deep respect for her in a different way because she used to be little, vulnerable Emilie, who needed to be taken care of. But she's super tough and can take care of herself. Now she has two children, and I'm pregnant. She's doing so well, so that makes me think I can figure it out too.

**WHAT IS UNIQUE ABOUT BEING A RELATIVE TO A SIBLING?**

I am connected in a special way to my sister and my brother. None of my friends or my parents can compare to what my siblings mean to me. We are products of the same. We grew up together and have the same genes. We are each other's life witnesses. I'm a total big sister. I will protect them, and I should be the one to go first.

**WHEN YOU LOOK BACK NOW, IS THERE SOMETHING YOU WISH YOU HAD KNOWN?**

You direct all your energy towards the sick person and towards the system that needs to treat and diagnose, but you also have to remember to stop and stay in your own body and your own needs for a while. You don't have to lose yourself completely because someone close to you is ill. You also need energy to continue being there for them. You can't do that if you're completely worn out alongside them. Remember to set boundaries. It's hard to set boundaries with someone who is sick, but you become unreasonable sometimes, especially in a family because it's a safe space to be unreasonable in. I have also been unreasonable, and it's not easy, but it's actually okay to tell each other that it's too much.



**JULIE'S BEST ADVICE FOR  
FRIENDS AND OTHER PEOPLE  
WHO ARE CLOSE**

Keep being curious and ask about how they're doing. Even if it's been a long time, and you might think it's time to move on. It may not be the same for those going through it.



## ANNE, FRIEND TO CHARLOTTE AND CHARLOTTE

💬 It's perfectly fine to make mistakes and say something wrong. That's okay. It's only wrong if you don't say anything. No matter what you believe, it matters that you write: "I'm thinking of you".

Anne works as a doctor and lives in Odense with her partner and two children. Anne's two childhood friends, both named Charlotte, were diagnosed with breast cancer shortly after each other. Here she talks about being very close to their processes and how it has changed her friendship with them.

#### ***WILL YOU TELL US WHAT HAPPENED?***

My first friend who fell ill was 27 when she found a lump in her breast, which turned out to be cancer. The second friend and I were on maternity leave together when she was diagnosed with breast cancer. At that time, her son was five months old, and she had to stop breastfeeding and give up returning to her job as a nurse. All the happiness in her life was suddenly overshadowed by illness and treatment.

#### ***WHAT HAS YOUR ROLE BEEN?***

My role has been somewhat different in the two processes. With my first friend, I was there for the good talks. I wasn't with her in the hospital, she didn't want that. She sent out a joint text message to her closest friends, saying she needed to cope with it all herself before we came running. We had to respect that, even though we really wanted to visit. She was good at keeping us updated along the way, and we went for many walks and talked a lot about where we were in life and the difference between my life moving forward and hers coming to a halt. With my second friend, I was very close and involved in everything. We were on maternity leave at the same time, so I was free to visit her often and help where needed.

#### ***WHAT HAS BEEN THE HARDEST?***

It's tough when someone becomes sick at such a young age. It's so unfair, and there's so much fear that follows along. Even though both of them are healthy now, no one can remove the

fear that it might come back. There's a huge shift in the things you worry about and talk about with each other. Life becomes so serious. They both also said that everyone around them said, "Oh, but it's so good that you're still here." And in reality, they would rather just have an ordinary, dull everyday life like the rest of us, where you complain about the rain. You can't wake up every day and be grateful that you're here.

#### ***HAS THE ILLNESS CHANGED YOUR FRIENDSHIP?***

So much has changed for both of them, which I find difficult to understand. They've gained a new circle of friends and a sense of security in Ung Kræft, and as an old friend, I don't need to be a part of that. I've thought about that it's okay for them to have other friends now, whom they're very close to. No matter how much I want to understand how they feel, I haven't been through a cancer patient pathway. They also think that the lives of me and others just continue in a way that they would have liked to be a part of, and they can get frustrated and upset and think that our problems are insignificant and silly.

#### ***HOW CAN YOU BE A GOOD FRIEND?***

You have to be persistent, and you have to be careful not to say, "Just let me know what you need." When you're sick, you don't necessarily have the energy to reach out and may not even know what you need. One of my friends and I made an agreement that we didn't have to talk every single day. I checked in when I didn't hear anything, and if she didn't respond, I just texted her again two days later. I didn't expect an answer, but I persevered, even though sometimes she would say, "You're the fourth person calling today, I don't actually want to talk on the phone anymore." You learn a lot along the way, even in a friendship. It's perfectly fine to make mistakes and say something wrong. That's okay. There's only one wrong thing, and that's if you don't say anything. No matter what you think, it matters that you write: "I'm thinking of you".

***SOME PEOPLE DON'T KNOW WHAT TO SAY OR DO, DID YOU ALSO EXPERIENCE THAT?***

Both of my friends have experienced that some friends couldn't handle it and disappeared. I think it's important to remember that both the sick person and the relatives are new to this kind of illness. The friendship is being tested, even now in the aftermath. For example, one of my friends has problems with her memory after the chemo, and it can affect me when she can't remember things I tell her and find important in my life. There has also been a shift in our relationship. She has needed a lot of care and support, and I can catch myself thinking that it must be over now, but perhaps it isn't. She recently said that she's tired of being dependent on others and that she misses her independence. Being diagnosed with cancer and becoming so ill really affects a person.

***HOW HAS BEING SO CLOSE TO TWO CANCER PATIENT PATHWAYS AFFECTED YOU?***

It still moves me enormously. My friends call me mother-Anne. Every time there are new updates in their lives, it can actually take me a couple of days to digest it. My stomach gets upset and I get in a bit of a bad mood. I haven't discussed it with a professional yet, for example, a psychologist, because I have a good support system where we talk completely openly about it, but that's my plan. I will definitely recommend it to others if needed. It can really get under your skin, especially because you feel so powerless. You can't remove it for them.



***ANNE'S BEST ADVICE FOR FRIENDS AND OTHER PEOPLE WHO ARE CLOSE***

Continue checking in and send greetings, and feel free to offer something concrete. For instance, you could suggest going for a walk on Friday. It's perfectly fine to offer what you can handle in your life. If you're pregnant or have small children, nobody expects you to show up four times a week with a lasagna. It is better to do some than to do nothing at all.

A man with short dark hair, glasses, and a light beard is looking upwards and to the right. He is wearing a dark jacket. The background is a wall of horizontal blue wooden planks. The lighting is soft, highlighting his face against the textured wall.

## JESPER, LOST HIS PARTNER LOTTE

“ I have experienced some things that are really tough, but I also believe that you can use it to enter into a new relationship with a belief that life is a wonderful thing.

Jesper lives in Åbyhøj near Aarhus. He is a trained electrician and works as a property service technician at a public school.

Jesper lost his partner, Lotte, to inflammatory breast cancer in 2018. Lotte, a qualified nurse, and Jesper had been living together for two years when Lotte was diagnosed. Today, Jesper is ready to meet a new partner and start a family, but it's crucial for him that there's room for remembrance.

#### **WHAT HAPPENED BACK THEN?**

One morning, out of the blue, Lotte felt a strange lump under her armpit. It was around September 2017. We visited the doctor, who was uncertain and, as a precaution, referred her to a cancer patient pathway. From there, everything moved swiftly with diagnostics and treatment. We had just bought a house. Both of us wanted children, and the house was the foundation – a place to build a good life together. But fate had other plans. Lotte passed away in hospice on June 7, 2018, the day before my 32nd birthday. It's a part of the baggage I'll carry with me in life. Now, hopefully, I can start a new chapter.

#### **WHAT IS THE NEW CHAPTER?**

I've always wanted to start a family, and I'm mentally preparing for it now. I miss having someone to share my everyday life with, someone to wake up next to and give a good morning kiss to. And having children, that's something I really want. Perhaps I'll meet someone who already has children, and I'll become a step-parent. I'm ready.

#### **HOW WAS THE CANCER TREATMENT PATHWAY FOR YOU?**

When Lotte underwent chemotherapy, she often felt very unwell with high fevers, leading to hospitalization. Ambulances would pick her up. She was too weak to sit upright in our car, so it was better for her to be transported lying down. This happened at all hours of the day. Sometimes, I'd be woken in the middle of the night because she was feeling unwell. The first few times were extremely tough, but gradually, I learned that it was part of the game, being involved in Lotte's cancer patient pathway. We had a hospital bag packed with essentials like a toothbrush, and whatever else we might need for the first two or three days. When we returned home, we'd replenish it, keeping it ready in the closet. So, if we had to rush off in the middle of the night, it was easy for me. It became a routine.

#### **HOW DID YOUR EVERYDAY LIFE CHANGE?**

I was a partner. I was a secretary. And I was the handyman at home. I cooked, tended the garden, and tried to keep everything in order, including all the numerous appointments and medical consultations. Initially, I continued going to work as usual. I had an arrangement with my supervisor that I'd attend necessary appointments. If I needed time off, I took it, using my accrued leave and flexible hours. They were very accommodating. When Lotte was admitted to hospice, I got my work hours reduced and my boss said that I could decide if I came into work or not. I could choose my hours, or I could simply come and have a cup of coffee if I needed a break. Their support was incredible.

#### **WHAT WAS MOST IMPORTANT TO YOU?**

It was ensuring Lotte's day was as good as possible. I put my own needs aside. Sometimes, it was tough, but I had to cut back on some of the things I'm passionate about. I couldn't manage to do that alongside having a sick partner at home. Some mornings, she felt terrible, and it was a significant struggle for me to leave the house, knowing she'd be alone. I made lunch ready for her, and even though I had tried to prepare a lot for her, I sometimes



felt that I didn't measure up as a partner and as a man – that I couldn't make it work. But once I got out the door, it was okay.

***WAS THERE ANYTHING SPECIFIC YOU DID ALONG THE WAY TO TAKE CARE OF YOURSELF?***

I prioritized being around Lotte, so there wasn't really time to see friends. Some of the nurses in the hospital ward reminded me that I needed to remember to give myself a break. When I needed a break and felt there was room for it, I'd go home and sit on the terrace with my feet up, enjoying a cold soda or a cup of coffee. Or something as mundane as putting on a headset and walking back and forth with the lawnmower – or trimming a hedge. Just pacing back and forth, entering my own little world, and listening to music.

***WHAT ABOUT THE POSSIBILITY OF HAVING CHILDREN, DID YOU AND LOTTE DISCUSS IT?***

We had to decide whether we wanted fertility treatment. If Lotte survived, should we ensure the option of having a child and extracting eggs? The doctors advised us not to spend time on it. They wanted to start treatment, and we had 24 hours to make a decision. It was a difficult conversation and a long evening. We looked deep into each other's eyes and discussed what we wanted. Deep down, we were quite in agreement that we wanted her to start treatment, also in consultation with Lotte's parents. The doctors were good at guiding us, but the decision was ours.

***LOOKING BACK NOW, WHAT DO YOU WISH YOU HAD KNOWN?***

I wish there had been a group I could consult with, like now in Ung Kræft. It's nice to talk to someone who dares to ask questions and isn't afraid that I'll be hurt. My former father-in-law was good at asking me how I was doing. Both of us being craftsmen, we had a lot of things we could tinker with and do together. Many people were afraid to ask and avoided me. That was tough. People are welcome to ask, and I'll let them know what I feel like talking about. It's more hurtful when you don't ask.

***HAS BEING A RELATIVE TO LOTTE AND LOSING HER CHANGED YOU?***

After Lotte died, I suffered from nausea for a long time and couldn't understand what was wrong. The doctor talked about stomach acid, but maybe it was actually physical tension? After six months of intensive physiotherapy, at least I didn't have nausea anymore. I also played a lot of badminton, but my head couldn't handle being in a badminton court, focusing, and thinking tactically back then, nor could it handle all the noise in a court. It was fine to be out there and watch, but it wasn't very fun to experience suddenly not being able to hit the shuttlecock or just getting in the way of my badminton partner. So, I chose to stop playing badminton, but I'm still active as a volunteer on the board. I'm very happy about that.

***WHEN YOU GET A NEW PARTNER, WHAT DO YOU THINK YOU CARRY WITH YOU?***

I have experienced some things that are really tough, but I also believe that one can use it to enter into a new relationship with a belief that life is a wonderful thing. I won't forget what I've been through. It's part of the package I bring, and my next partner should also be okay with me needing to visit the cemetery occasionally or talk to my former in-laws. There should be room for remembrance.



### **JESPER'S BEST ADVICE FOR FRIENDS AND OTHER PEOPLE WHO ARE CLOSE**

Don't be afraid to ask or to initiate contact. It's helpful if you ask or offer your help. Just do it. Build up the courage and come over.



🗨️ In the beginning, I had a lot of that fighting spirit and determination: 'This is really crappy, but we'll get through it.' I tried to give Rasmus good energy, especially when I was in his room. I slept in the room with him for the first many nights, and I was also home at one point during the daytime to talk to my parents. And then the emotions came, I cried and was scared and felt it was unfair.

Lene

# *YOU'VE JUST RECEIVED THE NEWS*

When someone you love is diagnosed with cancer, it also affects you as a relative. Here you can read about how others have reacted and find information and good advice for navigating through emotions and reactions.



## FEELINGS AND REACTIONS

The first days after receiving the news about cancer often feel like a state of exception for many. It's as if time has shattered into a thousand pieces, and everything stops, yet moves incredibly fast. You may doubt everything one moment and be entirely clear-headed the next.

Whatever emotions you're experiencing right now – anger, fear, powerlessness, inadequacy, determination, or something entirely different – are natural responses to extraordinary circumstances. Your partner, sibling, or friend who has received the diagnosis are likely experiencing many of the same things.

“ At times, you can live a normal life, and at other times, it's very much about hospital visits and illness. It fluctuates back and forth, with ups and downs.

Anne I.

It's individual when and how you react to the changes happening in your and their lives. In the beginning and during the treatment process, you may hold back your own feelings and just want to help and be there for the person who is ill. As your daily life begins to regain some coherence, you may start to notice your own reactions more clearly. You may feel physically unwell because the body naturally reacts to the many upheavals. Some have trouble sleeping, dizziness, headaches, and a reduced appetite.

You might also experience irritability, fear, or sadness. Your mood may fluctuate, and you may have difficulty concentrating at work or at school. Your tolerance may be low because you feel you must be strong all the time and take care of everything. Or you may feel alone and unsure.

These experiences, alongside any other emotions you're encountering, are entirely valid responses. Understandably, they can be challenging.

“ People often ask me: How do you manage it? It's a natural question, I know, but how can I answer it? I don't know how, and I don't even know if I can keep managing it. You just do it, a bit like when we had our son Carl. We didn't know a fraction of what we thought we knew, but we made it through. I wish people would stop asking me how I manage it.

Casper

## YOU ARE AFFECTED TOO

Especially in the beginning of a cancer patient pathway, you may find that there are many questions directed towards the person who is ill and not as much towards you as a relative. This can be frustrating and contribute to you feeling alone and overlooked. Perhaps you keep it to yourself?

As a relative, you may not want to be a burden and typically don't consider your own need for breaks and help from others. But you are allowed to take up space. You are also affected and need to be seen and listened to.

“ It was a great challenge for me to leave the house and go to work, knowing she would be alone at home. Even though I had tried to prepare a lot and made lunch ready for her, I sometimes felt that I didn't measure up as a partner and as a man – that I couldn't make it work. But as soon as I got going, it was okay. I did the best I could.

Jesper

## DON'T BE ALONE WITH YOUR THOUGHTS AND FEELINGS

It can be tough and sometimes lonely to be in a cancer patient pathway – even as a relative. Some days are good and full of hope and love, while other days can feel hopeless and out of control. It's okay to feel sad alone, but it can also be a heavy burden. It may feel like you're the only one in the whole world who knows how you feel.

It's important that you have someone to talk to. A good friend, partner, parent, teacher, colleague, or other young relatives. Use them. You can also write down your thoughts, for example, in a diary or in an email you'll never send. It may sound silly and banal, but it's usually better to express your feelings and thoughts than to keep them all to yourself.

**It's not always easy to reach out. On page 64, you can find inspiration on how to tell others about what you're going through.**

If your thoughts become too numerous and chaotic, it may also be a good idea to seek professional help, for example, from a counselor at the Danish Cancer Society, or a private psychologist. They can help you gain an overview of your situation.

It's also a conversation where you can comfortably focus on yourself. And where you can share thoughts and feelings that are difficult to share with family and friends – or with the person diagnosed with cancer.



### REMEMBER... YOU'RE DOING THE BEST YOU CAN

You're in a very demanding and uncertain situation. You can't possibly know everything in advance – not even with this book available. There's no special, elegant way to handle the role of a relative, or the changes and crises that arise in a cancer patient pathway. You handle it in your own way and as well as you can under the circumstances, and that's always good enough. Always.

### TALK TO OTHER RELATIVES

It can be a great help to talk to someone who knows what you're going through without you having to explain too much. You can share experiences with other relatives in Ung Kræft and on [Cancerforum.dk](https://www.cancerforum.dk)

### MEET OTHER REALTIVES IN UNG KRÆFT

Ung Kræft offers a community where young relatives and young people who have lost a loved one share knowledge and experiences about dreams for the future, love, fear, grief, and much more. It's for you who are a young relative to a partner, sibling, or friend, and for you who have lost a young person you love to cancer.

Learn more about the community at [ungkraeft.dk](https://www.ungkraeft.dk). Get in touch with Ung Kræft by sending an email to [ungkraeft@cancer.dk](mailto:ungkraeft@cancer.dk) or calling **35 25 74 72**

### FIND A GROUP AT CANCERFORUM.DK

You can also meet other relatives on the Danish Cancer Society's online forum [Cancerforum.dk](https://www.cancerforum.dk). Here, you can share thoughts and experiences with others in a similar situation.

Cancerforum has many different groups for both patients, relatives, and people who have lost. You need to create a profile to participate, and you can be anonymous if you wish.

### ONLINE SUPPORT GROUPS IN ENGLISH

The Danish Cancer Society offers online groups for relatives to cancer patients who are more comfortable speaking English than Danish. In the group you talk about life as a relative and share experiences. The group is led by a professional counsellor.

To learn more contact counsellor Dorthe Andersen by sending an email to [dorthea@cancer.dk](mailto:dorthea@cancer.dk) or calling **51 85 46 41**

# HELP AND SUPPORT FOR YOU

## Call the Cancer Helpline

The Cancer Helpline is the Danish Cancer Society's telephone and chat counseling service. Here, psychologists, doctors, nurses, and social workers are available, all with extensive knowledge about cancer and everything that comes with it. They can help you gain an overview of your situation, find options for action, and help you articulate any concerns you may have.

Call the Cancer Helpline on **80 30 10 30** or learn more and find chat options and opening hours at [cancer.dk/faa\\_raadgivning/english](https://www.cancer.dk/faa_raadgivning/english)

## Visit the Cancer Counseling Centers

Throughout the country, you will find cancer counseling centers ready to welcome you and provide help and advice in the situation you are in.

The counseling centers offer various services, but in all centers, you have an opportunity to speak with a professional counselor either alone or together as a couple or family. All services are free. You can find an overview of the cancer counseling centers at [cancer.dk/faa\\_raadgivning/english](https://www.cancer.dk/faa_raadgivning/english)

## Tilskud til psykologhjælp

As a cancer patient and relative, you can receive a subsidy for 12 consultations with a psychologist. You must be referred by your general physician within 12 months after the diagnosis is made.

If you are a member of the "danmark" Health Insurance, you can receive additional subsidies. Many workplaces also have a health scheme that provides employees with free psychological help or subsidies.

“ It’s completely normal for you as a relative to feel overwhelmed and not understand anything.

Sofie

# *ENCOUNTERING THE HEALTHCARE SYSTEM*

As the closest relative, you typically help maintain an overview of the situation so your loved one can focus on their treatment. It’s a big task. We have gathered knowledge, advice, and experiences about collaborating with healthcare professionals, daily life in the hospital, and the follow-up process after treatment.

## ASK IF YOU'RE IN DOUBT

When the diagnosis is given, you'll learn about the available treatment options. The initial conversations with the doctor and the news about cancer are very overwhelming, and it can be hard to remember what's being said when you're in shock, scared, and confused.

There's a lot of information to take in. You're not a bother if you need to ask again afterward or contact a doctor together with the one who's ill to refresh some information or have something explained more thoroughly. This also applies to subsequent conversations with the doctor and throughout the entire cancer patient pathway. Don't hesitate to ask the hospital staff if there's anything you're unsure about. Better to ask too much than too little.

You may have questions about everything from unfamiliar words you don't understand to the content of the treatment or whether you can eat together with the patient. Nothing is too big or too small. The patient is entitled to be involved in their treatment, and as a relative, you have the right to be there and ask questions when you're attending consultations.

“ I had doubts about everything. I had never been admitted to a hospital and didn't know the rules or the language. Can I stay overnight with him? Can I be there all the time or only for a few hours? Can I accompany him for treatment? I was with him during chemotherapy, and I actually didn't think that was allowed.

Catrine

## GOOD TO KNOW ABOUT VISITING THE HOSPITAL

The rules can vary depending on the hospital. Ask the hospital staff if you're in doubt. Here is what applies in most hospitals in Denmark.

### Visiting hours

As a relative, you can always visit the hospital. There are no fixed visiting hours.

### Overnight stays

As the closest relative, it is usually possible to stay overnight at the hospital. Ask the staff.

### Food for you

As a relative, you can eat together with the patient during mealtimes. In many places, this requires a meal ticket, which you can purchase yourself. Or you may bring your own food.



🗨️ I just felt so young. It was very anxiety-inducing, but I was the closest one. I threw all inhibitions aside and asked again and again until I got answers if there was something I felt was important. I had to take on that role.

Line B.

### LEARN MORE ABOUT CANCER

For some, it may provide a peace of mind to research more about cancer and cancer treatment. It can be a way to sort out the many chaotic thoughts. It can also equip you to support and talk to the person who's ill.

Be aware that there may be differences in how much information you, as a patient and relative, want to have. Perhaps your loved one doesn't want to know as much as you do. Therefore, always agree with your loved one on how much you share about what you're researching.

This also applies if you're googling different types of cancer and treatments. There is a lot of valuable information on the internet, but also many horror stories that can make you even more scared and uncertain. It's important to remember that all cancer patient pathways are different. The best thing you can do is to talk to the doctors in charge of the treatment.

You can always find more knowledge about different types of cancer and treatments on the Danish Cancer Society's website [cancer.dk](https://www.cancer.dk)



### A CHECKLIST FOR CONVERSATIONS WITH THE DOCTOR

Ung Kræft has created a checklist for conversations with the doctor. You can look at it together and maybe use it to prepare for and bring along to appointments. The checklist is in Danish.

Find the checklist here:  
[cancer.dk/ungkraeft/ungmedkraeft/materialer/](https://www.cancer.dk/ungkraeft/ungmedkraeft/materialer/)

## THE DIALOGUE WITH HEALTHCARE PROFESSIONALS

It's a good idea to prepare for conversations with the doctor so that you get answers to all your questions. It may also be a good idea to have several relatives present for discussions and treatment, if it's okay with the patient. This could be parents, in-laws, siblings, or others in your network who can also support you and help create an overview of the situation.

It is the responsibility of the doctor or other staff to ensure a good and comprehensive conversation about the illness and treatment. But if you participate in the conversations, you can contribute to good cooperation by asking questions and helping create clarity.

### CONSENT AND POWER OF ATTORNEY

As a relative, you can usually participate in everything from doctor's consultations to examinations and treatment, but it requires the patient's consent. The patient must consent to the sharing of information about the illness with you. The department staff is responsible for issuing a consent form. If you are unsure about consent, do not hesitate to ask the staff.

There is a difference between having consent or a power of attorney. The patient can choose to give you **digital power of attorney** to perform certain actions on their behalf in one or more public digital solutions, such as **Borger.dk** and **Sundhed.dk**.

This way, you can access the medical record. However, be aware that the power of attorney is limited to digital solutions and may not necessarily grant you access to, for example, contacting authorities in person.

You can read more on **Borger.dk**. Search for 'digital fuldmagt'.

☞ We did a lot to accept that now we're here, let's make sure to have some cozy moments. And in a strange way, you also get used to everyday life in a hospital. We watched movies and series, ate a lot of take-out, and explored the hospital.

Lene

There is also something called a **lasting power of attorney**. If the patient gives you a lasting power of attorney, you can act on behalf of the patient who is ill. Such a power of attorney is only relevant in the event that the patient, due to the illness, can no longer take care of themselves.

You can read more on **Borger.dk**. Search for 'fremtidsfuldmagt'.

#### YOUR KNOWLEDGE IS IMPORTANT

Regardless of whether consent is given, the staff may engage in dialogue with you, and you are allowed to contact the staff and inform them about what you see and experience with your loved one. It could be symptoms or needs. Your information can be valuable in ensuring that your loved one receives the right help, so please share the knowledge you have.

Furthermore, you can also discuss your own needs or those of your children with the staff. They may be able to provide referrals to support services or assistance options. Ask the doctor in charge of the treatment if you are unsure.

#### DISCUSS TREATMENT AND FERTILITY WITH THE DOCTOR

Some cancer treatments can reduce the ability to conceive or become a parent. If the person who is ill wishes to start a family or have more children, it is important to discuss with the doctor whether the treatment may affect the ability to have children. If this is the case, in some instances, it's possible to freeze eggs, ovaries, or sperm before starting treatment, so there's an opportunity to have children later.

## GOOD ADVICE FOR DAILY LIFE IN A HOSPITAL

To you from other young relatives ❤️

#### Allocate tasks

If there are several relatives, it may be a good idea to divide the tasks among yourselves, so that you can gather information and relay it to family and friends collectively.

#### Bring an extra relative

If it's okay with the patient, it's a good idea to have more than one relative attend medical appointments. We all react differently and having an extra person listening can be helpful.

#### Buy a notebook

For some, it can be helpful to jot down questions about the treatment. Also, take notes during conversations with the doctor to remember what was discussed and agreed upon. You can use these notes for future appointments with other doctors.

#### Keep a diary

Consider keeping a diary to record impressions and experiences from the days. It can be a good way to structure the days, which can otherwise easily blur together.

#### Remember the little things

Do small things to make the days in the hospital as pleasant as possible. Perhaps you bring delicious take-out for a shared meal while you watch a favorite series, or you arrange visits from good friends.

Talk to the doctor and staff about the options for fertility-preserving treatment, and also about your feelings surrounding it. These are significant considerations to have amid everything else happening.

You can read more about cancer treatment and fertility on [cancer.dk/fertilitet](https://cancer.dk/fertilitet)

## FOLLOW-UP PROGRAMS AND POST-TREATMENT REACTIONS

When the treatment is finally over, it marks the transition from one chapter to another. The person who has been ill needs to rediscover themselves, and so do you.

The outside world often expects everything to be fine now. Friends stop checking in, and it feels like life just moves on. But returning to your routine might not be so straightforward. You've been through a lot, and your emotions have been all over the place.

It's typically only after some time has elapsed since the treatment that the emotional aftermath becomes evident. It may take some time for the person who had cancer to recover, and as a relative, you may also become impatient and think, "Phew, that's it, let's move on!".

Your roles may also be reversed for a while. Some experience that it is the relative who needs extra support and care when the treatment is over. It can actually be a relief for your loved one to be able to step into the helper role.



### REMEMBER... IT TAKES TIME

Communicate openly about the shifts in everyday life and your emotions. Understand that it might take time to rediscover yourselves and your relationship in this new phase without illness, in the middle of new experiences and existential and emotional reverberations.

## FACTS ABOUT FOLLOW-UP PROGRAMS

In Denmark almost everyone who has had cancer is offered a follow-up program. It is what used to be called a control program.

The follow-up is an individual plan for the subsequent contact with the healthcare system. Not just in the hospital - there may also be services in the municipality or with your own doctor that make sense for you.

Therefore, before the first follow-up appointment, it is important that your partner, sibling, or friend considers their potential physical and mental challenges in everyday life and the support that is – or is not – available to handle them. Depending on the illness and the needs that may arise, the doctor and your loved one create a plan together.

“ I felt very alone and was not at all prepared for how much it affected me afterwards. It had been an ongoing process of tests and treatments. You knew what you were dealing with, but when the last treatment was over, it was like being let go. Also as a relative.

Julie

## FEWER VISITS TO THE DOCTOR, BUT STILL MANY EMOTIONS

The follow-up program varies depending on the type of cancer and treatment regimen, and whether there are late adverse effects after the cancer diagnosis. Therefore, it may not necessarily be the end of doctor visits when your loved one is declared cancer-free. But fortunately, there will be fewer of them. Follow-up and ongoing monitoring such as scanning and mammography are associated with reassurance for most people, but also with many emotions and nervousness. It is comforting to know that your loved one is being monitored, but the fear of recurrence can weigh heavily on both of you.

### YOU MAY ALSO EXPERIENCE REVERBERATIONS

After the cancer patient pathway, your needs and responses can differ significantly. Some relatives are so immersed in supporting their loved ones during treatment that they barely have a chance to process their own emotions. It's common for these emotions to surface once treatment concludes.

The person who has had cancer may experience late adverse effects such as sleep disturbances, fatigue, pain, and anxiety. But you may also struggle with reverberations. It is tough to be a close relative to someone diagnosed with cancer, and it can leave its mark - both as physical and psychological reactions.

Some relatives struggle to recall details or find themselves in survival mode with stress-like symptoms. Others experience anxiety and depression once the treatment pathway concludes.

Regardless of the reverberations you experience, it may be helpful to speak with a counselor at the Danish Cancer Society, a psychologist, or your own doctor if it significantly impacts your life.



#### TALK TO A COUNSELOR

At the Cancer Helpline, you can talk or chat with professional counselors who can help you gain an overview of your situation. They can also help you articulate any concerns you may have. Counseling is free.

Call **80 30 10 30** or start a chat at **cancer.dk/kraeftlinjen**

“ You're directing all your energy towards the sick person and towards the system that needs to treat and diagnose, but you also need to remember to stop and focus on your own body and your own needs.

Julie



“ He always wanted to help clean or cook, but he couldn't, and it was difficult for both of us. He felt really guilty about me running around. So I said to him, "That's just how it is right now. It won't last, and if it were me, you'd do exactly the same." And he knew that was true.

Lene

# *YOUR DAILY LIFE AS A RELATIVE*

As the closest relative, you typically help keep track of things so your loved one can focus on their treatment. It's a substantial task. We've gathered information, advice, and experiences about working with the healthcare staff, everyday life at the hospital, and follow-up care after treatment.



## HOW MUCH SHOULD YOU HELP?

Whether it's your partner, sibling, or friend who has been diagnosed with cancer, you will likely experience changes in your everyday life. Your relationship with each other will change as well. Some days you may feel closer to each other than ever before, while other days everything may seem much harder. You may become unsure about what to say and do, or how much you should help.

Most cancer patients need help with things they used to be able to manage themselves, such as getting up, going to the toilet, or taking a shower. It can be difficult for your loved one to accept being helpless and dependent on you for such tasks, and it can be overwhelming for both of you to experience the physical limitations and fatigue that often accompany serious illness.

Even though your help is needed, your loved one may still become frustrated with receiving it, and you may doubt what you should do. It's a highly sensitive issue. If possible, it's a good idea to talk about how much help your partner, sibling, or friend wants to receive and from whom? Or how you and other relatives can provide support without overwhelming or smothering. It's a delicate balance, and it may take some time to adjust to new roles and a new daily life.

### THERE ARE LIMITS TO WHAT YOU SHOULD BE ABLE TO HANDLE ALONE

There's an inherent dilemma in the role of a relative. It can be hard to say no to helping and supporting when you genuinely want to. But sometimes you may need to do it for the sake of your own daily life and perhaps your own family and children – and to take care of yourself.



### REMEMBER... YOU MUST BE ABLE TO BREATHE

There are limits to what you should be able to handle alone. You might be capable – because many don't feel they have a choice when they're in the midst of a life crisis. But it's important to remember that you must be able to breathe on your own in order to be there for your loved one – and for your own sake. And it's okay to say it out loud. In fact, it's also an expression of love.

“It's one's entire daily life that one must figure out how to piece together, and that's what I had to do so that my wife could focus on being a patient. I was a partner. I was a secretary. And I was the practical man at home. I cooked, tended the garden, and tried to keep everything organized, including all the numerous dates and appointments for medical consultations.

Jesper

It's not easy to say, now I'm going to a football game, to the movies, or for a long walk. Especially not if the person who has cancer becomes upset or disappointed, even unintentionally. Try to be honest about what you can handle and discuss what's possible, including accepting help from friends and family. And remember, it's okay, and perhaps even necessary, to experiment and set boundaries.

**On page 72, you'll find some advice on how to take care of yourself while taking care of your loved one.**

### PRACTICAL HELP FOR EVERYDAY LIFE

Getting help with practical things can free up more time to do enjoyable things together with your loved one. Spending quality time with family and friends, as well as taking breaks to recharge, is vital.

### HELP FROM FRIENDS AND FAMILY

The help you require and the help you can get varies. Many people hear the phrase: “Let me know if there's anything I can do?” You may not necessarily find that phrase useful. You rarely know what you need, and if you do, it can be difficult to ask for it. Remember that family and friends say it because they want to help you, but they don't always know what to do.

Continues on page 62 →



### USE AN APP TO COORDINATE ASSISTANCE

Sammenholdet is an app that makes it easy for the cancer patient and you as a relative to organize help and support in your network.

You can download 'Sammenholdet' for free on the **App Store** or **Google Play**

●● My bonus mom took care of all the practical matters and cooked for me, my husband, and my children. It meant everything.

Gülay

●● I was the one who slept at Meryem's every time she had chemo, and I helped with her daughter. I juggled two worlds – one was with my sick sister, where I lived with her, monitored her, gave her injections in the back, cooked, and everything that came with it – and the other was with my own family, husband, and children. It was tough. Especially to see my sister so ill.

Mercan

If you have the energy for it, you can try suggesting tasks that you think might be easy to handle. Perhaps buying groceries or picking up a package. It could also be cleaning the apartment while you get some exercise. Or taking care of the children for a couple of hours so you can rest a bit or do something else beneficial for yourself.

It's also okay to decline help if, for example, you're offered assistance with laundry but prefer to do it yourself. Or if someone offers childcare, but you need to spend time with the children yourself. In that case, you can suggest something else you need help with.

## SUPPORT FOR THE CARE YOU PROVIDE

As a relative in Denmark, you have various options for receiving support and help that can make your daily life a bit easier. Here, you can find a brief overview of the diverse forms of leave and assistance available to you in your municipality.

### YOUR OPTIONS FOR CARE DAYS AND LEAVE

As a partner, family member, or close friend, you have the option of taking leave from your work to care for your loved one. Depending on the situation, you can either take care days, care leave, or filial leave.

#### >Care days

These can be useful if, for example, you need to attend medical appointments or treatments. You are only entitled to them if you are an employee. Care days are unpaid, and as a relative, you have the right to up to five days per calendar year.

#### >Care leave

You can apply for care leave if you need more time to care for and assist the sick person.

#### >Filial leave

If your partner, sibling, or close friend is dying and wishes to spend their last days at home, you can apply for filial leave.

### GET HELP IN YOUR MUNICIPALITY

It's a good idea to accept the help offered by the public authorities. Talk to your municipality about your options:

#### >Talk to a cancer coordinator

Many municipalities employ a cancer coordinator who can help you gain an overview and coordinate processes between the hospital and the municipality. The cancer coordinator can also be the contact person for your loved one in the municipality.

Contact your municipality or one of the Danish Cancer Society's counselling services to inquire about the possibility of speaking with a cancer coordinator.

#### >Get help from a coordinator with a specific focus on relatives

Some municipalities employ a staff member to assist relatives in navigating the municipality's different services. In Danish this person may be called a 'pårørendevejleder', 'pårørendekonsulent', or 'pårørendekoordinator'. In some municipalities, you can also participate in courses and theme days for relatives.

#### >Home relief

Perhaps you need relief at home? It's also possible to ask the municipality for help with practical tasks at home or personal care.

The municipality can also lend out various aids to help ease daily life at home. It varies from municipality to municipality what kind of help you can get.



### GET HELP GETTING AN OVERVIEW OF YOUR RIGHTS

At the Cancer Helpline, you can speak or write to a social worker who can support you in getting an overview of your specific situation, rights, and options. The counselling is free.

Call **80 30 10 30** or start a chat at [cancer.dk/kraeftlinjen](https://cancer.dk/kraeftlinjen). You can find more information about your rights on [cancer.dk/rettigheder](https://cancer.dk/rettigheder) or in the brochure "Dine rettigheder – som kræftpatient og pårørende".

The brochure can be downloaded on [cancer.dk/pjecer](https://cancer.dk/pjecer)



## WHAT YOU CAN TELL OTHERS ABOUT WHAT YOU'RE GOING THROUGH

You may feel better if as many people as possible know what's happening in your life and how you're feeling. Or you may prefer to keep it private and only talk about it with those you know well. There's no right or wrong.

👉 **Sometimes it's nice to talk, other times it's nice to let go and just feel normal.**

Casper

### DEALING WITH OTHERS' REACTIONS

When discussing illness, treatment, and the events in your life, you may notice a wide range of reactions from the people around you. Some become upset, some become quiet, while others offer good advice or suggestions on how they can help you. If you feel that others' reactions are affecting you negatively, it's okay to speak up and tell them what you need – whether you prefer a hug, a cold beer, a good conversation, or all of it at once. Whatever makes you feel comfortable and gives you strength and hope. You may not know what you need, and it can be a great help for both you and your surroundings to say it out loud.

👉 **I wrote to my friends and to my parents a lot. Long messages about how I was feeling and what was happening. I needed to have some extra people with me who could help me bear it.**

Line B.

## YOU MAY EXPERIENCE RELUCTANCE

It's a frightening thought that serious illness like cancer can affect someone so young. You may find that people become uncertain about what to say and do when they hear about the cancer diagnosis and your situation. It may also happen that some become so unsure that they completely refrain from saying or doing anything. They may even avoid you.

It's frustrating and hurtful that people are reluctant to engage with the subject, even if you understand why it can be difficult and unfamiliar to talk about illness, grief, and fear of death

👉 **I sent a long message to my good high school friends because I felt that they hadn't really checked in on me. But even after sharing how things were going, they didn't ask about chemotherapy or anything else. It became a bit superficial and rushed. That was tough for me.**

Lene

## HOW YOU CAN START THE CONVERSATION

It's important to remember that you are new to dealing with illness, and that many of your friends and acquaintances are too. Awkward situations can arise, and you can be both disappointed by others' reactions and pleasantly surprised. Try to be patient with both friends and acquaintances – and with yourself.

Here are some sentences constructed together with other young relatives. You can use them to start a conversation or to give your friends and others around you a few hints about what you need. You can also create your own sentences and practice them aloud. It's often easier to say things if the words have already been said a few times

**Here are a few suggestions on how to start the conversation:**

*"I'm a bit nervous to tell you how things are going. Maybe you'll think it's too much? Or get upset. I'll just try..."*

*"You're welcome to ask. I'll let you know if there's anything I don't want to talk about."*

*"Don't be afraid to make me upset. It's okay. I can say no."*

*"A hug is nice. Sometimes I don't feel like talking."*

*"You don't have to say much. It's okay. It's nice that you are here, just listening."*

## WHAT ABOUT YOUR STUDIES AND WORK?

Being a relative requires time and energy. For many, the role is almost a full-time job and can therefore have consequences for your student and/or work life.

Your job is essential for financial stability, and your studies are critical for your future plans. But they can also offer a break from the stress of illness and help you maintain a sense of normalcy. Balancing work, studies, and caregiving is personal and what you need depends on your situation.

Here are some practical suggestions to help you manage these responsibilities:

› **Be open with your employer and teacher**

It can be challenging to tell your boss or teacher that you're struggling with your family member's, partner's, or close friend's illness, but it's usually a relief. It can bring a peace of mind that they know about your situation and your need for flexibility if, for example, you need to attend hospital appointments, take an extra break, or take more time off than usual.

› **Consider being open with colleagues and/or classmates**

Only you know how open you want to be about your situation. If you're worried about what your colleagues or classmates might think if you withdraw from social events or get upset, it might be a good idea to tell one or more people about what's happening in your life. It can be a relief not to have to keep up a facade and nice to feel others' care and understanding.

› **Talk to your union representative or a student counselor**

If you're unsure about your rights at work or in your studies, it's a good idea to talk to your union representative or your union if you have one – or to a student counselor.

› **React in time**

Many who experience what you're going through struggle to concentrate. Or struggle with fatigue. It's understandable. Take it seriously and talk to your employer or teacher about the options for adjusting tasks to what you can handle.

### APPLY FOR THE DANISH CANCER SOCIETY GRANT

The Danish Cancer Society awards grants to cancer patients and relatives with low income. The grant can be applied for by both the cancer patient and one cohabiting relative.

The relative applying for the grant can be the spouse or partner of the cancer patient – or a cohabiting child, sibling, or friend. Only one relative in the household can receive the grant.

You can read more about the conditions and apply for the grant at [cancer.dk/legat](https://cancer.dk/legat)



“ We are a small workplace and know each other well. I needed my colleagues to ask about what was going on. It’s easy to end up living in two separate worlds, one revolving around illness and suffering, which is at home and at the hospital – and another where you have an ordinary daily life and do the things you’re used to. I needed to be a whole person, where the illness was allowed to occupy all spheres of my life.

Catrine

“ I postponed my thesis for six months but continued with my student job, and I was really happy about that.

Julie

“ Work is a breath of fresh air for me. I have good colleagues and a good boss who has also had cancer. We have received fantastic support from family, friends, and my boss. Perhaps that’s the advantage of being a relative to a young person with a serious diagnosis? People are quite tolerant and understanding.

Casper

☞ Music has helped me. Listening to music with strong emotions. Medina's 'Lige bange' describes that feeling really well. You're just so fucking scared of what's going to happen.

Line F.

# HOW YOU CAN TAKE CARE OF YOURSELF

It's important that you take care of yourself while taking care of your loved one.

We have gathered experiences from other young relatives as well as good advice that can hopefully give you strength and inspire you.

## LISTEN TO YOUR OWN FEELINGS

Being a caregiver is a significant responsibility and it can be very challenging. It's crucial that you prioritize self-care so you can effectively assist and support your loved one, and also for your own well-being. Some people find it best to take breaks from the demands of caregiving, while others prefer to spend as much time as possible with the person who is ill, despite the difficulties it may entail. Whatever approach you choose, it's important to find ways to look after yourself that work for you.

It can be small things like taking a long bath, watching a good series, or listening to music. Alternatively, you may recharge by spending time with a group of friends or doing something nice for yourself and the person who is ill. The key is to find something you can realistically fit into your schedule, so you don't feel guilty about taking time for yourself. Although, it's normal to feel a bit guilty during tough times like this.

“ I couldn't manage to go for a run or contact a psychologist. I could manage the immediate and the obvious, for example, ordering some delicious take-out or making myself a nice cup of coffee.

Lene

## TAKE BREAKS FROM THE ILLNESS

Make sure you give yourself those breaks you need, even if they're just tiny ones. Take five minutes to sit by the window, give a friend a call, or listen to some music you really enjoy. It's all about finding those moments that let you focus on yourself and what you need. When you take a break, however small it may be, you may feel guilty about prioritizing yourself. As mentioned, that's natural, but you can't be everywhere all at once or use up all your energy without recharging yourself.

“ The patient can't take a break from the illness, so it can feel so wrong and like cheating when you do it as a relative, but it's not. You need to.

Casper

Perhaps it can help you knowing that your partner, sibling, or friend wants you to be well. When you take a break from your role as a relative, it can also give the person who is sick a break from the patient role.

## YOUR FEELINGS ARE VALID

You have a lot of roles as a relative, and your own feelings can almost feel forbidden. They are not, and they are allowed to be there – even when they are conflicting.

### ›It's okay to lower your efforts

It's frustrating not being able to do the same as before, both for the sick person and for you as a relative. You may sometimes need to lower your ambitions and expectations in terms of what you can manage. This can also apply to your studies and work. You'll still get everything done. It may just happen in a different way than you expected.

### ›It's okay to be happy

You're allowed to laugh. Sometimes you're happy, and that's okay. Many relatives feel guilty about doing something that's nice and fun. But no one can be sad or talk about cancer all the time, not even your loved one. Your joy is contagious and uplifting. Perhaps you feel sad again five minutes later, and that's okay too.

### ›It's okay to be angry

Forgive yourself if you lose patience, get upset, or scold. The situation is stressful, and nobody is perfect.

☞ I have learned that it's okay to be happy and laugh. Sometimes you're just happy, and that's allowed, even if your loved one is sick. It helped me that we also have a son. You have to joke and laugh with him too. Then it doesn't feel so heavy.

Casper

☞ I felt that I was worn out, and it affected the family. So I took a bath to relax. Or went down to the car and had a good cry and then came back and was a mom. Then I could manage for a bit again.

Gülay

☞ We have even thrown rolls of toilet paper at each other in desperation.

Line F.

## LET OTHERS TAKE CARE OF YOU

You might not think about it, and it can also be difficult to ask for. But you also need help and support. You need your own relatives. It could be your partner, a parent, or good friends who support and help you.

Perhaps you're fortunate to have someone in your network who excels at making to-do lists and getting things done practically. And others who are great listeners when you're worried or scared. Tune into what you need and speak up about it if you can.

## SEEK HELP IF YOU FEEL OVERWHELMED

It may happen that the illness takes a toll on you, causing health problems of your own. It doesn't happen to everyone, but if you experience trouble sleeping or symptoms of anxiety, stress, and depression, it's important that you tell someone about it and get the help you need.

It may take small things to prevent you from becoming overwhelmed. Or if it still happens, make sure to rest and regain some balance so you can function in your daily life.

You are always welcome to contact the Danish Cancer Society and Ung Kræft if you need help getting an overview of your situation or talking to someone about your concerns. You don't need to prepare a lot of questions. It's okay to call or write and be unsure about what you need. The counselling is free. Call **80 30 10 30** or start a chat at **cancer.dk/kraeftlinjen**

“ It's so important to have people come and add value to your life when it's shattered. As a relative, you need some extra relatives who can bring in new energy. You become so tired.

Line B.



Here you can read about how a cancer treatment pathway can affect your relationship with your partner. You can also read about what it can be like when your sibling or good friend is diagnosed with cancer. You can skip straight to the part that concerns you or you can read all sections. You will probably recognize a lot regardless of your relationship with the person who has been diagnosed with cancer.

# *ESPECIALLY FOR YOU IF ...*

*...YOUR PARTNER IS DIAGNOSED WITH CANCER 80*

*...YOUR SIBLING IS DIAGNOSED WITH CANCER 90*

*...YOUR FRIEND IS DIAGNOSED WITH CANCER 98*





# ESPECIALLY FOR YOU IF YOUR PARTNER IS DIAGNOSED WITH CANCER

When you got together with your partner, cancer was probably the last thing on your minds. It's truly a tough situation for both of you, and you probably feel many of the same things - fear, pain, anger, and confusion. Your love may also feel both more intense and fragile at times.

There's a big difference in how a cancer patient pathway affects your relationship, depending on whether you've just met, live together, and/or have children together. We've tried to outline this a bit bluntly here. You can also read about changes in your sex life and receive good advice for everyday life.

“ There are changes in our roles that can be very painful for both parties. Martin was so ill that he didn't have the energy to take care of me as he used to – and to protect me.

Line B.

## EVERYDAY LIFE AS COUPLES

You probably have a lot of thoughts and worries about how the illness will affect your daily life and your relationship. Can our relationship handle it? What happens if my partner doesn't become cancer-free?

“ Sometimes I've been so frustrated. Even though it's not you who's sick, you still feel like the illness hits you so hard because it has such a big impact on your life. Why me? Why us? What if I had become involved with someone else, then my life would have been so different. I wouldn't trade it for anything in the world, and it's silly to think like that, but you do.

Lene

It's easy to feel guilty as a partner – about anything. Wanting to have sex with your partner, or not wanting to. Or wishing everything was the same as before the illness. You may feel like you're sacrificing yourself and immediately feel guilty for feeling that way, even though they're natural feelings and thoughts. It's complicated and difficult to handle

## NEW ROLES

Now that your partner is sick, you typically take on a lot of practical tasks in your daily life, especially if you live together and/or have children. Perhaps, you also coordinate appointments with the doctor or communicate about treatment with family and friends.

If you're brand-new partners, your role isn't as obvious as if you've known each other for years. It can be really confusing and difficult to figure out how and how much you should help. Furthermore, because your partner's family is eager to help, they perhaps frequently become more intertwined with your daily life as a couple.

Serious illness can cause parents, and perhaps especially mothers, to take on a greater role in the lives of their adult children. This can be helpful and supportive for you too. But it can also be burdensome when your in-laws suddenly play a significant role in your relationship and daily life.

As a partner, you may feel overwhelmed and in need of your partner as a buffer and intermediary between you and your in-laws. It's vulnerable, also for your partner, who is sick and dependent on help and support and who wants to be there for you but may not always have the energy for it.

#### **IF YOU ASSIST WITH MEDICATION AND PERSONAL CARE**

As a relative, you can offer to help give your loved one their medication. This is something you arrange with the attending physician. It is never an expectation from the healthcare professionals, and you are never alone with the responsibility. Even though the task is straightforward in practical terms, it can still feel like a huge responsibility, and you may be nervous about doing something wrong.

You should never do anything you're unsure about. If you have any doubts or uncertainties, you should contact the hospital. It may also be that your partner occasionally needs help with showering or other personal care. This can provide some intimate and loving moments that bring you closer together, but it can also be challenging when your partner suddenly becomes your caregiver as well. Maybe you can talk about what you're experiencing? Or a parent, sibling, or friend can be good to talk to and seek advice from.

If you become doubtful or unsure about the care you provide regarding personal hygiene – or feel that it's difficult to handle – you should inform the hospital staff.

👉 **I helped Martin shower and gave him a lot of massages. It was quite natural; we were already intimate. With this we also found closeness and small moments where we were together and felt our love.**

Line B.

You can also contact the Cancer Helpline or the Danish Cancer Society's cancer counseling services, which can provide guidance.

## **WHAT ABOUT SEX, DESIRE, AND KISSES?**

The intimacy and closeness you share as partners may be challenged by a cancer patient pathway. There are many valid reasons for this, and it doesn't have to be a problem.

👉 **Remember to tell each other that you love each other and to praise each other in small ways. Rasmus could hardly walk, and at one point, shortly after he had proposed to me, we came through the door at home, and he said to me, "Well, I also need to do a few squats, I have to be able to dance with you at the wedding." I was deeply touched by that and thought, "Wow, you're fighting so hard".**

Lene

For many, a cancer diagnosis means that sex at times is moved to the background. Time and energy are devoted to treatment. Thoughts and emotions such as fear, anger, and despair can dominate, making it difficult to find the energy for sex and intimacy. You may also be hospitalized at times, and a hospital room is not the most romantic place. Nevertheless, it's not unheard of for someone to hang a "do not disturb" sign on the hospital room door, or for compression stockings and granny panties to be called sexy.

The impact of illness and treatment on your body is individual. Some couples choose to abstain from sex for a while and are comfortable with it. For others, maintaining their sex life can be a positive challenge. Talk to each other about what works for you.

It's common for the body to change during and after treatment. Your partner may lose hair, eyebrows, and pubic hair due to chemotherapy. Muscles may atrophy, and physical strength may decrease. Many feel that their sexuality and gender identity become affected, and your partner may feel embarrassed and shy about showing their body, with surgical scars and all.

“ I wanted Lotte to feel good. There were no expectations placed on her, so sex and other normal couple things were put on hold. It wasn't something we talked about. It just happened naturally.

Jesper

“ We kiss each other good morning and several times throughout the day. When we have the energy for it, we cuddle on the couch to be a little closer together.

Casper

As a relative, you may also find it challenging to adjust to your partner's changed appearance, and you may fear hurting them if you touch them incorrectly or in places where they've had surgery. It's a vulnerable situation.

If having sex is challenging for you, you can find intimacy in other ways, such as massage, kisses, closeness, and touch. There are many ways to be intimate and in touch with your own and your partner's desires and sexuality. It's common for almost all cancer treatments to cause physical symptoms that can make it difficult to feel like having sex or to complete intercourse. If you and your partner experience such problems, know that many others do too



### CANCER AND SEXUALITY

You can find more information and other's experiences as well as good advice and exercises in the Danish Cancer Society's brochure "Kræft og seksualitet". It can be downloaded and ordered for free at [cancer.dk/pjecer](https://cancer.dk/pjecer)

## GOOD ADVICE FOR INTIMACY AND CLOSENESS

### Check in with each other

It can be beneficial to check in with each other from time to time and talk about how you feel about everything that's happening and the way it affects your love and desire. On the other hand, it can be a conversation you don't just dive into easily. Maybe you don't have much experience being in a relationship. It's completely okay and difficult for many, with or without a serious illness, but just asking about each other's desires is a big step.

### It's okay to be a boring couple

It might be that people around you are indulging in sex and wild adventures, and it's certain that both of you curse the cancer that consumes so much of your energy, enthusiasm, and sense of attractiveness. Allow yourselves to be a boring couple. If it feels safe and good to cuddle on the couch every night and watch Netflix while eating instant noodles, then that's what you do.

### Start small

If things have been stagnant with eroticism, and you both want to get back into it, you can try starting small. Spooning, feeling each other's warmth and scent, taking a long bath together, or gently massaging each other. You could agree not to take it any further, even if you feel like it. And then only proceed when you're both completely ready. It could also be something else that works for you. Scents, gentle touches, and sweet words. Or a new vibrator. Whatever works for you

### Seek advice and guidance

Talking about sexuality, body, and desire can be delicate. If it's been a long time without closeness, physical contact, or touching, distance can grow between you. It might help sharing any concerns and frustrations with a good friend. There's no shame in seeking professional help either. The doctor or nurse at the hospital can assist your partner or refer you to help. The general physician can also provide good advice, or you can seek out a sex therapist – together or individually.

## GET HELP ORGANIZING EVERYTHING ABOUT FINANCES, PENSION, AND INSURANCE

If you live together without being married and/or have children together, you might already have everything in order regarding finances, pension, and insurance. However, it might also be the case that you don't, which is common for many.

Now that your partner is diagnosed with cancer, significant questions regarding rules and regulations that demand attention and organization arise. This includes how you are positioned financially regarding housing and inheritance if you separate, or if one of you passes away. There are different rules to ensure financial security depending on whether you are married, cohabiting, and/or have children.

If you live together without being married, it's worth considering whether getting married could be advantageous. If you're not married, it might be a good idea for some to establish a so-called cohabitation agreement.

It can be difficult to understand what is relevant for your specific situation. It can be overwhelming to read about and think that you have to deal with all of this while managing everything else you're keeping track of.

### CONTACT A COUNSELOR

Our best advice is to contact a counselor at the Danish Cancer Society. They can help you get an overview of your situation and advise you on your options and rights. You can receive counseling over the telephone at the Cancer Helpline on **80 30 10 30**.

You can also visit the nearest cancer counseling center, where professional counselors are available to assist. Find the closest counseling center at [cancer.dk/faa-raadgivning/english](https://cancer.dk/faa-raadgivning/english)

## GOOD ADVICE FOR YOU AS A COUPLE

### Talk about other things

Neither of you can bear to talk about cancer all the time, so make sure you also talk about what you usually do. Maybe about the future and things you dream of doing together. Even though it's vulnerable, and you're unsure about what will happen.

### Talk about yourself

Your partner still wants to have the opportunity to be your confidant, friend, and lover. Taking your partner's needs into account is necessary and good, but it's not the same as packing away your own feelings and yourself entirely. So talk about your workday, the conflict with your mother, or the soccer match you attended last weekend.

### Cry and laugh

A cancer patient pathway is intense, and you'll probably laugh and cry and be afraid, hopeful, and powerless in one big mess. It may feel absurd to laugh in the middle of a cancer patient pathway, but it can really lighten the load.

### Plan time together

If possible, plan time to do some of the things you love to do together and enjoy each other's company. It doesn't have to be something big and fancy; it can be small things as long as they matter to you.

### Remember the little things

Remember to cuddle, hug, and praise each other. You may not have as much sex as before, very few do in that situation, but you still need to feel each other and feel close. It can be small things like getting scratched on the back, rubbed on the neck, or being told you're lovely.

## HELP AND SUPPORT IF YOU HAVE CHILDREN

Navigating a cancer treatment pathway while juggling parental responsibilities for one or more children can be incredibly daunting. It's natural to be concerned about how the situation will affect the child. You may be unsure about how to talk to your child about the illness, how to handle your own fear of loss, or how to make everyday life work.

When a cancer diagnosis affects a family, both children and adults need a daily life filled with care, extra reassurance, and room for breaks. Other supportive adults in your circle, such as teachers, sports coaches, educators, or healthcare professionals, can play a vital role in maintaining balance and provide assistance.

Remember that you have the option of professional assistance from the Danish Cancer Society tailored to your situation.

## KNOWLEDGE AND HELP FOR YOU AS A PARENT

On the Danish Cancer Society's website, you can gain more insight into how a parent's cancer diagnosis affects a child's life. There is knowledge and good advice on how you can help children through a parent's cancer patient pathway. You can find it at [cancer.dk/boern](https://cancer.dk/boern)

You can also get help and counseling as a family in the Danish Cancer Society's counseling centers nationwide. They can support you in talking to your child and help you get an overview of your situation and options for financial and practical help in everyday life. You can find an overview of counseling centers at [cancer.dk/faa-raadgivning/english](https://cancer.dk/faa-raadgivning/english)

The Danish Cancer Society also has material, films, and podcasts about children's and young people's grief and reactions, which can support professionals in helping grieving children. Read more at [omsorg.dk](https://omsorg.dk)

# ESPECIALLY FOR YOU IF *YOUR SIBLING IS DIAGNOSED WITH CANCER*

Perhaps you've just received the news that your sibling has cancer? You may feel shock, anger, helplessness, or loneliness. Whatever you're going through, it's completely normal, and you probably feel many of the same things as your sibling.

A lot will change for both of you. Some days you may feel closer than ever, while other days you may not be able to stand each other. Right now, everything may seem daunting and overwhelming. That will change over time.

Sometimes you can continue your life almost as before, while sometimes your sibling's situation will affect your daily life and quality of life. Here you can read about some of the feelings and changes you as a sibling and your family may experience.

## **YOUR FEELINGS AND WORRIES**

Throughout the process of coping with your sibling having cancer, various emotions may naturally arise. We've listed some of them here, so you have something to relate to. You're not alone with these feelings.

### › **Feeling scared**

You may feel like your world is falling apart. Perhaps you're afraid your brother or sister will die? And how it will affect your family if your sibling is suddenly no longer here? It's normal to feel scared and confused

### › **Feeling guilty**

You may feel guilty for being healthy when your sibling is sick. Or you may feel guilty for being able to do the things you usually do when your sibling can't. Even if you don't actually do the things, you usually do, it just shows how much you care about your sibling. It's important and okay for you to do things that make you happy and give you energy

### › **Feeling frustrated**

You may also feel angry and feel that it's unfair that your sibling, your family, and you have to go through illness. Or that you don't get the help, support, and understanding from the outside world that you need. Even if you can understand the changes happening right now, you don't have to like it. It's okay to feel angry. Try to find an outlet for it. And remember, when you're angry, you're not a bad person or less loving. You're just angry about the whole situation.

### › **Feeling overlooked**

In the face of illness, the family's attention naturally shifts, often keeping your sick sibling at the center of focus. You may easily feel overlooked and neglected. Maybe you miss talking to your family about something other than cancer. It's perfectly okay if one day you don't want to talk about cancer. Now you need to talk about something else.

“ I was furious that all my friends had just finished their education and were starting work, while I had to be a relative for my sick sister. It was damn unfair. Seeing the others charging ahead with jobs and some even starting to have children, and there we were, just sitting there. And my sister thought it was even more unfair: Why me? But she was super tough and got through it.

Julie

Expressing your feelings to siblings, parents, and other family members can be challenging. You may worry about burdening them. However, it's crucial to try to communicate despite these concerns. Remember, you are valuable and deserving of love and attention, even if you feel like you're not receiving it to the same extent from your parents at the moment.

“ I remember being disappointed that my parents didn't visit me more often in the apartment, where I lived, and took care of me.

Julie

## HOW YOU CAN HELP AND SUPPORT

You may know your brother or sister so well that you know exactly what's needed. You may also be unsure of how best to help and support your sibling through this whirlwind of emotional and physical changes. It's okay to ask what's needed but be patient if your sibling gets irritated when you ask. It's not always easy to know what you need when you have cancer, and it can be hard to accept help.

Continues on page 96 

# GOOD ADVICE FOR YOU AS SIBLINGS

## Spend time together

Do the things you usually do, even if it means arguing and debating. No one expects you to change your personality or stop finding each other irritating sometimes. In fact, it can be a relief to argue and tease as you used to, so your sibling can feel normal. It doesn't have to be a big setup when you meet. It can be a movie on the couch, a cup of coffee, or a walk – maybe around the hospital.

## Talk about what's happening in your life

You might wonder if it's okay to talk about what's happening in your life now that your sibling is sick. It's just an expression of your consideration. But no one wants to talk about cancer all the time. Talk about what you're doing and what's going on. Your sibling might feel a pang of envy and sadness for not being able to participate in the same way as before, but it's better to be updated than to feel left out.

## Help contacting friends

When you're sick, you may need help keeping in touch with your friends. You can offer to create a Facebook group or send a message to your sibling's friends. Some people will have a hard time dealing with a cancer diagnosis and may start acting strangely. Some might even stay away. Here you can support your sibling and help communicate how things are going and what's needed.

## Assist with practical things

It can be a big help if you lend a hand with cleaning, doing laundry, or whatever is needed. If your sibling has a child/children, there may be need of more help to make everything work. You may also be the extra adult your sibling's child/children can share worries with – or be spoiled rotten by.

☞ We created two groups on WhatsApp and Facebook. Mercan manages the Facebook group with her friends, so they don't have to constantly call Meryem and ask a hundred things, and I manage the family group. We talk to Meryem's husband and mother-in-law and plan who will pick up the little one, and who will cook and take care of all the practical things.

Gülay

☞ Everything my parents did revolved around my brother and his illness. I was 18 at the time, and it wasn't obvious that I was included along with my parents. So I ended up in a lonely hole, where I on one hand was connected to the daily life in my parents' house and my brother's illness, and on the other hand was completely disconnected, lonely, and a so-called adult.

Lise



## YOUR RELATIONSHIP WITH YOUR FAMILY

You may be used to sharing your thoughts and feelings with your family. Now you're holding back to protect them from extra worries. This is natural and an expression of love. But no one can be strong all the time. You're allowed to be angry and upset. And it's okay to let your parents or other family members know that you find it hard.

Perhaps you have a feeling that your mother and/or father aren't telling you everything? It could be that your parents omit to inform you about changes in the illness and treatment because they're trying to protect you, or they become unsure about what to say and do. If possible, try to talk to your family about needing to ask questions and be informed if there are changes in the illness and treatment. You may feel guilty about expressing your needs in this way. You shouldn't. You are important and loved.

### YOUR RELATIONSHIP WITH YOUR SIBLINGS

Many people find that a cancer patient pathway changes their relationship with their family and challenges the roles you typically have in a family. If you're the oldest in a group of siblings, you might be used to taking care of your younger siblings, or vice versa, if you're the youngest, you might be used to being the little one and viewing the others as the ones who can do everything.

During a cancer patient pathway and afterwards, everything can be turned upside down, and roles can be reversed. You may experience new sides of yourself and your siblings, which can be difficult to handle, but can also bring you closer together.



#### HELP AND SUPPORT FOR YOU AND YOUR FAMILY

Remember that you and your family can receive free family counseling and assistance with difficult conversations at the Danish Cancer Society's counseling centers. You can find an overview of them here:

[cancer.dk/faa-raadgivning/english](https://cancer.dk/faa-raadgivning/english)

“ If I had a lot of money, I would have flown my sister around for everything.

Line F.

“ Rikke's determination is absolutely insane, I truly admire that. When I find it tough to carry two heavy grocery bags, I think: Relax, Line, your fingers hurt a little, it'll pass.

Line F.

“ She gave us a bracelet that she had made for us, with a clover where she had engraved our initials. It's a symbol that the three of us siblings have fought together.

Mercan

# ESPECIALLY FOR YOU IF *YOUR FRIEND IS DIAGNOSED WITH CANCER*

Maybe you've just been told that your good friend has cancer? It's impossible to prepare for what you say and do in that situation. You may doubt how to best help and support.

You should know that just being there, as you usually are and in your own way, makes a difference. Maybe you're the best at listening and talking about feelings and concerns? Perhaps you fill the freezer with delicious food, share notes from class, or help run errands and with childcare. Contribute where you can. Everything is needed.

🗨️ **It's perfectly fine to offer what you can handle in your life. If you're pregnant or have small children, nobody expects you to show up four times a week with a lasagna. It is better to do some than to do nothing at all.**  
Anne S.

## HOW YOU CAN SUPPORT AND HELP

If you're unsure what your friend needs, you can always ask. Your friend may not know or doesn't have the energy to answer. Then you can suggest something specific you can help with or ask again later.

Perhaps you can also ask about how their work or studies are going while all of this is happening? Or something completely unrelated to cancer and illness. Often, it's just nice that you ask how they're doing. Don't be afraid of saying something wrong. It happens for everyone.

### COORDINATION IN THE FRIEND GROUP

It differs how much help you want to accept if you have cancer. If there are several friends helping with practical matters, it can be a good idea to divide the tasks. If there's energy for it, you can perhaps meet with your friend and talk about what's needed.

For most young cancer patients – and their relatives for that matter – it's a huge relief when someone takes the initiative to coordinate the help being offered. Maybe it's a task for you to create a task schedule.

You can also use the Danish Cancer Society's app 'Sammenholdet' to coordinate tasks such as cooking, childcare, and transportation. It can also be used to update friends and family on how the disease is progressing.

You can download **'Sammenholdet'** for free in the **App Store** or **Google Play**.

## WHEN FRIENDSHIPS CHANGE

You may experience that your friendship deepens during the process, but the opposite can also happen, and you may drift apart. It can be difficult to communicate as you used to, now that your lives are so different. Perhaps your friend also gains new friends among other young people with cancer and has a community with others that you're not part of.

At the same time, you may feel that your problems are trivial compared to what your friend is going through. Therefore, you may refrain from talking about what's happening in your life. Your friend wants to hear about all your little problems but may also have difficulty accommodating it because they just want to have a normal life themselves.

This can create a lot of conflicting feelings and considerations, which can pose a challenge in the friendship and make it awkward to be together. It's entirely natural and difficult to avoid. The best thing you can do is to say it out loud if you become unsure. Maybe you really need to vent about your boss or about your partner forgetting to empty the dishwasher. You can ask if it's okay and if your friend can handle hearing it. It's easier said than done, and we're all different. But it's usually easier for both of you if you have the energy to be open and honest in the situation, even though it's vulnerable.



### TALK TO A COUNSELOR

Remember that you can get free counseling from the Danish Cancer Society if you have questions about cancer or need help putting your worries into words.

Call the Cancer Helpline on **80 30 10 30** or start a chat at [cancer.dk/kraeftlinjen](https://cancer.dk/kraeftlinjen)

“ You learn a lot along the way, also about friendship. It's perfectly okay to make mistakes and say something wrong. There's only one wrong thing, and that's if you say nothing. No matter what you think, it matters that you write: I'm thinking of you.

Anne S.

# GOOD ADVICE FOR YOU AS FRIENDS

## Reach out and stay in touch

It means everything when you call to say hello, and your friend feels that you stick around. Or write a message. Ask how the treatment is going and keep sending messages, even if you don't always get a response. A cancer patient pathway can be long and exhausting, and it's often the little things that make a big difference.

## Offer your help with specific tasks

This could be shopping, cooking, and cleaning. You can also offer support for tasks related to your friend's treatment, such as keeping track of medication, appointments, and doctor visits.

## Come along for treatment

Perhaps your friend would appreciate it if you went to doctor's appointments or treatments together? Ask your friend if you're unsure.

## Visit

Make sure to visit your friend in the hospital or at home, unless the treatment requires isolation, of course. It makes a big difference to have a friend visit whom you can talk to about anything, even things other than illness. Talk about your everyday life as you normally would.

## Keep inviting

Your friend may say no to most things but keep inviting them anyway. For birthdays, dinners, concerts, parties – anything. It's a good way to ensure that your friend still feels included.

## Listen – even when it hurts

Having cancer is tough. Your friend may want to protect you and may not tell you about their worries, thoughts, and pains. You can try asking how your friend is doing. If your friend wants to talk, it's a good idea to just be there and listen. It makes a big difference when someone listens and dares to be with you when you're sad and afraid – even without giving advice or suggesting positive things to do.

## Remember yourself

It's hard when someone close to you has cancer. Talk to your family, friends, or colleagues about how you're feeling. You can also talk to other young relatives through Ung Kræft.



“ We thought it was unfair. We truly believed that love could overcome it. It didn't seem right that even with our love so strong it should end. We stubbornly clung to hope, and the day after we were told that there was no more treatment to be had, we went to the beach and Rasmus got down on one knee and proposed to me.

Lene

# *IF YOUR LOVED ONE IS TERMINALLY ILL*

This part of the book is written especially for you, who have been told that your loved one is terminally ill. You can read about what other young relatives have experienced and what has helped them. Read it when you feel ready. We know it's not easy.



## WHEN YOU'RE IN THE MIDST OF CHAOS

If you've received the tough and challenging news that the treatment isn't working and the cancer is incurable, you're facing something incredibly forceful and difficult to handle. Death becomes imminent, and life becomes profoundly intense. Some may prefer not to think about what lies ahead, while others choose to prepare themselves as best they can.

👉 **It has helped me and Rasmus to keep up with the treatment and try to understand it well. And then to dare believe in the best and continue to hold onto hope.**  
Lene

No handbook can provide you with the answers or precisely tell you what to expect. However, it may help to know that other young people have faced similar situations and have managed to cope.

We've learned from them that when the future is uncertain and fear looms, it can be helpful to:

### › Do meaningful activities together

The possibilities vary. Even small activities that you both enjoy can make a significant difference. Whether it's listening to your favorite podcast, going to the movies, reading aloud to each other, enjoying a cup of coffee, or simply sitting close on a comfy couch and reminiscing about old times. You likely have better suggestions yourselves.

### › Hold onto your daily routines and responsibilities

Upon receiving bad news, it may feel like you're living outside yourself. The events seem surreal, and life carries on, yet you feel disconnected. It's a good idea to maintain as normal a life as possible, even though it may sometimes seem inhumane.

Doing so can serve as a reminder of your own needs, preventing the illness from overshadowing everything.

### › Discuss life and your dreams

Despite the looming presence of death when your loved one has incurable cancer, life can still be the focal point. Talking about your dreams can breathe life and joy into your shared experiences. Although it can't replace real-life experiences, many find solace in sharing their thoughts with each other. However, for some, discussing dreams can be painful. Do what feels right for you.

### › Be compassionate towards yourself and each other

For some, the course of the illness is brief and intense, while others live with chronic, incurable cancer for years. Consequently, the experiences of the person who is sick and you as a relative can vary greatly after receiving the news. Don't expect yourself or your loved one to follow a pre-determined reaction or behavior pattern. Respect each other's coping mechanisms and acknowledge that you're both doing your best under the circumstances.

### › Share your worries and fears

When death draws near, it can feel incredibly lonely. You're confronted with existential realities that can weigh heavily on your mind. Even when you feel isolated, there's still much you can share with the sick person and those close to you, making the burden a little easier to bear. You might already sense what you can share with your loved one and with others.

### › Be with someone who dares

It can be comforting if those around you dare to discuss fear and perhaps what specifically you fear. Having extra loved ones who are willing to accompany you into the darkness and simply be present with you can be a tremendous gift.

### TREATMENT AND RELIEF OF SYMPTOMS

Some receive the news that the disease is incurable when they are first diagnosed with cancer. This may be due to the cancer being detected late or it being very aggressive. Others experience relapses, spread, and long treatment pathways that unfortunately do not eradicate the cancer.

Although it's not possible to completely eliminate the cancer, it may be possible for some to receive treatment that keeps the disease at bay. This could help you regain some stability and begin to adjust to a life with incurable and chronic cancer.

For others, it's not possible to treat the cancer, but the patient can receive treatment to control and alleviate symptoms. This is known as palliative, relieving treatment. It's good to know that palliative treatment has several stages and can begin early and run parallel with the treatment of cancer.

An option is staying in hospice. It doesn't necessarily have to be in the final stages but can provide a much-needed break in a difficult process – for you as a relative as well. Your loved one can stay temporarily to alleviate pain or other symptoms and then return home afterwards. Staying in hospice is free of charge.

You can read more about hospice and palliative teams at [cancer.dk/densidstetid](http://cancer.dk/densidstetid)

“It's painful to feel that we can't be there for each other in that way. I wasn't angry, but rather sad that we can't share this anymore. It was a feeling of already losing him before he was completely gone.

Line B.

### ANTICIPATORY GRIEF

When you receive the news that your partner, sibling, or friend is terminally ill or dying, it can feel like you're already in the process of losing them. You may grieve over a future that will be different from what you had imagined, or over your partner, sibling, or friend not being the same as they were before. This is called anticipatory grief.

As a relative, the period of illness before death can feel like a state of exception characterized by uncertainty, worry, and anxiety. During this period, grief revolves around what you will lose when the sick person passes away. It may involve loss of identity, love, dreams, and future plans.

The cancer patient may also experience anticipatory grief – grief over what they will lose alongside life. Anticipatory grief is a natural part of the grieving process, but not everyone experiences it.

“It's like I'm grieving over something that hasn't happened yet. It has been meaningful for me to put a word to it: Anticipatory grief.  
Sofie

### THE FINAL STAGE

Your needs vary greatly when you receive the unbearable news that your loved one is dying. Your needs may also differ significantly from those of the dying person.

As you approach the final stages together, it can be helpful to discuss what will happen when your loved one is no longer here. As a relative, you may need to discuss and come to terms with death, both existentially and spiritually, as well as practically.

Not everyone feels comfortable discussing death, and it's also possible that you're too scared. For young people like you, it can be particularly difficult to grasp that life will end, and it can feel both absurd and too painful to talk about. The dying person may also fear that discussing death is the same as giving up. You may feel the same way as a relative.

### TALKING ABOUT DEATH

Talking about death isn't the same as giving up hope. It can also be an expression of appreciating life together and the good experiences you may still have. If you find it too challenging to talk with your loved one about death and the practicalities surrounding it, you can ask if it's possible to write it down for you and your family.

Consider whether there are any particularly difficult topics or practical considerations that can be discussed with others close to you - without your loved one present. If there are several close relatives, you may be able to air concerns and unresolved questions together. This way, different needs for coping with things can be gently accommodated.

If it's impossible for your loved one to discuss what will happen, it may help you to think that for some, it's a way of coping with the final stage. It doesn't necessarily mean they haven't acknowledged that they're going to die. It may also be about not wanting to upset their loved one.

### PRACTICAL THINGS CAN BE CHALLENGING

Many cancer patients find solace in ensuring that all practical matters are attended to prior to their passing, alleviating the burden on their loved ones who may otherwise be overwhelmed with grief. This could involve securing your ability, as a partner or spouse, to keep living in the apartment or house, organizing financial matters comprehensively, and establishing clear

arrangements regarding inheritance, which is particularly crucial when children are involved. For some, it's comforting to have made arrangements for memorial services and hymn choices beforehand, while for others, it's completely absurd to think about and deal with such matters.

### SOCIAL MEDIA PROFILES AND PASSWORDS

It may seem absurd to have to deal with, but we know from other young relatives that it can be important to consider what will happen to your loved one's social media profiles after their death. Some prefer the profiles to be closed, while others wish for them to continue. When your loved one is no longer here, it's usually possible to close the profiles without passwords, but it's easier for you if your loved one has written down their passwords for profiles and email.

It may also be a good idea for your loved one to write down their passwords for their mobile phone and computer so that you, as relatives, can benefit from, for example, photos and documents. Or you may have access to bank accounts, apps, and streaming services depending on what is relevant to your situation. It may also happen that the final days are so short and intense that you don't get around to discussing such matters, or it's too difficult to deal with.

### YOUR LOVED ONE'S WISHES

Some prefer to die at home, while others prefer hospice or a hospital. If your loved one wants to die at home and you live together, it's important to discuss whether you can handle the task.

“ I wish we had talked about what would happen if Mikael died. We never had that conversation because we wanted to keep hope alive. If we had started this conversation, we would no longer have had hope. I regret that.  
Catrine



You have great love for your loved one, but it's physically and mentally challenging to care for someone who's dying. While professional assistance will be available, most relatives experience it as a significant responsibility and task, albeit one that can provide space for peace and intimacy during the final period at home.

Speaking with your general physician or hospital doctor about your options can be helpful. They can provide more information about pain relief and the possibility of obtaining various forms of practical aids and home care.

🗨️ **Rasmus and I agreed that we would cherish the short time we had together. Death shouldn't dominate our thoughts, and when we discussed it, it was on Rasmus' initiative. Of course, we told him that we were willing to listen and talk if he needed it, but he genuinely didn't. The practical matters would sort themselves out when the time came.**

Lene

### HOSPICE CARE IN THE FINAL STAGE

Staying in hospice during the final stage may be an option. While the idea of hospice care might seem overwhelming to some, being there together can provide a different sense of extra energy and closeness that might be challenging to find in a hospital or at home, where you might be managing everything on your own. At a hospice, the staff focuses on providing care and relief. In many places, you may be allowed to stay with the patient, and the staff also offers support and guidance along the way.

### URGENT MARRIAGE

Some young couples, where one partner is dying, choose to get married in the hospital. This decision is made not only to celebrate love during a difficult time but also to ensure legal and financial security. The hospital staff can assist in contacting a priest and arranging necessary declarations and documents

## PRACTICAL ASSISTANCE

You can receive support and guidance regarding funeral arrangements and testamentary and inheritance matters.

### Funeral arrangements

For some, discussing funeral preferences and arrangements can be eased by utilizing resources like the 'Min sidste vilje' document. This document assists in articulating funeral wishes and cremation details. You can obtain this material from Landsforeningen Liv & Død or access it through their website:

[livogdoed.dk/materialer](https://livogdoed.dk/materialer)

### Testamentary matters

Navigating inheritance and wills can be daunting, but it's crucial for many cancer patients to ensure the well-being of their loved ones. Some may find it natural to initiate discussions about what is going to happen with financial matters and property, while others might find it challenging.

Remember that you can seek assistance from counselors at the Danish Cancer Society.

You can also contact inheritance advisors with general questions about inheritance and wills. You can reach out to them on **35 25 77 70** or [arv@cancer.dk](mailto:arv@cancer.dk)

Additionally, [cancer.dk/arv](https://cancer.dk/arv) offers information on inheritance laws and will creation.

●● All our dreams for the future vanished. The life we were building together disappeared. It's different when you're 60 and have shared memories. But we were still creating ours. This has been one of the hardest things.

Casper

●● If I have something to pass on, it's the need to find meaning in the chaos and mess. You can insist on finding small moments of significance when time falls apart. I've never felt so present; it was all we had. We had no sense of time. It was so simple and pure.

Line B.



☞ Grief is unfamiliar territory. It's not something our culture prepares us for, and as a young person, you might find yourself without others who understand or have been through it. Sometimes, grief defies words.

Casper

# *LOSING A LOVED ONE AND COPING WITH GRIEF*

Here, you'll find information about loss and grief, along with quotes from young people who have lost that offer firsthand insights into the experience of losing someone and navigating through grief, each in their own way.



## PUTTING GRIEF INTO WORDS

Losing someone we are closely connected to and love deeply is a profound sorrow. It's one of the most painful experiences we can endure. How we react to loss varies greatly, depending on who we are, where we are in life, and our relationship with the person we've lost. But it's always difficult and leaves a mark on our lives.

Everything you read here can't fully encompass your situation, but we still hope that you can find inspiration, comfort, and hope in the words and experiences of others.

### YOU HAVE LOVED

It is said that grief is love without a home. You lose a person, but the love remains. Grief is also hard to put into words and hard to grasp. But trying to find those words—maybe by reading about grief or listening to podcasts that tackle tough topics—can help.

It gives you a way to understand what's happening, how you're feeling after the loss, and what you can do to start moving forward, all at your own pace and while remembering your loved one. Eventually, it might help you find a way to live with the loss.

Grief is individual. But perhaps you can recognize your feelings and thoughts in some of the words and stories in this chapter from other young relatives who have experienced loss. And remember that grief exists because you have loved. You are full of love and life.

Continues on page 124 

“ How does one survive losing someone they love so deeply?

Catrine

☞ When you're grieving, you change.  
You don't have the same desires as before  
or want to talk about the same things.  
Honestly, I couldn't care less about diets  
and makeup. It makes me feel different.  
I'm in a different place in life.

Line B.

☞ If you ask my friends, I'm not grieving.  
They don't see it. That's the dilemma I'm facing  
now. How do I tell them that I know it's been  
two years since my little brother died, but  
potentially, I'm struggling more now than I did  
right when it happened?

Lise

“ In the beginning, I thought I couldn't be happy, but now I sit here with a feeling of both happiness and sadness inside. You can be happy even while grieving.

Lene

## HELP AND SUPPORT FOR YOU DURING A DIFFICULT TIME

### Get help with your grief

It can be a great help joining support groups, where you can share your thoughts and feelings with others going through similar experiences.

These groups are available nationwide, and you can find one near you through the Cancer Helpline or local cancer counseling services.

You can also read more about cancer and grief in the “Kræft og Sorg” pamphlet, which is available for download at [cancer.dk/pjecer](https://cancer.dk/pjecer)

### Access financial support

If you've lost a spouse or partner, you may be eligible for financial assistance such as benefits and funeral support.

You can learn more about eligibility and how to apply at [borger.dk/sundhed-og-sygdom/Doedsfald-og-begravelse](https://borger.dk/sundhed-og-sygdom/Doedsfald-og-begravelse)

### Seek professional counseling

Through the Danish Cancer Society's cancer counseling centers and Cancer Helpline, you can receive personalized support and guidance for practical and financial matters. Expert counselors are available to help you navigate the process.

Find the nearest counseling center at [cancer.dk/faa-raadgivning/english/](https://cancer.dk/faa-raadgivning/english/) or contact the Cancer Helpline on **80 30 10 30** or start a chat at [cancer.dk/kraeftlinjen](https://cancer.dk/kraeftlinjen)

## REMEMBERING

There are many ways to honor the memory of a loved one you have lost. Some who have lost – friends and family – gather annually at the cemetery and share a special meal, perhaps the favorite dish of their loved one. Others play specific music or meet with their former in-laws for lunch on the anniversary. Alternatively, you may remember your partner, sibling, or friend through small daily rituals. Remembering can be tough, yet comforting, as it allows you to recall and feel the love and all the good experiences you shared.

👉👉 **I'm really lucky that right where Lotte is buried, there's a large, beautiful park bench. So sometimes I sit there with a soda and just switch off my brain and exist for a while.**

Jesper

## YOU GRIEVE AND MOVE FORWARD AT YOUR OWN PACE

The grief and love for the one you lost do not fade away, but rather, you grow with them and make room for new beginnings. Sometimes, new opportunities arise on their own, even when you don't feel entirely ready for them. You have plenty of wonderful life to live, filled with new experiences and dreams – and if your partner has passed away, perhaps eventually a new partner, children, and family.

You may feel pressure from your surroundings to move on. This pressure is an expression of concern but can be frustrating and painful. Conversely, you may also feel guilty for having a good day and being happy. Grief ebbs and flows. Some days, you are busy with other things in your day to day, and life feels normal. Other days, grief takes hold and fills everything.

## WE GRIEVE IN DIFFERENT WAYS

There are as many ways to react and handle grief as there are people. For many who have lost someone, it may feel like the deceased will return shortly, perhaps just out traveling or at work. This is normal.

You move forward at your own pace. Do not feel guilty for still feeling sad and mournful, or conversely, for being happy and laughing during your grieving process. The most important thing is to acknowledge your own needs and not feel pressured to deal with it in a specific way. We know it's easier said than done. Give it time and reach out when you need help and support. There is plenty of life to be lived.

👉👉 **It's hard for me to reconcile that I have to talk about him in the past tense. I still say that I love him, and I will continue to do so. He's not here like we are, but I love him, and for me, he's still here – just in a new way.**

Lene

●● I'm ready. I've always wanted to start a family, and I'm mentally preparing myself for it. I miss having someone to share my life with, someone to wake up next to and say good morning to. And regarding having kids – that's something I truly desire. I've faced some tough experiences, but I believe I can use them to enter a new relationship with optimism about life. I won't forget what I've been through; it's part of who I am.

Jesper



# ASSISTANCE AND SUPPORT FROM THE DANISH CANCER SOCIETY

Both you and the cancer patient can receive counseling, information, and support from the Danish Cancer Society.

Information in English can be found on the Danish Cancer Society's English website: [cancer.dk/faa\\_raadgivning/english/](https://cancer.dk/faa_raadgivning/english/)

You can also call the Cancer Helpline on **80 30 10 30**

## Ung Kræft

Ung Kræft is a community within the Danish Cancer Society where young cancer patients, young relatives and young people who have lost young loved ones aged 18-39 support and inspire each other.

In Ung Kræft, you can exchange experiences with other young relatives and people who have lost a loved one to cancer. You can also find inspiration and stories about life as a relative and someone who has lost on Ung Kræft's Instagram, Facebook, and website.

You are always welcome to contact Ung Kræft if you have any questions.

Send an email to [ungkraeft@cancer.dk](mailto:ungkraeft@cancer.dk)

Call **35 25 74 72**

Follow on [Facebook.com/ungkraeft](https://www.facebook.com/ungkraeft)

Follow on Instagram [@ungkraeft](https://www.instagram.com/ungkraeft)

You can also search [#ungkraeft](https://www.instagram.com/ungkraeft) or [#duerikkealene](https://www.instagram.com/duerikkealene)

## The Cancer Helpline

If you have questions about cancer or need support and guidance, you can call or chat with the counselors at the Cancer Helpline.

Here you can talk to psychologists, doctors, nurses, and social workers, all of whom have extensive knowledge about cancer and related matters. They can help you get an overview of your situation and help articulate any concerns you may have. This could include questions about cancer treatment and side effects, relationships and cancer, your children's reactions, sick leave, rights, and finances.

Call **80 30 10 30** or start a chat, read more about the Cancer Helpline and find opening hours on [cancer.dk/faa\\_raadgivning/english/](https://cancer.dk/faa_raadgivning/english/)

## Cancer counseling centers across the country

Throughout the country, you will find cancer counseling centers. Many are located close to the hospitals where cancer treatment takes place. You are always welcome to drop by and have a cup of coffee, for example, as a little break when you are in the hospital. You can talk to professional counselors who can help and guide you in the situation you as a relative are in.

The cancer counseling centers offer various services, but everywhere, there is an opportunity to talk to a counselor either alone or together as a couple or family. All services are free of charge.

You can find an overview of the cancer counseling centers at [cancer.dk/faa\\_raadgivning/english/](https://cancer.dk/faa_raadgivning/english/)

## Translator


Most of the staff on the Cancer Helpline and in the counseling centers can answer basic questions in English, but you can get a translator if you need it. The service is free.

# *POSTSCRIPT: HOW THE BOOK CAME TO BE*

No one knows more than those who have experienced it themselves. Therefore, this book was created together with many young people who have been in the same situation as you have as a relative. All the topics, quotes, and stories in the book have emerged from two workshops and 10 individual interviews conducted in 2021 and 2022, where 20 young people courageously and honestly shared their experiences, thoughts, and challenges.

The focus of the conversations with the young people has been twofold. On one hand, to learn more about what they think has been lacking and what has been helpful. On the other hand, to gain insight into their experiences as relatives of a young person with cancer, and how it has affected their lives and relationships with family, friends, and others around them.

From the team behind the book, a big thank you to everyone who helped make the book a reality. A special thank you also to all you young people who inspire us, move us, and make us wiser every day. Best wishes and good luck to all of you in the future.

You are not alone   
Ung Kræft



# SOURCES

The book is based on the experiences of young relatives and young people who have lost as well as knowledge from counselors from the Danish Cancer Society and the Danish Cancer Society's website [www.cancer.dk](http://www.cancer.dk)

We have also gathered inspiration and knowledge from:

*How to support someone with cancer*, Teenage Cancer Trust:  
[www.teenagecancertrust.org](http://www.teenagecancertrust.org)

*Håndbog til unge kræftpatienter: Fuck. Jeg har kræft. Hvad nu?*  
Ung Kræft (2017)

*Kreft. Shit. Hva nå? Ung Kreft (2020)*  
[www.ungkreft.no/nyheter/bok-for-unge-kreftrammede](http://www.ungkreft.no/nyheter/bok-for-unge-kreftrammede)

*Patientguiden*, Region Hovedstadens guide til patienter og pårørende.  
[www.regionh.dk/Sundhed/Patientguiden](http://www.regionh.dk/Sundhed/Patientguiden)

*Pårørendeguide – håndbog for dig, der er tæt på én med psykisk sygdom*,  
Bedre Psykiatri

*Råd til pårørende*, Danske Patienter:  
[www.danskepatienter.dk/patienter-paaroerende/raad-til-paaroerende](http://www.danskepatienter.dk/patienter-paaroerende/raad-til-paaroerende)

*Til pårørende og etterlatte*, Kreftforeningen:  
[www.kreftforeningen.no/rad-og-rettigheter/til-paroerende-og-etterlatte](http://www.kreftforeningen.no/rad-og-rettigheter/til-paroerende-og-etterlatte)

*When Your Brother or Sister Has Cancer: A Guide for Teens*,  
National Cancer Institute, (2013). The book can be downloaded at:  
[www.cancer.gov/publications/patient-education/when-your-sibling-has-cancer.pdf](http://www.cancer.gov/publications/patient-education/when-your-sibling-has-cancer.pdf)

“ I alternated between being there for my parents, for my sister, and for myself – probably least of all for myself.

Julie

This book is written especially for you, who is a young relative to a young person with cancer. You can read about other young people's experiences, feelings, and thoughts and find good advice for everyday life as a relative. The book also includes a chapter on loss and grief.

***You are not alone.***



UngKræft

