

LISTEN. BE AT THEIR SIDE. HELP.

How to help children and young people when parents become ill with cancer

Sabine Brütting

 BAYERISCHE
KREBSGESELLSCHAFT E.V.



Contents

Contents	02
Foreword	03
1. Introduction	04
2. Diagnosis	05
2.1. How children and young people see things	05
2.2. Suggestions for a conversation	07
3. Therapy	10
3.1. Hospitalization and surgery	10
3.2. Side effects of chemotherapy	11
4. Everyday life	13
4.1. In kindergarten and at school	13
4.2. In the family	14
4.3. How children react physically and emotionally	19
4.4. Children of divorced parents	22
5. Saying goodbye	24
6. Further reading	28
7. Useful addresses in Bavaria	29
Legal Notice	35

This brochure was made possible with the kind support of:



gefördert durch
Bayerisches Staatsministerium für
Umwelt und Gesundheit



Dear readers,

A cancer diagnosis represents a big disruption in the lives of those affected and their families. For children, a family member becoming ill with cancer truly means a loss of innocence. On account of this, the Bavarian Cancer Society Inc. (Bayerische Krebsgesellschaft e.V.) has developed this patient guide entitled “How to help children and young people when parents become ill with cancer”. The Bavarian Ministry for Health is pleased to have supported this valuable project as part of its “Healthy.Life.Bavaria” (Gesund. Leben.Bayern) initiative.

When and how do you explain your own illness and the effect it has on life to your children? Which emotional or even physical reactions can this cause? How can the illness be integrated into the daily life of children? How do you prepare them for saying goodbye, should it come to the worst? This brochure answers these and many more questions and helps finding the right words at the right time.

*Dr Marcel Huber
Minister of State*



Dear readers,

A child's world is shaken to the ground when a family member becomes ill with cancer. With our booklet we want to help parents find the right words to say to their children in this situation. One parent becoming ill with cancer often has major effects on the children, especially when parents are unable to speak to them openly. Young children in particular often feel responsible and develop feelings of guilt because they believe that they have contributed to the disease with their behaviour. They may become withdrawn, aggressive or maladjusted. It is important that parents respond calmly and openly to their children's questions. But many adults are unable to do so because they are themselves worried and anxious. In such crisis situations, affected families can access individual counselling at our psychosocial cancer counselling centres, offering the family some relief.

*Markus Besseler, Psychologist
Managing Director, Bavarian Cancer Society Inc.*



1. Introduction

Every year in Germany, 150,000 to 200,000 children under 18 are for the first time confronted with the situation that their mother or father has been diagnosed with cancer, according to estimates of the Robert Koch Institute.

This means that there are underage children living in every third family where one parent becomes ill with cancer. The disease affects the lives of all members of the family. Children too are affected and also carry the burden that cancer becomes for the family - often for years. Unfortunately, the hardships experienced by the children are often underestimated, or they go unnoticed, even by their own parents. But such a dramatic experience has lasting effects on children – both on their experience of childhood and on their development.



Often, parents are unsure about whether to tell their children about cancer and how, and about what support the children may need during the illness. This booklet provides answers by

- encouraging parents to tell their children about the disease.
- providing practical hints for talking to children about the disease.
- opening a window into the emotional world of children whose parents have cancer, and by making them aware of their needs.
- suggesting ideas about how children can be supported.
- giving people the courage to also talk about dying.
- providing addresses that can offer professional help.

All quotations marked * are taken from the book "What does cancer do to us? - Explaining a parent's illness to children".

2. Diagnosis

2.1. How children and young people see things

Everyone is shocked by a cancer diagnosis: those affected, their spouse, family and friends. Many patients feel like losing the ground beneath their feet. They feel at the mercy of rising feelings of fear, sadness, anger and despair.

In addition, parents are often uncertain about whether and how to inform their children about the diagnosis. For many, the desire to protect their children and leave their world intact is at the forefront. They therefore hesitate - often encouraged by family and friends - to tell their children about the disease. But this is not helpful for children because they can tell that something is wrong in the family. **For this reason, tell your child as soon as possible that you have cancer.**

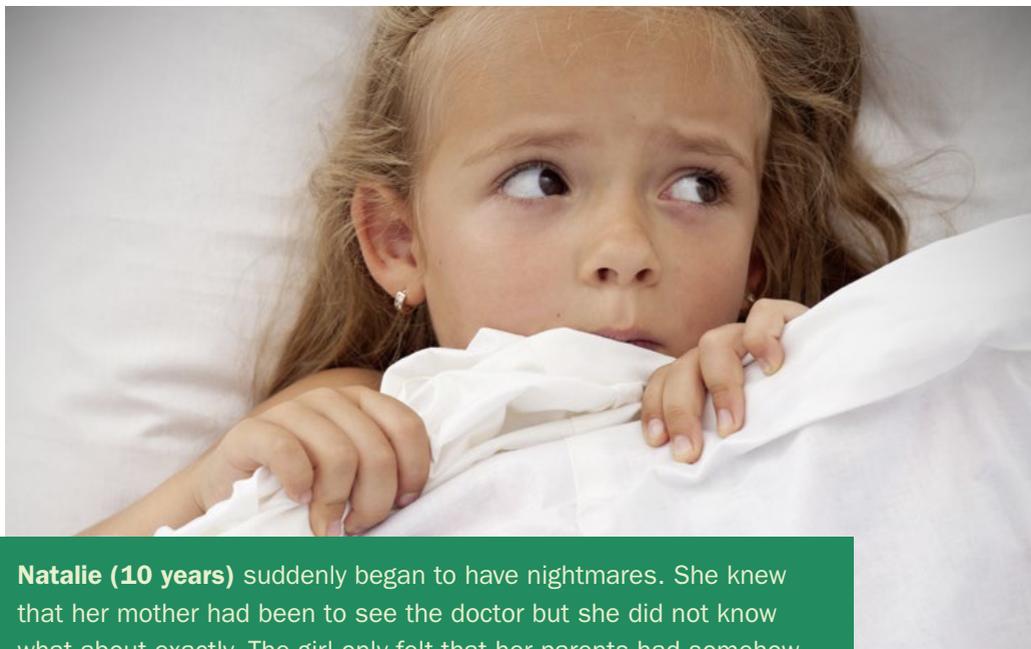
Even toddlers can detect a change in their parents' mood. They sense it if parents are frightened by the diagnosis, sad or desperate, and may have problems sleeping, eating disorders or react with anxiety or increased crying.

Older children, too, register the tense emotional state of their parents much more strongly than adults suspect. If they don't know the reason, they often blame themselves for their parent's changed behaviour.

They may ask themselves questions like: „Is mum acting weird because I haven't tidied my room again?“ Children are reassured when they learn from their parents that they are not the cause of their stress. **Confirm your child's impression that something is different from the usual and state clearly that the cancer diagnosis is the reason.**

Children who don't know what is going on often develop inflated, frightening fantasies and suffer from generalised fears to which they respond with aggressive behaviour. Older children may become increasingly quiet and more and more withdrawn.

2. Diagnosis



Natalie (10 years) suddenly began to have nightmares. She knew that her mother had been to see the doctor but she did not know what about exactly. The girl only felt that her parents had somehow changed, and that the mood at home was low. Natalie responded to her parents' changed emotional state with nightmares and she sensed that there was something wrong with them. Natalie did not know that her mother had been diagnosed with breast cancer a few days earlier. *

When parents shy away from telling their children about the cancer, there is a danger that the child will find out from others - often unprepared and in a blunt fashion. When this occurs, children may feel marginalized and betrayed - and in many cases react with anger. They have a sense that they can no longer trust their parents. This loss of trust is underestimated by most parents. Children have a fundamental need to be able to rely on their parents.

But to tell a child the painful truth is not just a big ask, it also conveys the message that "You are important to me and I want to be open and honest with you. I know that you are strong enough to cope!"

Despite all the stress, many a child emerges a stronger person from the difficult life event that the illness of a parent represents.

2.2. Suggestions for a conversation

In general, the illness of a parent causes many changes in daily family life. It is inevitable that hospital stays, treatments and frequent doctor visits also affect the lives of the children. At this stage it really is high time to tell the children about the cancer.

As a parent, do not put yourself under pressure to explain everything fully in this first conversation. There will be further opportunities later. The important thing is to make a start. **State clearly that mum or dad has cancer.** For small children it is enough to explain that mum or dad goes "ouch" and needs to go to the hospital. From kindergarten age onward, parents should specifically name it as cancer. Avoid vague descriptions such as "a bad disease" or the term "tumour". This often leads to misunderstandings because children cannot fully understand these terms.

Young children often suspect cancer means that an animal (a crab, translator's note: Krebs in German means both cancer and crab) now lives in mum's tummy. The parents should set the record straight. It is often helpful to visualize where the cancer is located in the body by drawing or looking at a picture book of the body. Parents can also easily demonstrate this on a doll.

Explain that cancer is not a contagious disease. This is important because many children avoid close contact to the patient for fear of infection. Say that the sick mum or sick dad can still be cuddled - this is equally beneficial for the child and for the parent.

It is a good idea if parents talk to their child about the illness together. There is no standard "right" moment for this conversation. **It is most important that you are honest and allow enough time for the emotions and questions that arise.**

2. Diagnosis

It's perfectly normal to cry during this talk - that goes for the parents, too. If parents try to protect their children by concealing their own concerns, the message they convey is: "We must be strong and brave" – even without any words.

If parents show their feelings however, it serves as an invitation for children to express their own emotions. Children are best able to talk about their feelings if parents show them by example. **Reassure your child that it is fine to have all kinds of feelings at this time and that it's okay to express them.** Ask neither yourself nor your child to be brave right now. But be careful not to swamp your child with your own fears; expressing emotions must remain within a range that the child can deal with.



"I would have liked a conversation where we had talked more about the fear. I always had the feeling that all of us in the family were scared, but everyone was alone with his fear because we didn't talk to each other."
(Viola, 13 years) *

All of the children's questions must be taken seriously and responded to. You will probably not find answers to some of the questions for some time. But the statement "I don't know yet exactly" helps a child and is better than a well-intentioned lie. Children returning to their game or changing the subject are giving a clear sign that it has been enough for one day and these signals should be taken seriously.

"My father explained to me what a brain tumour was and what it was doing to my mother, and also that she would probably die before her time. That was very important for me. Many people think that children don't get it or don't understand, but it is very important to talk about it, even if it means a huge effort, because I just knew that there was something wrong."
(Alexander, 13 years) *



Encourage your child to ask you again if he or she would like to know more.

Some children want to know whether mum or dad is now definitely going to die of cancer. Such a question is often difficult for parents to hear. But please resist the temptation to assert that this could not happen under any circumstances. An honest answer is better, for example: "Yes, some people who have cancer also die from it. We do not know yet whether dad will get well again, but the doctors are doing everything they can."

Right from the beginning, young people also think a lot about what the diagnosis means for the patient and the family. The more honest information they get, the less they need to search on the Internet themselves and come across unfiltered and often frightening information and statistics. Young people do not want to be living with false hope; they appreciate honest answers from their parents.

3. Therapy

3.1. Hospitalization and surgery

As a next step, children need to have the different kinds of treatment explained to them.

Inform your child about an upcoming hospital stay and tell her how long mum or dad will probably have to be in hospital for. It is also important to explain that the patient will still need rest once back at home. Children assume that everything is fine again as soon as the hospital stay is over and are disappointed when they notice that mum or dad is still not well.

Talk to your child about upcoming surgery as well. Explain what happens during the surgery, how the body can change in appearance as a result and what impact that could have on the child. One explanation could be, for example: "You know how mum has cancer in one breast. It will now be cut out by the doctors during surgery. Afterwards, there will be a scar on the chest, which must heal first. That's why mum won't be able to lift you up for a while, but we can still cuddle." If you are sensitive to pain, give your child specific guidance about what kinds of physical contact are possible and where to be cautious.

Patients have to decide for themselves how soon after surgery they show their child the scar. First and foremost it has to be the right moment for them. But the more openly all those affected deal with the disease, and also with the changing body, the easier it will be for all members of the family.

Let your child decide for herself whether she wants to visit a sick parent in hospital or not. If your child decides in favour of the visit, describe in advance what she will get to see at the bedside, such as the intravenous drip and breathing tubes. Then she will be prepared and the unusual sight won't be such a shock.

If a child does not want to go to the hospital with you, do not pressure him or even make him feel guilty. Children often refuse a visit out of fear. In this case it is helpful for the child if you suggest painting a picture for mum or dad, or writing a letter. The healthy parent can then take that with him and present it on the child's behalf. It is also easy to maintain contact by phone.



3.2. Side effects of chemotherapy

With many types of chemotherapy, hair loss is to be expected: tell your child in time. If the child is unprepared, seeing mum or dad bald can be a shock and often triggers feelings of panic. Explain to him that the chemotherapy is so strong that the hair will fall out, but that it will grow back again after the treatment is finished.

Many patients decide to shave their heads beforehand if hair loss is to be expected. If the patient agrees, children

can be asked if they want to be there when the hair disappears at the hairdresser's. It is also possible to involve the children in choosing a wig. When mothers decide against a wig and show their baldness confidently, children often feel embarrassed and ashamed in front of their peers. They fear stupid comments, a fear that is unfortunately quite often justified. Maybe in this case you can agree on a compromise with your child: you wear a wig or scarf when other children are present.

It is especially difficult to convey to younger children that severe fatigue is also a result of chemotherapy and that there is not enough energy for many activities. Children quickly misinterpret a lack of energy as disinterest: "Dad doesn't want to play football with me!" is how they see it. In this case, parents need to disagree and explain very clearly that the patient's lack of energy has nothing to do with the child, but is a result of the medication.

If possible, give your child a time frame of how long the treatment is expected to last. For example: "I hope that I will have finished with the therapy by Easter. Then my hair will grow back and we'll be able to do more things together again." This will allow your child to adapt to the situation. During the various therapies, parents should also inform their children about medical appointments and test results.

3. Therapy



"When my mother comes home from her chemotherapy, I feel strangely uncertain because I'd love to know how she's doing every second. But this isn't possible because she usually sleeps twenty hours a day. There is also helplessness in me, because I would like to help her. Mostly I would like to know whether she is in pain or if she is not feeling well when she's sleeping. My mother always tells me, though, whether she's in pain or not, but when she sleeps it's very difficult."

(Luke, 12 years) *

4. Everyday life

4.1. In kindergarten and at school

Unfortunately, in most cases, the illness determines the daily lives of affected families over a longer period of time. **Inform carers and teachers in kindergarten, at the day care centre and at school about the family situation.** Often they are the first to notice a change in a child's behaviour. Adequate support can only be provided if they know about the stresses the child is subject to. It is best if children and young people decide for themselves whether friends and classmates should be informed about the cancer.



In some families, the subject is taboo. As few people as possible are supposed to know about it. Unfortunately, some people experience shame when they talk about the illness. Many patients want neither pity nor unsolicited advice, and they fear other people's curiosity. But it is precisely this silence that puts a heavy burden on children.

Older children and young people choose carefully whom they tell about the disease. Often it is only a few friends who are in their confidence. The desire not to stick out at school is much more important. Under no circumstances do young people want pity from teachers or classmates. One should also never underestimate how important it is to have a place like school, where everything continues as usual. This way, kindergarten, day care or school can develop into "cancer-free zones" that can create some distance to the stressful situation at home.

Unfortunately, many young people find that friends are unable to cope when they tell them about their mother or father's cancer and the resulting stress. Instead of the

4. Everyday life



"Sometimes I met up with friends but it was no longer the same. I had the feeling of being misunderstood more often. They were not considerate of me and I had the feeling they wanted to keep away from the whole situation. They did not understand the way I was acting anymore (...). Only very few offered help and asked me how I was really doing. Of course it is difficult to understand for outsiders, but I just wished sometimes that they had said they were there for me."

(Melissa, 17 years) *

encouragement they'd hoped for, they get the feeling of not being understood by anyone. They feel left alone by their friends in this emergency situation. Some react by withdrawing, others put on a brave face for their classmates and friends. They pretend that everything is okay and that they're fine. No one gets to see the sadness and fear behind the mask.

4.2. In the family

When a parent is diagnosed with cancer, stress levels rise for all family members.

Tell your child about changes that affect her daily routine, especially because they create uncertainty. For example, it is important for young children to know who will take them to kindergarten and who will pick them up when mummy is sick. Structure and fixed rituals in everyday life – e.g. at bedtime in the evening - help to create a bit of normality.

In this difficult family situation, older children almost invariably need to take on more responsibilities and duties at home. Some do this without complaining, others only under protest. In this case it may be helpful to indicate the period for which the

additional tasks will have to be taken on. Above all, children must still have enough time for their own interests and hobbies. Particularly in case of young people it is often overlooked that the amount of help required of them and the level of responsibility that is imposed on them are sometimes excessive. This way, children of parents with cancer easily slip into the role of an adult, a role that is beyond them in most cases.

Especially when the main breadwinner becomes ill, families quickly find themselves facing financial problems. Children often notice this. **Avoid talking to your children in detail about your financial situation and your fears for the future.** Children worry, but they cannot really change this situation and feel helpless and powerless.

Children are always relieved when their parents get support from adults. Then they can just be a child and do not have to worry about the parents and their welfare. **Have the courage to ask other adults to care for your child if you lack the time and energy for it yourself.** For example, ask your friends to pick up your child from kindergarten or to spend a completely normal, "cancer-free weekend" with him. When children spend time with their peers, it is an opportunity to let the stresses at home fade into the background and recharge their batteries.

"Sometimes I forget that my parents have cancer, e.g. when I meet up with friends. I'm busy with other things then. When I forget all about the cancer, I feel great because then I can simply let the whole load slip off my shoulders."
(Luke, 12 years) *

Especially in times when the illness seems to dominate all family life, "cancer-free times" are important for everyone. **Agree on certain times to spend with your child where the disease does for once not take centre stage.** For many patients, longer excursions are not possible, but the main thing is that the family spends time together and that the sick parent participates also. It's good for everyone to play together and laugh and enjoy being carefree for a little bit. When parents laugh again, it has a positive and relaxing effect on the children. Some carefree hours spent together compensate everyone for the arguments that are often unavoidable in this tense situation that they all find themselves in.

4. Everyday life

Unfortunately, family conflicts that existed prior to the disease do not simply disappear, but often become heightened during times of illness. Caused by the constant stress, many parents' nerves begin to fray. They no longer have their usual patience and understanding when dealing with their children. Often it is a relief for parents when they realize that not all their problems are associated with the cancer. Puberty in particular is always a



challenge for everyone - young people as well as parents - and even cancer can't change that. At such times it may be generally advisable to contact an experienced counsellor from a psychosocial cancer counselling centre like the Bavarian Cancer Society Inc. in order to find some relief.

"2 years ago it was found that my mother had breast cancer (...). Suddenly nothing was like it was before. My entire family life changed. There was a lot of fighting between my parents and also between me and my parents (...). My mother kept saying, „You can do all those things when I'm dead.“ This really made me scared. I could hardly think about anything else at those moments. My mother was not her usual self anymore. Suddenly she got really annoyed by really trivial things. The stress just got worse and worse. There was always stress (...). This stress also had an impact on me (...). Today, it is much better already. My mother and I are still afraid that the cancer might come back, but my mother has already calmed down a little. But all of us are still stressed."

(Paul, 15 years) *

Puberty is a stage of life characterized by the emotional separation from the parents and by reorientation. When a parent suddenly becomes ill with cancer, this separation is often interrupted and leads to paying increased attention to the family again; worrying about and caring for the sick parent become priorities. For young people it is often difficult to find a good balance between support for the patient and the demands of school, training or study and the pursuit of their own interests.

Young people appreciate it when parents allow them to pursue their own interests and to be able to go their own way even during the illness phase. Some children, older and younger alike, feel that in the face of their mother or father's serious illness they are not allowed to have fun any more and give up things that they really enjoy. **Reassure your child that fun – despite everything - is allowed.**



4. Everyday life

"In this time of my dad's illness, I was always struggling within myself. The balancing act between day-to-day life and life at home with a sick father was just too extreme. I often had to think about whether or not I'd better stay at home to be there for my family, or if I should rather do something with my friends and distract myself. I still remember very well that I usually chose the former. I just did not have the heart to leave my sick father behind, even though I knew that my mum and my siblings were at home, too. Adding to this was the constant fear. Fear that something would happen if I weren't at home at exactly that moment. But also fear that he wouldn't be there anymore when I got home."

(Melissa, 17 years) *

Many children put their own interests and needs to one side during their mother or father's illness, and show great care and concern. They are completely absorbed by doing something for the sick parent. Through their assistance, for example fetching a blanket, they feel that they're part of what is happening and no longer powerless in the situation. It is important to ensure that children - regardless of age - do not take on too much responsibility. Even young people should not be responsible for looking after or caring for a parent on their own. If this is expected of them and they take on the role, sometimes to the point of physical exhaustion, they are overstretched. Often, parents do not notice this because they are too preoccupied with themselves.

The roles in the family must not become reversed for good. Children should not become the comfort of their sick parents - and especially not replacements for a partner. **If you feel that it is all getting too much for you, seek help from other adults.** This also helps your child.

During puberty, young people increasingly discuss their problems with friends rather than with their parents; this remains unchanged for some, even when a parent becomes ill with cancer. The expectations of many parents that the young people will open up to them and will be willing to talk, now that there is this crisis situation, often remain unfulfilled. The more pressure parents exert, and the more they keep asking, the less young people actually reveal about their feelings. Some simply do not want to hear any more about the illness. When your child refuses to talk, make him an

offer from time to time, e.g.: "If you want to talk or want to know something, tell me, I'm always here for you."

In principle, you should always inform your child about upcoming tests and major changes to your health.

4.3. How children react physically and emotionally

Children's reactions to the cancer and the changed family situation will be different and vary depending on age, level of development, personality, the family and social environment, and they are affected not least by the nature of their relationship to the sick parent. Some changes in the behaviour of a child are also completely normal for certain developmental stages and should be regarded as such.



Infants and young children do not yet have a real understanding of disease and cannot judge the significance of a parent having cancer. But they notice when their parents are sad or irritable, and often react with crying, restlessness and problems with sleeping or eating. Closeness to their parents, physical contact and a serene atmosphere help the child to feel calm and safe again. Toddlers are always frightened by the temporary separation from a parent. Regular relationships with caregivers provide a sense of security, for example with a grandmother who now looks after the child more intensely. **Allow your child to keep in touch with the absent parent, too - for example with the mother in rehab.** Often enough, mum's voice on the phone is enough to overcome the separation more easily.

Children of kindergarten age are very aware of a parent being sick. They also suffer from the separation from mum or dad as a result of illness. Many are very clingy

4. Everyday life

when the patient has returned home. After the separation they seek closeness to the adult even more strongly.

Some children react to the stressful family situation with setbacks in their development. Their language becomes simpler or they wet themselves again. Only understanding is helpful here - pressure only aggravates the situation. These occurrences are usually only temporary and disappear once calm and structure have returned to the everyday life of the child. When backward steps in development persist for a longer period, a paediatrician or a counselling service should be consulted in order to get help for the child.



Some children now get scared of becoming sick, too. As a reaction to cancer, many children develop real physical complaints. Young children often complain about stomach ache when mum or dad is sick. Often, the paediatrician finds nothing. In this case, the symptoms should be interpreted as a sign of inner tension and psychological insecurity. Here, affection and physical closeness are most helpful. Some children and young people also suffer from disturbed sleep and nightmares. Eating disorders can also occur.

Some children become increasingly quiet during the illness of a parent and withdraw more and more. A few are also overly well-adjusted and try to make it as easy as possible for their parents. Children try to protect their parents because they feel how strong the tension is, and do not want to add to their troubles with their own worries - this phenomenon occurs throughout all age groups. Many children think they can



A mother whose husband has cancer says:
"Our daughter (8 years) is currently thinking a lot about death and also dreams about it. She is also preoccupied with cancer and other diseases and always asks me: „How will I know if I have cancer too, and how can I protect myself from it?“ *

actually hide their sadness and fear from their parents. When you notice your child acts overly well-adjusted, talk to your child about it directly. Ask him what it is really like. **Make sure that your child understands that it is normal to be scared and sad in the present situation. Reassure your child that you will continue to be there for him and his worries and troubles.**

Other children become conspicuous on account of their loud and often aggressive behaviour. They do this to seek attention. If the behaviour is particularly pronounced, it

expresses an inner anguish that the children often cannot otherwise show. Aggressive behaviour therefore needs understanding as well as limits.

Together with your child, look for a way for him to express his anger. Exercise and physical activity often help.

Children and young people are in many cases confused by the range of emotions they experience now and feel insecure and helplessly subjected to their own changing moods. **Reassure your**



4. Everyday life

child that this rollercoaster of emotions is normal and that she is reacting appropriately to a threatening situation.

Many thoughts children have in relation to cancer centre on the topic of guilt. They feel guilty, they believe to be the cause of the disease. "Mum got cancer because I fought so much with my brother and she was upset about it" is a typical assumption. Parents must relieve these feelings of guilt in their children. **Tell your child very clearly that there is no link between his behaviour and the illness.** Conversely, this also means explaining to a child that particularly good behaviour does not lead to the desired cure.

A large proportion of the affected children and young people aren't able to concentrate well at school. Instead of following the lesson, their thoughts focus on the sick parent and, quite often, the future of the family. Weaker school performance is often the result. But instead of pressure to perform, these students need support and parents who now and then let bad grades pass and accept them as normal. Some children, though, perform very well at school during the illness. They want to make it as easy as possible for their parents. Intensive study helps some to put their fears and worries aside for a while.

4.4. Children of divorced parents

Children of divorced parents are under even more strain when a parent is ill with cancer, emotionally and sometimes also physically. Often the family is missing an additional adult to care for the patient and to be his primary contact. In these cases it is often the children who carry the responsibility. Many children experience stress through the divorce itself, sometimes to the point of feeling burdened. **Make sure there are enough adult helpers in the family so that your child is relieved of some of the burden.** For children of divorced parents it is particularly difficult to pursue their own interests and leave the patient home alone.

It becomes particularly difficult for all family members when the disease has progressed so far that it is no longer possible for the sick person to care for the child, and it may become necessary for the child to go and live with the separated parent.



”Because my dad saw that I was getting worse and I simply could not stand this pressure anymore, he took me to his place. But this decision was not easy for me at first ... This whole situation was totally beyond me ... I was scared to leave my mother there on her own ... and also afraid that I was hurting her feelings ... I had such a bad conscience”
(Annabelle, 17 years) *

Children feel torn between the two in this situation, and have the feeling they are leaving the sick parent in the lurch.

Even if the children do not live with the ill parent, they should still be informed about the cancer. **Give your child the opportunity to visit the sick parent as often as she wants, as long as it also works for the sick person.**

Adopted children have already experienced being left by their parents once, and usually respond to the disease with severe fears of loss. Fears of loss must always be taken seriously. It helps children when you decide together who else is there to provide for them in an emergency situation.

5. Saying goodbye

Children should not be left in the dark if the cancer is incurable. Many sense it anyway when the death of a parent is to be expected. It is very stressful for them if they notice the imminent death of the mother or father and this is not spoken about.

Finding the right moment to inform children about the impending death of a parent is difficult. Precious time is often wasted by hesitating for too long, quality time that could be spent together, and time to say goodbye. If it is clear that a parent is going to die soon, this needs to be discussed with the child. False hope does not help. **Make no promises about the course of the disease that you cannot keep.**

As in the conversation about the cancer diagnosis, you should choose a calm environment and take plenty of time. **State from the beginning that you need to tell them something sad.** Then say outright that the patient will die soon. You may show your sadness and crying is fine - this makes it easier for your child to express his feelings. Crying, tantrums and denial are normal reactions to this sad news. Try to remain calm in the face of these emotional outbursts and to give them space. Comfort your child as you do in other situations.

Some children understand the information about the expected death and learn to live with that knowledge. Others deny the awful truth for as long as possible - you have to respect that. Everyone, children as well as adults, need sufficient time to comprehend this unimaginable and painful reality.

It is almost impossible to inform children about the impending death of a parent when the patient himself is in denial, does not want to talk about it and acts steadfastly optimistic. Children should not become secret-keepers in such situations – something you need to consider in this situation.

Young children in particular wonder whose fault it is that mum or dad has to die now. **Emphasize that no one in the family is to blame and that the doctors have done everything to make mum or dad well again.**

Children also want to know where dead people go. Parents should answer this according to their own attitudes and beliefs and in a way that makes sense to them.

Children are mostly told that the dead go to heaven and continue their life there in a modified form. For children, such explanations are comforting and helpful.

Make it possible for your child to say goodbye awarely. It will make the grieving process easier later on. When a farewell is made impossible by silence, an opportunity is irretrievably lost, and something will always remain unresolved.

”When my mum was in a really bad way, I went to hospital every day and stayed there for several hours. One might think that this was the worst time of the disease, ...but it was, I think, one of the best times. We talked about everyday things, what it said in the newspaper, played word games and slept, but we also talked about dying. My mum was the only one who was strong and did not cry; I burst into tears of course, and when my father was there, there were tears rolling down his cheeks as well.”

(Leonie, 14 years) *



If the dying parent manages to tell their children how much they love them and how proud they are of them, it is an enormous gift that can sustain a child his whole life.

Letting young children say goodbye means to „fill up“ with as much closeness as possible and to still do something for the person concerned, e.g. to make an angel who will watch over the mother or the father, or to paint a pretty picture for them. **Ask your child what he still wants to do for the sick parent.** Your child then has the opportunity to determine for himself what remains important to do.

5. Saying goodbye

For older children and young people, a "good" conversation with the dying parent often remains an important thing to do. They sense which questions they are looking to have answered and what they still want to say.

After death, the sight of the dead father or of the dead mother often makes it easier for the family to comprehend death and its finality. Children of kindergarten age live very much in the here and now and see death as something reversible. They believe that people who die will eventually come back. Therefore the sight of a dead person is often helpful for them to understand what has really happened. They can see that the deceased is actually not moving anymore and is no longer breathing. **Let your child decide for herself whether she wants to see the deceased parent again, and accept it if your child does not want to.**

It is also helpful for children to be involved in the funeral, for example by painting the coffin or by participating in the decision about what clothes the dead person should wear. Many children place a picture they made or a letter into the coffin for the dead parent.

Ask your child if it would like to come to the funeral. The ceremony should be explained to children who have not yet experienced a funeral. This helps to relieve anxiety.



Widowed parents are relieved if a close friend is by their child's side during the funeral, someone whom the child knows well, but who is not directly affected by the bereavement.

Children of a parent with cancer have an increased risk of behavioural problems as many studies have shown. The more openly the

family talks about the disease and the more support children have, the easier it is for



"I was tired of being miserable, I wanted to be a normal person again, I wanted to laugh again, to be happy and cheerful!"

(Leonie, 14 years) *

them to survive this stressful family situation well. Frequently, an irrepressible will not to let the harsh blow that the family had to deal with get them down can be observed in the affected children.

Many children manage to do this - despite everything.

6. Further Reading

- Brandes, S. (2001): Ein Baum für Mama. Allitera Verlag, München.
- Broeckmann, S. (2002): Plötzlich ist alles anders – wenn Eltern an Krebs erkranken. Klett-Cotta, Stuttgart.
- Brütting, S. (2011): Was macht der Krebs mit uns? Kindern die Krankheit ihrer Eltern erklären. BALANCE, buch + medien verlag, Bonn
- Deutsche Kinderkrebsstiftung (o.J.): Radio-Robby und sein Kampf gegen die bösen Krebszellen. Bezug über: Deutsche Kinderkrebsstiftung und Deutsche Leukämie-Forschungshilfe - Aktion für krebskranke Kinder e.V., Adenauerstraße 134, 53113 Bonn.
- Fessel, K.-S. (1999): Ein Stern namens Mama. F. Oetinger, Hamburg.
- Hermelink, K. (2005): Mein wunderschöner Schutzengel. Als Nellys Mama Krebs bekam. Verlag Diametric, Würzburg.
- Mehr Zeit für Kinder e.V. (2009): Warum trägt Mama im Sommer eine Mütze? Bezug über: Mehr Zeit für Kinder e.V., Fellnerstraße 12, 60322 Frankfurt a.M.
- Motzfeldt, H. (2010): Der Chemo-Kasper und seine Jagd auf die bösen Krebszellen. Bezug über: Deutsche Kinderkrebsstiftung und Deutsche Leukämie-Forschungshilfe – Aktion für krebskranke Kinder e.V., Adenauerstraße 134, 53113 Bonn.
- Trabert, G. (2012): Als der Mond vor die Sonne trat. G. Trabert, Mainz.
- Trabert, G. (2009): Als der Mond die Nacht erhellte. G. Trabert, Mainz.
- White, S. (2011): Sparkys Geschichte. Bezug über: MSD Sharp & Dohme GmbH Lindenplatz 1, 85540 Haar



7. Useful addresses in Bavaria

Professional associations and working groups

- Arbeitsgemeinschaft Supportive Maßnahmen in der Onkologie, Rehabilitation und Sozialmedizin der Deutschen Krebsgesellschaft - Working Group on Support Measures in Oncology, Rehabilitation and Social Medicine of the German Cancer Society (ASORS) www.asors.de
- Arbeitsgemeinschaft für Psychoonkologie in der Deutschen Krebsgesellschaft e.V. - Psycho-Oncology Working Group of the German Cancer Society Inc. (PSO) www.pso-ag.de
- Deutsche Arbeitsgemeinschaft für Psychosoziale Onkologie e.V. - German Working Group for Psychosocial Oncology Inc. (dapo) www.dapo-ev.de
- Bundesarbeitsgemeinschaft für ambulante psychosoziale Krebsberatung e.V. - Federal Working Group for Psychosocial Outpatient Cancer Counselling Services Inc.(BAK) www.bak-ev.org
- Deutsche Krebsgesellschaft e.V. - German Cancer Society Inc. www.krebsgesellschaft.de
- Deutsche Krebshilfe e.V. - German Cancer Aid Inc. www.krebshilfe.de
- Krebsinformationsdienst KID des Deutschen Krebsforschungszentrums DKFZ - Cancer Information Service (KID) of the German Cancer Research Centre www.krebsinformation.de

Websites

On the following web sites you can find additional helpful hints and advice. We would like to emphasize at this point that information cannot replace a personal conversation, and encourage you to actively speak to your children about your illness.

- Hilfe für Kinder krebskranker Eltern e.V. - Assistance for Children of Parents with Cancer Inc. www.hilfe-fuer-kinder-krebskranker.de
- BelaJu – ein Projekt der Medizinischen Psychologie und Medizinischen Soziologie des Universitätsklinikums Carl Gustav Carus Dresden - A project of the Department of Medical Psychology and Medical Sociology at the Carl Gustav Carus University Hospital Dresden www.belaju.de

7. Useful addresses in Bavaria

- Rexrodt von Fircks Stiftung - Rexrodt von Fircks Foundation www.rvfs.de
- Verbundprojekt „Hilfen für Kinder krebskranker Eltern“ - Joint Project „Assistance for Children of Parents with Cancer“ www.verbund-kinder-krebskranker-eltern.de/
- Projekt Tigerherz - Project Tigerheart
www.uniklinik-freiburg.de/tumorzentrum/live/Patienten-Info/kinder-krebskranker-eltern.html

Counselling centres for children and young people in Bavaria

- Regensburg University Hospital, Department of Haematology and Internal Oncology, Head of Department: Prof. Dr. med. Reinhard Andreesen, contact person Dr. med. Marion Böger, Franz-Josef-Strauß-Allee 11, 93053 Regensburg, Ph.: 0941/944-5563, Email: marion.boeger@ukr.de
- Psycho-oncological family clinic session at the Clinic for Internal Medicine and Policlinic III, Munich University Hospital - Großhadern Campus, Maria Erlbeck, Dipl. of Educ., Children's and Youth Psychotherapeutic Services, Ph.: 089/7095-7905 or 0800 0 117 112 (free call). Wednesdays 12 noon to 1 pm
- Psychosomatic Counselling Service for Cancer Patients, Richard-Wagner-Str.9, 80333 Munich, Ph.: 089/52 64 63, Beate Drobniak, Dipl. of Social Work (FH)
- Psychosocial Cancer Counselling Centres of the Bavarian Cancer Society Inc. in Kempten and Passau by appointment and at the Bad Trissl clinic on Mondays from 2 pm to 4 pm

Psychosocial Cancer Counselling Centres of the Bavarian Cancer Society Inc.

For 85 years, the Bavarian Cancer Society has been helping patients with cancer and their families in coping with the disease. Throughout Bavaria, we have a statewide network of 18 cancer counselling and psycho-oncology services (PODs).

There, qualified staff assist people seeking advice and support them regarding all psychological and social issues – competently, confidentially and free of charge.

Lectures and courses, as well as medical question and answer sessions supplement our comprehensive services, which are unique in Bavaria. We professionally support the volunteer leaders of our affiliated 210 self-help groups in their work.

In this way, those affected are provided with invaluable assistance by their peers

locally. In addition, we participate in health services research and professional training, cooperate with certified organ and tumour centres and carry out educational work. As independent advisors in government advisory committees we advocate for the needs of those affected.

The Bavarian Cancer Society Inc. is a member of the German Cancer Society Inc. as an autonomous association. Our work is funded by public grants and by donations.

Activities throughout Bavaria

There are psychosocial cancer counselling centres of the Bavarian Cancer Society in all seven Bavarian administrative districts. Psycho-oncology services can also put you in touch with the more than 200 self-help groups in Bavaria.

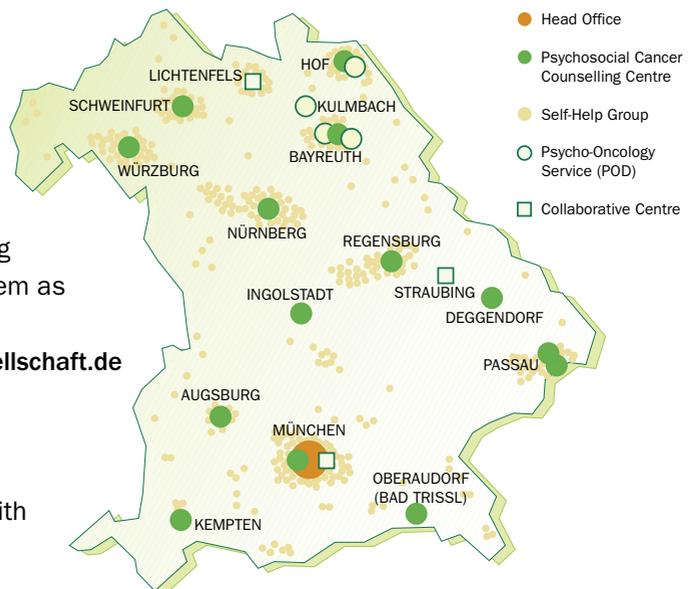
In cooperation with various medical facilities we offer further counselling services for people with cancer in Bayreuth, Deggendorf, Lichtenfels, Passau and Schweinfurt.

Important to know: our counselling services are confidential and free of charge.

Literature

You can order the following brochures or download them as pdf files for free at www.bayerische-krebsgesellschaft.de

- Psycho-oncology
- Side effects
- Cancer and sports
- Fatigue – How to deal with cancerrelated fatigue



7. Useful addresses in Bavaria

Psychosoziale Krebsberatungsstelle Augsburg

Schießgrabenstraße 6, 86150 Augsburg

Tel. 0821 - 90 79 19 -0

Fax 0821 - 90 79 19 -20

brs-augsburg@bayerische-krebsgesellschaft.de

Psychosoziale Krebsberatungsstelle Bayreuth

Opernstr. 24-26, 95444 Bayreuth

Tel. 0921 - 150 30 -44

Fax 0921 - 150 30 -46

brs-bayreuth@bayerische-krebsgesellschaft.de

Psychosoziale Krebsberatungsstelle Hof*

Altstadt 2-4, 95028 Hof

Tel. 09281 - 540 09 -0

Fax 09281 - 540 09 -29

kbs-hof@bayerische-krebsgesellschaft.de

Psychosoziale Krebsberatungsstelle Ingolstadt*

Levelingstr. 102 / 3. OG (Aufzug), 85049 Ingolstadt

Tel. 0841 - 220 50 76 -0

Fax 0841 - 220 50 76 -20

kbs-ingolstadt@bayerische-krebsgesellschaft.de

Psychosoziale Krebsberatungsstelle Kempten*

Kronenstraße 36 / 2. OG, 87435 Kempten

Tel. 0831 - 52 62 27 -0

Fax 0831 - 52 62 27 -99

kbs-kempten@bayerische-krebsgesellschaft.de

*gefördert durch die Deutsche Krebshilfe e.V.

Psychosoziale Krebsberatungsstelle München

Nymphenburger Straße 21a, 80335 München

Tel. 089 - 54 88 40 -21, 22, 23

Fax 089 - 54 88 40 -40

brs-muenchen@bayerische-krebsgesellschaft.de

Psychosoziale Krebsberatungsstelle Nürnberg

Marienortgraben 13, 90402 Nürnberg

Tel. 0911 - 49 53 3

Fax 0911 - 49 34 23

brs-nuernberg@bayerische-krebsgesellschaft.de

Psychosoziale Krebsberatungsstelle Passau

Kleiner Exerzierplatz 14, 94032 Passau

Tel. 0851 - 720 19 50

Fax 0851 - 720 19 52

brs-passau@bayerische-krebsgesellschaft.de

Psychosoziale Krebsberatungsstelle Regensburg

Landshuter Straße 19, 93047 Regensburg

Tel. 0941 - 599 97 83

Fax 0941 - 599 97 84

brs-regensburg@bayerische-krebsgesellschaft.de

Psychosoziale Krebsberatungsstelle Würzburg

Ludwigstraße 22, 97070 Würzburg

Tel. 0931 - 28 06 50

Fax 0931 - 28 06 70

brs-wuerzburg@bayerische-krebsgesellschaft.de

Additional counselling centres are set up at hospitals in Bayreuth, Deggendorf, Kulmbach, Lichtenfels, München, Oberaudorf, Passau, Schweinfurt and Straubing. Full addresses and contact details can be found at www.bayerische-krebsgesellschaft.de

Head office

Bayerische Krebsgesellschaft e.V.

Nymphenburger Str. 21a, 80335 München

Tel. 089 - 54 88 40 -0

Fax 089 - 54 88 40 -40

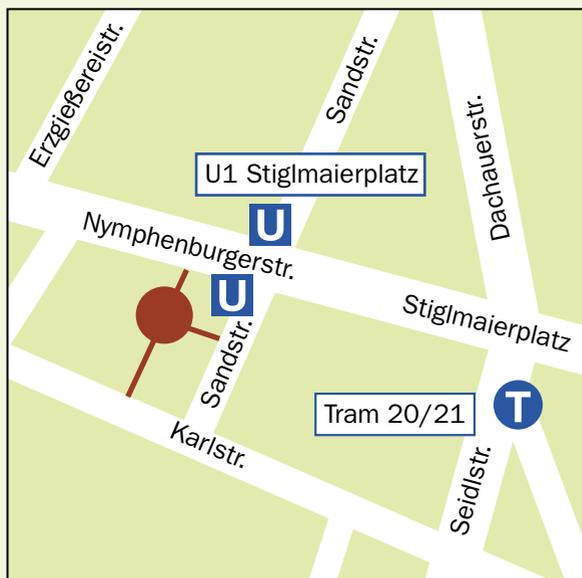
info@bayerische-krebsgesellschaft.de

www.bayerische-krebsgesellschaft.de

Directions for travel by car (see internet), 4 underground car parking spaces available

Using public transport: stop at Stiglmaierplatz

U1 / U7 Olympia shopping centre / Red Cross Square, tram 20, 21



Legal Notice

Publisher: Bayerische Krebsgesellschaft e.V.
Nymphenburger Straße 21a, 80335 München
Phone 089 - 54 88 40 -0
Fax 089 - 54 88 40 -40
info@bayerische-krebsgesellschaft.de
www.bayerische-krebsgesellschaft.de

Author: Sabine Brütting, Frankfurt
Proofreading: Reinhild Karasek, www.rkarasek.de

Design: GoodwinGraphics, Anca Goodwin, München

Photo credits:

Title: nailia-schwarz@photocase.com

Content: **istockphoto** p. 4 (digitalskillet), p. 9 (Fertnig), p. 12 (cglade), p. 13 (mangostock), p. 14 (SimmiSimons), p. 16 (akurtz), p. 19 (mediaphotos), p. 20 (Yarinca), p. 21 (slobo), p. 23 (airportrait), p. 25 (mikespics), p. 26 (Rubberball), p. 27 (SimmiSimons)
photocase p. 17 (manun@photocase.com)
shutterstock p. 6 (llike), p. 8 (JulijaSapic-portfolio), p. 11 (BlueOrangeStudio)

Donate & Assist

Donations account: Bank for Social Economy, account no. 7801700, BSC 700 205 00
BIC: BFSWDE33MUE, IBAN: DE02700205000007801700

 BAYERISCHE
KREBSGESELLSCHAFT E.V.

Bayerische Krebsgesellschaft e.V.
Nymphenburger Straße 21a
80335 München
Tel. 089 - 54 88 40 -0
Fax 089 - 54 88 40 -40
info@bayerische-krebsgesellschaft.de
www.bayerische-krebsgesellschaft.de

Gesund. Leben. Bayern.



Bayerisches Staatsministerium für
Umwelt und Gesundheit

