Bianca Senf

Honesty requires courage

Discussing cancer with children – when parents are diagnosed with cancer

A guide for parents and professionals

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1. Preface

Dear readers,

my career as psycho-oncologist spans more than twenty years and I have worked with hundreds of families where one, or sometimes both, parents have been diagnosed with cancer. Time and time again I have witnessed the feelings of devastation that arise when being a patient co-incides with being a parent. In almost all cases, the thoughts of the affected parent quickly turn towards their children and the impact the illness will have on them.

- Will I be around for my children's first day at school?
- How will my children cope without me?
- How do I tell my children that I have cancer?
- How will my children respond when I tell them that I have cancer?
- Will my child understand the nature and meaning of a diagnosis of cancer?

The following guide is based on clinical practice, but it also includes relevant research findings. It seeks to provide answers to some of the most common questions parents may have during this difficult time. The guide also provides you with an overview of how children in various age groups may react to a diagnosis of cancer, and it invites you to consider information that is helpful as opposed to harmful when shared with children.

In addition, the guide suggests ways in which you may deal with your children's response to the situation. Ways of discussing the illness and its treatment are outlined, and ideas that may help you and your children work through the subject of "dying and death" are provided.

The following guide does not claim to provide a solution to all potential problems. Each family is unique and there may be many questions that strongly depend on the specific nature of the illness as well as family circumstances. Do not hesitate to seek professional help if you have specific questions.

The case studies included in this brochure are based on the author's clinical work. The names of all affected individuals have been altered, apart from Mr Engler, Saymon Engler and Sarah Fey.

I hope this guide will encourage you to be open and honest about cancer.

With all the best wishes,

Dr. Bianca Senf
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2. "My whole world fell apart" – a case study

Mrs Sinsa is 43 years old when she is diagnosed with breast cancer.
She is self employed and very successful. Her husband works as a GP in a partnership practice. Their two daughters are nine and five years old. Mrs Sinsa has always been independent in all aspects of her life. She will later tell me "I was in control of everything in my life". As the oldest of three children she has always been reluctant to accept help. She was quick to decline a consultation with a psychologist following her diagnosis. She had a go at her cancer specialist "I have cancer. That doesn't make me mad". She later explained that she was somewhat offended by the offer to speak to a psychologist. Mrs Sinsa demonstrated a very pragmatic way of managing the "situation". She advised that she was not scared of the surgery; She insisted that she was simply restless and struggled to sleep.
Mrs Sinsa underwent surgery. Several hours after her anesthetic wore off, her anxiety levels began to rise: What shall I tell my children? They're still so young. They won't be able to understand any of this. What will happen to my children if I die? Mrs Sinsa was unable to let go off these thoughts and worried about a range of catastrophic outcomes. She was not reassured by the knowledge that her children's father would still be around. Her fear of succumbing to breast cancer and leaving behind her children resulted in an acute panic attack: Mrs Sinsa began to sweat, she had palpitations, her hands were shaking, she was gasping for air and, as a result, she worried that she may suffocate. She finally pressed the call bell and when the nurse attended she was

crying, shaking and struggling to catch her breath. The nurse was worried and called me, saying: "Can you make your way over here quickly, please? We need you to deal with a crisis".

The above case study highlights three common themes:

- Reluctance to accept psychological and/or psycho-oncological support.
- Extreme fear of succumbing to cancer and not being around to watch the children grow up.
- Confusion about what information could or should be shared with children.

From my own personal and professional perspective I completely understand the reluctance to accept psychological support. To date, many people still have reservations about the profession of psychologists, psychotherapists and psycho-oncologists. In addition, many affected individuals struggle to envisage ways in which a psychologist may be of help in a situation where the primary problem affects the body and not the mind. As such, when patients are asked whether they accepted psycho-oncological support at the time of their diagnosis, many reply "No, I didn't have time to focus on my mind. I had to focus on my surgery."

Whilst such thoughts are understandable, it is regretful that patients do not allow themselves to be supported during this incredibly stressful time.

A person is made up of body, mind and spirit. Almost everyone would agree with this, however, at a time of crisis, people do not always act accordingly. This includes Mrs Sinsa:

Once I had introduced myself to Mrs Sinsa I utilised crisis intervention techniques in order to calm down her breathing and address her fear of suffocation. Once her initial panic had subsided, I explained to Mrs Sinsa that many women experience similar extreme emotional reactions during the course of their illness, and that this is not a sign of "going mad". On the contrary, mind and body raise the alarm when there is too much "pressure" (when stress levels are too high) without there being any form of pressure release. It is their way of saying: Look after your mind, your feelings and personal needs.

In Mrs Sinsa's case, the excess pressure was caused by her sense of losing control over her life. I explained to her that, as human beings, the belief that we have some element of control over our lives is an important factor when it comes to our mental well-being.
A perceived loss of control tends to trigger high levels of anxiety, especially in individuals who value their independence.
Mrs Sinsa was reassured by this. She was pleased that there was a rational explanation for the emotional turmoil she experienced. This allowed her to communicate what she had struggled to put into words over the past few weeks:

"Following my diagnosis of cancer, my whole world fell apart. I fell into a dark hole and was in denial about the things

that were happening to me. The pure panic and fear of leaving behind my children seemed at odds with my personality. I never imagined that I would react like this."

Almost all parents will experience the above fears and worries, to various extents, depending on their unique circumstances. Once Mrs Sina was able to share her ''story'' with me, I was able to help her transform her vague feelings of anxiety into very concrete and specific fears. This process allows patients to understand and address their inner emotional turmoil, and helps them return to proactive problem solving. For instance, Mrs Sinsa now felt ready to talk about the things that would matter to her over the coming days. At this stage, it was also vital to develop an ''action plan'' that would help her cope with any potential reemergence of anxiety and panic.

Mrs Sinsa attended a total of five subsequent consultations, which helped her address and problem solve specific concerns that she and her husband had identified. For instance, they were unsure whether they should refer to her illness as ''cancer'' when talking to their children. Would it not be sufficient to say ''I'm ill''? Another topic that was explored in detail concerned control and loss of control. Mrs Sinsa decided to use her illness as a catalyst for change. She was keen to take small steps that would help her delegate responsibility and accept help from her friends and husband. At the end of our last consultation Mrs Sinsa concluded: ''My only regret is the fact that I was too proud to accept psycho-oncological support at the time of my diagnosis. I needed to fall into a dark hole before I could consider accepting help. I promise you I'll never let that happen again.''

This case study is based on events that occurred ten years ago. I happened to bump into Mrs Sinsa at our local market and she was radiating with happiness. She told me that she continues to enjoy her work. However, she added that she had reduced her hours with the support of her husband, and that she no longer struggled to accept his help. She also reflected that her illness had prompted her to reevaluate her priorities, which very clearly included her children and husband. She felt that she had made an excellent recovery, although the journey was not easy.

3. Cancer and its impact on the family system

A diagnosis of cancer tends to cause significant emotional turmoil and primarily affects the life of the individual who is diagnosed. ''I felt as if I was about to fall into an abyss'' were the words chosen by a young woman to describe her experience of being diagnosed. Parents of school aged children typically worry that they may not be around to see their children grow up and guide them through life.
Thoughts and images arise that may suddenly call into question life as we know it:

Will I ever recover?
How long do I have left to live?
Will I need to suffer in pain?
Why do I suffer from cancer?
What did I do wrong?
What is rest of my life going to look like?
Will I be able to continue to work?
How will I cope?
What do I tell friends and neighbours, and most importantly, how do I tell my child?

The ground has slipped from underneath the affected individuals, their children and partners. Suddenly everything is different and the family unit is required to re-organise itself. There may be financial implications in cases where the main provider is affected. In families where the affected individual provides the bulk of the childcare, daily routines will have to be re-established. New challenges and duties concerning daily routines may arise at a time when individuals attempt to come to terms with their diagnosis.

The affected individual needs a lift to see their therapist or GP. Who will be able to take them? Who will prepare dinner? Who will pick up the children from nursery or school and who will look after them? Who will take them to the gym or to their ballet classes and who will help them with their homework? To complicate matters, the affected individual may not be able to work in the short- or long-term, and some individuals will never be able to return to work. This may cause financial pressures and hardship, especially for single parents.

A diagnosis of cancer is a big shock. Feelings of desperation, grief and anger at the perceived unfairness of life are common emotional responses. When parents are weighed down by these feelings and worries whilst trying to fulfil their usual parental duties, it is difficult to make time to fully attend to their children. Many parents can relate to this, especially those who receive little support from their social network. Children's daily routines may suffer because they can sense their parents' distress and are affected by this.

Children's outlook may change. Their world, which has been transparent and

predictable up until now, suddenly becomes an insecure place. This usually causes heightened anxiety that manifests itself in troublesome, uncomfortable and unpredictable ways. When parents are unable to recognise and interpret such manifestations, their own responses may exacerbate their child's anxiety and sense of insecurity. Their children's distress will remain undetected. In the long-term this may cause extremely high levels of stress, which in turn, may lead to significant psychological dysfunction. As such, your child will require a great deal of love and affection, and most importantly, a sense of security. Give your child a valuable gift that you will most likely benefit from, too:

Spend time together.

4. Do I need to talk to my child about my illness?

The answer is definitely ''Yes!''. Findings from both research and clinical practice indicate that efforts to conceal important family matters can have lasting negative consequences for children. Indeed, children of parents who suffer from cancer seem to be at higher risk of developing psychological and psychiatric illnesses.
Levels of stress experienced seem to be higher in children who are provided with little or no information regarding issues that affect their family. Children are very sensitive and may be much more clued-in to what is going on than parents realise.
Research has demonstrated that even ''healthy'' parents struggle to accurately judge their children's psychological distress. As such, they tend to over-estimate their children's psychological well-being compared to children's own perceptions of their well-being.
The above is not intended to add to the pressure you, the parents, already experience. Rather, it is important to outline ways in which you may communicate with your children when faced with such difficult situations. Being well informed and sticking to certain rules that are, admittedly, not always simple and straightforward, may help prevent a great deal of sorrow and distress.

5. Children's thoughts and imagination

Younger children in particular do not shy away from asking whether their mother or father will die from cancer. There are few questions that younger children do not ask. Common questions include: ''Are you well again?'', ''Why do you suffer from cancer?'', ''Are you going to lose your hair?'', ''Do you need to go back to hospital?'', ''Is daddy also going to get ill?'', ''Can I see your scar? Is it sore?'', ''Am I allowed to tell my friend?'', ''Will I get cancer, too?'', ''Did you get cancer because I was naughty?'', ''What will happen to my birthday party now you're ill?'', ''Am I still allowed to go on my school trip?'', ''When are you allowed to go swimming again?''.

The above questions illustrate that children are concerned with matters that affect their day-to-day life as well as matters that are far more wide-reaching. However, children do not always express their worries and concerns in such an open manner. Parents may report the following, for example:

''My child never mentions my illness and doesn't ask any questions''. Parents of teenagers are often irritated by the fact that their teenage child does not appear interested in the situation. Younger children tend to make comments that appear somewhat trivial. However, on closer examination, such comments often reflect children's efforts to deal with their parents' illness.

For example: Four-year-old Mitja and five-year-old Leonie's mother was worried because her children did not seem fazed by her illness in any way. They did not ask any questions and did not even mention her illness. Based on my experience, I was somewhat sceptical of this account and explained to her that children often make casual comments, especially at times when it is difficult to register or respond to such comments. Young children especially seem to be experts at communicating in this manner. This conversation helped her recall a number of relevant examples. For example, she recalled a recent situation when they were on their way home and Leonie told her out of the blue that Lara's grandmother had also died from cancer. At the time, she did not take any notice of this. Leonie's casual comment and her use of the word ''also'' highlights that Leonie does seem to be thinking about her mother's illness. Moreover, she is scared to lose her. In situations like this it is important to ask clarifying questions, such as: ''Leonie, you know I have cancer. Do you sometimes worry that my illness will get worse and I might die, just like Lara's grandmother?''

Children have a tendency to speculate when they struggle to understand specific feelings or circumstances: What happened? What might happen in the future? They may imagine scenarios that are far removed from reality. Adults often struggle to envision this. Of course, it is difficult to influence a child's imagination. At this point, it is helpful to provide the child with a clear explanation of the circumstances, tailored to their specific developmental level.

Imagine the following example: Five-year-old Clara's father suffered from leukaemia and she was extremely scared to visit him in hospital. When her mother attempted to take her to hospital for a visit, she protested heavily. When they arrived at the hospital, Clara let go off her mother's hand and locked herself in the bathroom. It took a lot of persuasion for Clara to unlock the door. The reasons underlying Clara's behaviour became evident during a psycho-oncological consultation: When Clara visited her father for the first time, she was required to wear a face mask, shoe covers and a green apron, in line with infection control procedures. Her father was lying in bed, hooked up to various drips. A doctor entered the room and gave him an injection. Clara imagined that, what happened to her father, might also happen to her during her next visit. This caused extreme levels of anxiety. Had Clara been provided with an age-appropriate explanation of the situation in a timely manner, her anxiety may never have escalated as it did. Thoughts about cancer treatment often revolve around ''worst-case'' scenarios. The following case example illustrates this point: Thirteen-year-old Sarah called me late at night, highly distressed because her father was suddenly admitted to an intensive care ward. She imagined in detail all the machines and drips that her father may be connected to. These ''horror images'' occupied her every thought and prevented her from falling asleep. She told me that the doctors did not allow her to visit her father as they were worried that she might not cope well when faced with the amount of medical equipment he required at the time. However, when they realised that Sarah's catastrophic thoughts were far more intimidating than reality itself, they allowed her to visit him. When reflecting on this experience the next day, Sarah said: ''I imagined it to be so much worse. Now I'm happy to leave dad in hospital. I know it's the best place for him right now.'' She almost sounded a little disappointed. It is important to consider that children's experience of hospitals and intensive care wards is mainly based on TV programmes, which often include very vivid and dramatic images in order to create maximum suspense.

Questions that sound trivial or concern future events, such as ''Will I still be allowed to go on the school trip?'' do not reflect a lack of empathy, as is often feared by parents. Instead, such questions may reflect attempts to gently explore just how safe the future really is. However, at other times, children simply long to have a break from their parent's illness and try to distract themselves. Children are frequently plagued by feelings of guilt. They may believe that they have caused their parent's illness by engaging in some form of ''bad'' behaviour. In addition, they may believe that ''good'' behaviour will improve their parent's condition. As a consequence, they try hard to put on their best behaviour, which might include listening to their parents and excelling at school.

You should consider the following points:

- Children inevitably worry when faced with a serious illness in a family member, and there is potential for significant anxiety to develop.

- Behavioural disturbances are not always caused by parental ill-health, but may reflect other factors, such as certain developmental stages. Sometimes it is hard to figure out the root of the problem. Where this is the case, professional support, for example via educational counselling, may be helpful. It may also be helpful for children to engage in leisure activities or group programmes developed specifically for children of parents with cancer, as this may help them discover that other children experience similar fears and worries.

- Do not dismiss your children's fears and worries. In other words, do not provide them with any false reassurances such as ''You don't need to be scared''. Children will not be reassured by such statements and they may feel as if their fears and worries are not being taken seriously.

- Pay attention to challenging behaviour, especially if such behaviour was not present prior to your illness. Extra caution is warranted when your child does not seem fazed by your illness.

- Behaviour that worries or angers you typically reflects your child's anxiety and insecurity. As soon as your child re-establishes a sense of security, such behaviour tends to subside

- Children have the potential to undergo significant psychological growth when faced with parental ill-health, as this experience may prompt them to develop effective stress management strategies. A stable parent-child relationship is an important prerequisite for this.

6. Parental concerns

Mr Engler contacted me one year after his wife had been diagnosed with cancer, describing significant concerns about his nine-year-old son Saymon. Saymon appeared to become increasingly aggressive as his mother's cancer progressed, he no longer listened and randomly lashed out at other children.

Mr and Mrs Engler wondered whether such behaviour was normal given the circumstances and whether it would settle down again at some point in the future. They were at a loss as to how they should deal with their son and reported that attempts to reprimand or talk to him had been unsuccessful.

Saymon had been kept in the dark about his mother's condition. His grandparents and family friends advised against telling him the ''whole truth''. They argued that he was too young to understand. In addition, they believed that Saymon was in a fragile state due to his mother's illness, and they worried that the ''truth'' would only add to his distress. Such concerns are understandable, and they are not uncommon in parents, grandparents and even professionals.

However, Saymon's parents were beginning to wonder whether it may actually be helpful to tell him the ''whole truth''. Their gut instinct told them that it would be - but how should they have this conversation?

Mr Engler was looking for an answer to this question when he attended our clinic. He was relieved when I supported his decision to have an open and honest conversation with Saymon. They had always had open discussions with their son, so why should this no longer be the case? However, Mr and Mrs Saymon's main concern related to the question of ''How should we tell him?''. They lacked confidence and it transpired that they, like many other parents, were worried about becoming overwhelmed by their feelings.

They also wondered who should speak to Saymon. His mother, his father, or both? And how should they tell him that his mother would not recover from her illness? They were extremely worried about how Saymon would respond to such devastating news, and how they, in turn, should deal with his response.
During our sessions we established a hierarchy of concerns and developed a hypothetical script intended to illustrate how the conversation may progress (see page 39/40).

This case example highlights the nature of questions parents may suddenly be faced with. Below, we intend to provide some answers. When considering the information and advice provided, please bear in mind that you know your child best. Trust your instincts if you have the desire to be honest and open with your child. If you are unsure about this, seek advice from professionals who are experienced in dealing with such matters.

7. What matters to families?

Each family has their own way of dealing with conflict and problems. What works for one family does not necessarily work for their neighbours next door. However, I shall outline some general advice that has proven to be helpful for families during the course of my clinical work.

7.1 An open approach

An open and honest approach to the illness and its consequences appears to benefit the entire family. Being able to cope with one's illness and its associated fears and worries and being open to all feelings, questions and behaviours can have a positive impact on children. Research carried out by Dutch psychiatrist Hans Keilson shows that it is not the traumatic event itself that determines our psychological response, but the way in which we deal with and process the situation.

Parents or caregivers who struggle to adjust to their illness send out mixed messages, and this can add to their children's confusion. As such, it is important to make efforts to come to terms with the illness, possibly with the help of a professional. Of note, this process can take many weeks or even months. Do not put yourself under unnecessary pressure to speed up this process.

For example: A young mother who always valued an open approach spontaneously chose to deal with her mastectomy in the following manner:

''When my five-year-old daughter came to visit me in hospital after my mastectomy, I greeted her and put the flowers she gave me in a vase. Then I gave her a big hug and sat her next to me in bed. I asked her outright: 'Would you like to see?' She nodded her head with curiosity and I showed her my wound and dressing. This helped break the ice and I'm now able to act natural when she's around''.

The young mother and daughter did not go on to experience any difficulties in this regard. Of course, not all difficult subjects had been dealt with. However, the young mother's behaviour signalled to her daughter that all matters would be dealt with in an open manner, right from the start of her illness. This helped foster a sense of security that is so desperately needed during times of uncertainty.

7.2 Will an open and honest approach cause unnecessary stress?

Many parents, and especially grandparents, worry that open discussions about their illness will add to their children's distress. During a consultation Mrs Weber said: ''Maybe my child doesn't fully realise what's going on; Maybe I'll make matters worse if I choose to be open''. Parents often lack confidence because they do not know how to deal with their children's feelings.

One thing is for sure: Your child will

show a response of some sort. Perhaps he or she will be sad. Perhaps they will cry. Other possible responses include an apparent lack of interest, anger or aggression. Cancer and the threat it poses to your child may cause a vast array of emotional responses. It is important to note that there is a great deal of diversity when it comes to ways in which children respond emotionally. This can help you feel prepared. Comfort your child if he or she needs to be comforted, using your usual strategies. For example, give them a cuddle, allow them to express their feelings, no matter what they are. If your child leaves the room, you could follow them and tell them that you understand they are shocked or scared. Comfort your child by telling them, for example: ''I was shocked, too. It would be strange if you weren't shocked or scared.'' Do make room for your own feelings, too. Parents worry when their children do not show any obvious response to their illness. However, it often transpires that the parents themselves do not show their emotions and try to be strong in order to protect their children. It is important to allow your child to see your emotions. This sends the important message that it is ok to show feelings. Do not prevent your children from witnessing your emotions, but do not overwhelm them by ''oversharing'' your feelings either. Try to find a healthy balance between these two extremes.

7.3 The truth, and nothing but the truth

Children are extremely attentive, no matter how young they are. Parents are proud to point this out, time and time again. However, when faced with adversity, parents sometimes fail to remember this. There is no doubt that children are quick to pick up on their parents' inner turmoil.
They quickly pick up on minute changes in facial expressions or bits of conversation. Failure to inform your children about important matters may cause them to experience threatening and irrational thoughts about the situation. This, in turn, may result in a pronounced sense of insecurity.

Imagine the following situation: You are standing by the window and notice that it is raining outside. A friend enters the room and tells you ''No, it's not raining.'' How would you respond? You would probably start to doubt yourself or your friend, depending on your own sense of stability and confidence. Children may experience similar thought processes.
However, they tend to doubt themselves in the first instance, because their parents are usually right and are considered to be true heroes. When parents are diagnosed with cancer the following situation may arise: Children can sense that something bad has happened, but their parents pretend that everything is ok. The resulting sense of uncertainty may cause a degree of inner turmoil. Children may begin to mistrust themselves or their parents. An already complex situation becomes even more complicated as exposure to ambiguous and confusing messages may result in behavioural disturbances. The truth has a habit of revealing itself, sometimes via pure co-incidence: You or your partner suffer from cancer. Failure to tell your child in person may hurt their feelings and may be interpreted as a huge betrayal of trust. Your child may conclude: ''My parents don't trust me and I can't rely on them''.

For example: A mother who suffered from cancer and who usually wore a wig collected her daughter and a friend's child from nursery. Her daughter's friend proclaimed ''Your mum has cancer and now she is bald.'' Her daughter stopped in her tracks and then ran away crying, in a state of distress. She was very upset that her mother had not told her about her illness and her friend knew what was going on before she did.

Remaining silent or lying about matters can have extremely negative consequences. In fact, it may contaminate the situation and may contribute to further insecurity at a time when a healthy parent-child relationship is the main source of a stable sense of security.

7.4 Getting the timing right

You have decided to talk to your child. But when should you have this conversation? At the breakfast table, in a casual manner, or at bedtime? Should you tell your child even before your diagnosis has been confirmed?

Talk to your child as soon as possible, especially when your illness is likely to affect your child's routine. When talking to a three-year-old, you could say the following, for example: ''Mummy is ill and has to go to hospital. Daddy will collect you from nursery today and then we'll talk on the phone, alright?''

At this point you should refrain from sharing details regarding the possible diagnosis. If your child wants to know more you could reply: ''I don't know exactly what is going on. The doctor needs to carry out more tests, but I'll let you know as soon as I know more.'' Your specific response will depend on your child's verbal abilities and their level of interest.

It is difficult to hide from your child the shock that you may experience when you are diagnosed with cancer. When you decide to have a conversation, choose a moment that suits both you and your child. Avoid times when you or your child are tired, hungry or distressed.

It is unhelpful to have this conversation at bedtime, as your child should be given the opportunity to distract him- or

herself afterwards, for example through play and physical exercise. This may help reduce the levels of stress hormones that are released during difficult conversations (= stress experiences). However, this rule is not set in stone. Sometimes opportunities do arise at bedtime. Once the conversation has taken place, make plenty of time for cuddles and affection.

It is helpful for both parents to be involved in the initial conversation. This may reduce the sense of unease your child experiences and conveys the important message that everyone will adopt an open approach. Make sure that you have spoken to your partner beforehand and that you have agreed on the details you wish to share with your child.

Respond to your child's questions. As a general rule of thumb: If your child asks a question at a time that is inconvenient, e.g. at the supermarket check-out or whilst you are driving, tell them why you are unable to answer their question there and then. Tell them when you will provide them with an answer and stick to this agreement.

7.5 Choosing words that are appropriate for your child and their developmental stage

In 1957 Jean Piaget, an influential developmental psychologist, observed that children think in strikingly different ways from adults. As such, it is important to take into account your child's age and developmental stage when discussing your illness. It is also important to note that some children aged six, for example, fit the description of "a proper school child", whilst others are much more playful and immature and can therefore appear younger than their age.

The following example illustrates how a conversation may progress:
Mrs Schulz, has finally decided to tell her twelve-year-old son David that his father suffers from cancer.
Mrs Schulz: "David, I have to talk to you about a difficult subject." David: „What's the matter? Is it to do with daddy?" Mrs Schulz: "Yes, and I find it hard to tell you." Her eyes well up with tears.
David (fearful): "Is daddy going to die?"
Mrs Schulz (relieved because David has touched on the "worst case scenario" and the news she is about to share is less devastating): "No, I don't think so, but daddy has cancer, testicular cancer."
David: "So that's why he hasn't been playing football recently. Can you die from it?"
Mrs Schulz: "That's a difficult question. In principle, people can die from any form of cancer, but testicular cancer is a type of cancer that is less malignant and can often be cured. The doctors have spotted daddy's illness very early on, which means that there's a good chance he'll recover. If you're interested, I can show you some information in a book".
(She tries to explain the nature of his father's illness. David asks a number of questions and she tries to answer them as best as she can).
David: "Does daddy know that you've told me?"
Mrs Schulz: "Yes, David. We talked about it and decided that we want you to know as much as possible."
David: "Good, I'm glad. What will happen now? Is daddy going to lose his hair?"
Mrs Schulz: "No, daddy will be treated with radiotherapy which doesn't cause hair loss. If you're interested the doctor will be able to explain things to you in more detail tomorrow."
David: "Yes."
Mrs Schulz: "You might like to speak to other children whose parents have cancer online. I know a good website."
David: "Maybe later. Can I watch TV now?"

How should parents deal with the subject of cancer in a manner that is appropriate for their child's age and developmental stage? The following example may illustrate this. The family have a five-year-old daughter. "I chose a wig straight after my first round of chemotherapy. It was similar to my own hair in colour and style and I was now able to wait for the hair loss to begin. When I began to lose my hair I asked my daughter and husband to accompany me to the hairdresser's.
Here my daughter was allowed to cut off my long hair using scissors. They trimmed my hair to a length of 2mm using special clippers. Following this, my wig received a final trim and I left the hairdresser's with my usual hairstyle, the only difference being that I wore a wig.
I had spoken to the hairdresser beforehand and he had ensured that no other customers were present at the time, which helped create a relaxed atmosphere." This example yet again demonstrates the merits of adopting an open and honest approach. The child seemed curious and interested in what was going on.

Some general advice for communicating with your child:

- Choose words your child is familiar with.
- Refer to experiences your child has had in the past, for example: "Do you remember when granny was ill last year and had to go to hospital? I need to go to hospital now, because my tummy is really sore."
- Refer to your illness as "cancer", especially when speaking to children who go to nursery, or who often watch TV or overhear telephone conversations (the latter of which should be avoided!).
- Allow speaking in absolute terms. For example, avoid statements such as "Everything will be ok" and use the following words instead: "I really hope that things will be ok. We're all trying very hard to make that happen".

- Make space and time for questions and emotional responses.
- Acknowledge and learn from your mistakes. Even professionals sometimes use the wrong words and regret this at a later stage. A stable relationship that is built on honesty and openness is able to withstand occasional ''slip ups''.

7.6 Eyes say more than words

Communication entails both spoken language and non-verbal messages. Non-verbal messages include all messages that your body sends automatically, without utilising spoken language. Examples include facial expressions, eye gaze, gestures, body posture and the manner in which you speak (e.g. fluent versus halting speech). These messages can convey more than a thousand words.

Even children who appear to respond in a calm and sensible manner can experience significant inner turmoil. Perhaps your child is trying to protect you or they are scared to show anxiety, weakness or feelings in general. Body language is extremely revealing and may provide you with some important insights into your child's emotional experiences.

7.7 Sharing the right amount of information

In the early 1500s the famous Swiss doctor Paracelsus noted that ''The dosage makes it either a poison or a remedy''. In its wider sense, this can mean the following: The amount of detail you share should depend on your child's developmental stage and level of interest. Try not to share too many details unless your child specifically asks for this information and you feel able to have this conversation. Do not overwhelm your child with information - judge how they respond and provide explanations at every step along the way.

It would be unhelpful to discuss the subject of rehabilitation at the time of diagnosis. You should also consider the level of detail that you feel comfortable with. A mother who is scared of her child's response in addition to her own response may withhold important information and fail to provide clear explanations. As a consequence, the child may misunderstand the information provided, which, in turn, may result in the type of response the mother had feared in the first place. Psychologists refer to this phenomenon as ''self-fulfilling prophecy''. The mother's belief that it is unhelpful to share information is thus confirmed. However, most parents fail to appreciate that the nature of the information conveyed, as well as the manner in which this information is conveyed, are critical factors.

A word of advice: Carefully consider the level of information you and your child will be able to cope with in any given situation. Trust your instincts, speak to your partner and observe how your child responds.

7.8 Sharing information appropriately

Provide your child with information that is both appropriate and easy to understand. Bear in mind that your child's attention span is limited; It is ok to omit details that do not directly aid their understanding of diagnosis or treatment.

Moreover, information provision should not be the sole purpose of any conversation. Aim to make space for feelings. Many people struggle to discuss their feelings. They find it easier to say ''Your liver is located in your right upper abdomen'' than: ''I'm really scared and that's why I cry a lot.'' Allowing your child to see that you are able to tolerate emotions may be of tremendous benefit.

7.9 Keeping promises

Do not make empty promises. Children cling on to everything their parents say. This provides them with a sense of security and reliability. Children may lose trust in their parents when they realise that they have not kept their promises. They may conclude ''You lied to me'' and may agonise over why this is the case. They often blame themselves in order to protect their parents. Empty promises also send the unfortunate message that it ok not to commit when dealing with important matters.

7.10 Discussing changes to daily routines

Be sure to inform your child of any potential changes to their daily routines. What will remain the same, what will change? These are concrete questions that matter to children. A child's daily routine tends to be fairly structured. This structure fosters a sense of security. When you are ill, your child may lose confidence in their belief that most things in life are stable and permanent. This may cause significant anxiety. You may be able to counteract this process by preparing your child for potential changes, whilst emphasising that some things will remain the same. For example: ''From now on granny will collect you from nursery, and then we'll all have dinner together.''

At this point, it is important to consider your child's sense of time. Children live in the here and now, i.e. in the present time. A certain level of intellectual development is required for children to grasp the abstract concept of time. As such, a four-year-old child is able to utilise the terms'' mid-day'', ''evening'' and ''early'' in the correct temporal order. At the age of four, children are able to comprehend the rhythm between day and night, and by the age of six they can utilise and differentiate between the terms ''yesterday'' and ''tomorrow''. It is not until the age of seven that children are able to comprehend the meaning of the terms ''the day before yesterday'' and ''the day after tomorrow''. An understanding of smaller units of time (i.e. hours, minutes or seconds) is last to develop. It is helpful to bear this in mind when discussing changes or when making temporal arrangements.

7.11 Announcing significant events

It is vital to discuss significant events, such as the beginning of treatment, its side effects or a planned episode of in-patient rehabilitation. Explain to your child why granny will come and stay for a while, for example. Speak to your child as soon as possible if your cancer has returned or if it becomes clear that your cancer is not curable.

For example: Annika, aged twelve, was told by her mother that her father would recover. Her mother had said this because she had been hoping that her husband would make it "against all odds", and because she did not know how to talk to Annika about the possibility that her father might die. Her grandmother confirmed what her mother had said. Annika became more and more reluctant to visit her father in hospital. At times, she would act "touchy" and aggressive, according to her mother. Eventually she shouted: "You never tell me the truth anyway!" and stormed out of the room. During a consultation it became clear that Annika had a much better understanding of the situation than her mother had anticipated. Annika's mother realised that she urgently needed to have an open and honest conversation with her.

7.12 Making room for questions

Invite your child to ask questions. You can make your child feel more secure by gently prompting them: „Does all of this make sense to you? You can ask me later if anything seems unclear or worries you."

Children can sense when their parents simply fulfil their „educational duty" as recommended by a professional, such as a psychologist. Tell your child: „Look, I'm not entirely sure, but you know what, I can ask the doctor the next time I see her and then I'll let you know". It is then important to stick to your promise. Allow your child to see that you do not have all the answers either.

7.13 Has your child understood the information imparted

Do not assume or expect that your child has fully understood what you have told them. Perhaps your child is frightened by the bad news, but is yet unable to comprehend the full extent of the illness. Checking in with your child is key. For example, you might want to ask: "Any idea how my body might change during chemotherapy?" If it transpires that you have provided your child with too much information, provide less detail the next time you talk. In some cases, children do not seem bothered by their parent's illness and do not ask any relevant questions. Parents may wonder whether their child has understood what is going on. Having a follow-up conversation may then seem even more difficult. However, one thing is for sure: Your child has received the message, even if he or she shows no obvious response. On closer examination, you may notice that they make subtle comments. This is especially the case in younger children, as demonstrated by the case study below (also see section 4).

Sebastian is four years old when his mother undergoes in-patient rehabilitation. Sebastian and his father stay in accommodation close-by. Every evening, when Sebastian visits her, he wants to know what she has had to eat and he keeps commenting "Oooh, that's healthy." His parents are slightly irritated by this behaviour, because they do not understand his sudden pre-occupation with food. During a consultation it becomes apparent that Sebastian knows that a healthy diet is good for people's health.

This illustrates just how worried he is about his mother. His behaviour may also reflect a degree of worry about his own health.

7.14 Difficulties discussing your own illness

There are multiple reasons underlying parents' reluctance to talk to their children. Receiving a diagnosis may leave some parents numb, and they may have the desire to work through their own thoughts and feelings before they speak to their children. Sometimes parents are worried that their child may spread the news of their diagnosis, which they might find uncomfortable. This is especially the case for parents who work in the public sector, e.g. teachers or doctors. Having a conversation with your child may seem impossible under these circumstances. Reluctance to speak to your child may also reflect worry about your child's potential response and your ability to deal with this. Mothers in particular often believe that they are unable to talk to their child. Underlying this is a fear of a loss of control. For example, some mothers worry that they may burst into tears and may thus exacerbate their child's distress.

Case example: Mrs Karl, who has a three-year-old daughter, Saskia, suffers from advanced breast cancer. Saskia, who has been potty-trained for nine months, starts having ''accidents''. At night she often wakes up crying, and wraps herself around her mother's legs or, preferably, demands to be cuddled. It transpires that her mother has not yet had the heart to tell her just how advanced her illness really is. Saskia appears to become more and more distressed and Mrs Karl experiences significant feelings of guilt. During a consultation she voices the belief that she needs to be brave and remain positive. She attempts to suppress any thoughts relating to the possibility that she might not survive her illness. She believes that it is important to remain strong for her husband and children. The thought of speaking to her child triggers a ''worst-case scenario'' image . She imagines herself dissolved to tears, unable to comfort her own daughter. She is particularly worried that her carefully suppressed feelings, especially her fear of dying and leaving behind her child, will re-emerge when she starts to talk. Once Mrs Karl had managed to tearfully express her worst fears, we role-played a potential conversation with her daughter. The actual conversation with Saskia took place one week later. Although Mrs Karl found it difficult to talk to her daughter, the conversation went much better than expected. She was sad and shed some tears, but generally felt in control of the situation. Saskia seemed relieved and was less tearful in the days that followed. This encouraged Mrs Karl to continue to have open and honest conversations with her daughter.

If, for whatever reason, you are unable to talk to your child (or you simply do not wish to have this conversation yourself), a cancer information center may be able to help (see contacts section below). Professional input may help you understand why you struggle to talk to your child. You may also be directed to other relevant services. Sometimes close friends or family may enable you to have a conversation with your child. Finally, psycho-oncologists who are experienced in such matters could be of assistance to you.

It is extremely important for you to address your own concerns and worries!

For example: Mrs Miller, who had a ten-year-old son, Nikolaus, suffered from bowel cancer. One of the themes that emerged during her consultations with me concerned the nature of the information she should share with her family. Mrs Miller did not wish to burden anyone, especially not her son. She felt that he was far too young and she did not want to frighten him. We spoke in depth about Mrs Miller's worries. I outlined ways in which children might respond and we discussed what may be helpful versus unhelpful. Nevertheless, Mrs Miller did not have the heart to tell Nikolaus. She appeared to be in denial about the terminal nature of her illness. I was worried about the family and about Nikolaus in particular. However, I assumed that Mrs Miller had solid reasons for withholding information from her family and I accepted her decision. A forced conversation would certainly not have been helpful. When her illness progressed Mrs Miller chose to talk to Nikolaus, remembering a case example I had previously shared with her. At this stage, Mrs Miller had come to terms with her illness and this allowed her to have a conversation with her son and answer his questions.

7.15 Should you inform others?

Individuals diagnosed with cancer often wish to the keep the news of their illness quiet in order to avoid false sympathy or gossiping behind their back. This is completely understandable! However, children may experience a significant sense of burden when they are expected to keep such a big secret. The following case example illustrates this:

Mrs Schneider is a single parent. She is diagnosed with early-stage breast cancer. There is a very good chance that she will be cured. Anja, her 13-year-old daughter, is aware of her mother's diagnosis and seems to cope with it. They have a very close relationship. However, Anja's mother does not wish for anybody else to know about her illness. Anja respects her mother's request and remains loyal to her. Anja's friends struggle to understand why she is acting increasingly ''strange''. Her teachers are perplexed, too, and are angered by her evasive behaviour. This results in an open dispute, and Anja bursts into tears in front of her classmates. It is only now that Anja's teacher learns about her mother's illness. Anja feels guilty when thinking about the promise she has broken. Her inner conflict prompts her to seek professional help.

An important reason to inform caregivers, such as teachers, includes the following:
Behavioural difficulties first tend to emerge in the context of nursery or

school. When teachers or nursery staff are aware of the situation, they are able to interpret any behavioural difficulties accordingly, i.e. as manifestations of children's fears and worries. Punishing a child by means of detention, rather than supporting them emotionally when they are disruptive in class due to anxiety about their parents, might have devastating consequences.

If possible, involve teachers and nursery staff. Invite them to have a conversation with you or encourage them to cover the topic of cancer at school. A cancer diagnosis tends to generate many wrong and sometimes even absurd beliefs and assumptions.

Working with a psycho-oncologist allows you to discover ways in which you may inform neighbours, friends or customers in a manner that you do not find overwhelming and that feels "right" to you. A general rule of thumb: Trust your instincts when deciding whom to tell what and how much information you will share.

Many scientific studies show that social support enhances individuals' ability to cope with their illness. However, nowadays many families live apart. Granny and grandpa may not live locally or have perhaps passed away and contact with aunts and uncles may be limited. So who will be able to help? Family is not necessarily the only source of social support. Friends, neighbours and colleagues all form part of our social network, too.

Confiding in other people may enhance your family's ability to cope with and manage your illness. Accept help and ask for practical support. Many people are reserved and do not wish to intrude when you are ill. Individuals diagnosed with cancer often perceive this as a sign of withdrawal, even though this is usually not the case.

Most friends and acquaintances would be happy to discover how they might be able to help you.

Do not shy away from asking questions such as: "Whilst I undergo chemotherapy, would you be able to go shopping, prepare dinner, collect the children from nursery, etc.?"

7.16 Having fun and making time for relaxation

Establish a "cancer-free zone". How? You could agree not to discuss the subject of cancer during family meals, for example. Keep your daily routine as structured as possible, as this provides children with a sense of security. Schedule in time for your children. Let your children decide how to spend this this "together time". Activities may include cuddling, reading stories, drawing or dressing up. It is an opportunity to fully attend to your child and you are likely to benefit from it, too. If you feel unwell you could perhaps read stories to your child in bed. Children often believe that they are no longer allowed to laugh or have fun when their parent is seriously ill. Show them that this is not the case. Perhaps you may also find it helpful to burst into laughter when watching a funny movie on TV.

Feelings of sadness or despair have a habit of emerging at times when you are particularly happy in the company of your children. You may wonder: "Why now, when everything is so perfect? Why does it have to be this way?" It is only natural that happy and emotional experiences prompt you to reflect on the lack of permanence in life, as such experiences can highlight what's at stake.

8. Do all children respond in the same way?

No! Children, like adults, have idiosyncratic personalities and may respond in unique ways when faced with a diagnosis of cancer in a family member. Generally speaking, your child's response may depend on the following factors:

- The child's age at the time of diagnosis: Fifteen-month-old Lars does not seem fazed when his mother is diagnosed. However, he seems much more attached to his father. In contrast, his three-year-old brother refuses to leave the flat, clings on to his mother and frequently wets himself.

- The child's relationship with their parents and the ill parent in particular: Sarah's father means the world to her. She has a very close relationship with him. When he falls ill, Sarah is extremely worried that she may lose her main attachment figure.

- Difficulties and problems that predate the diagnosis: Just prior to her mother's diagnosis, eighteen-year-old Lissi was about to move out of the family home due to ongoing conflict with her mother. Now she feels obliged to stay, but she remains ambivalent and tensions rise.

- Social support from friends or family: Fourteen-year old Monika lives alone with her mother. Her father has never been involved in her care. Her grandparents live in a nursing home and she has few friends. She lacks social support.

- Availability of the „healthy" parent: Ten-year-old Jan's mother is required to work all day in order to provide for her family. Jan spends a lot of time by himself and has learnt to look after himself.

- The type of cancer and the child's gender: Sixteen-year-old Marco's father suffers from prostate cancer. This is particularly difficult for Marco who is undergoing puberty and who is highly focused on his body and masculinity. As a result, Marco and his father repeatedly clash. Marco no longer listens to his father, is aggressive and reluctant to talk. He even declines a consultation with me. He has a go at his father: „There's nothing wrong with my mental health!"

- The course of the illness: Fourteen-year-old Sarah is constantly faced with sudden deteriorations in her father's condition, as well as corresponding interventions. There is little time for rest and relaxation. She worries that her father may never recover, but needs to suppress this fear in order to find some enjoyment in life.

- The chance of cure: Three-and-a-half-year-old Lara constantly complains of animals in her stomach and believes that she will die if they remain „inside". When she asks her seriously ill mother whether she will „go dead", her mother replies: „Mummies never die". However, Lara has overheard a number of conversations during which the stage of her mother's illness was discussed.

- The level of honesty and openness that is present in the parent-child relationship: Ten-year-old Lars has a vague idea that his mother will not recover. He is upset because no one talks to him and family members seem subdued and tend to dismiss his fears and worries. He becomes increasingly aggressive and begins to hit his mother.

9. Different age groups

The following section outlines how children within various age groups may respond to cancer in a parent. Ways in which you could deal with such responses and contain the situation are discussed.

9.1 Being diagnosed with cancer during pregnancy

You may be surprised to find that this topic is covered here. After all, it is not possible to communicate with unborn babies by means of conventional language. Conflicts may arise, however, when parents are faced with the decision as to whether their baby should be delivered prematurely, for example, to allow their mother to commence chemotherapy that is urgently needed. Mothers who undergo treatment soon after childbirth usually cannot fulfil their role in the manner they would have liked to. This may lead to early attachment problems as well as maternal feelings of guilt. Some mothers subconsciously reject their child. Where this is the case, it is important to seek psychological help in a timely manner in order to prevent family difficulties from becoming established.

9.2 The first year of life

During the first year of life, children lack an understanding of the concept of illness. As such, there is little point in providing them with an explanation. However, you could tell an eleven-month-old child that mummy is „sore" and ill and needs to see a doctor. Babies are sensitive to the atmosphere that surrounds them and they may respond to being separated from their main attachment figure. Infants lack all sense of time and cannot anticipate when mummy or daddy will return. To an infant, five minutes can seem like an eternity and the child may become extremely distressed when their attachment figure is gone. If a parent remains absent for longer periods of time without being in touch, the child sometimes screams or rejects the parent when they return. This can be a disappointing experience for parents who believe that their child should be happy to see them. They fail to understand that their child has begun to withdraw in order to protect themselves from further disappointment. Parents of children below the age of one often feel as if their child is completely unaware of what is going on, because they do not show any noticeable response. This is far from true. Your voice, the atmosphere, or any type of physical contact conveys the message that „Mummy or daddy are here". Try to create a calm and safe atmosphere in amongst all the chaos. This may involve regular „cuddle time" with your child, during which interruptions should be avoided. Ensure that meal times and outings are calm experiences and avoid frequent changes in caregivers.

9.3 Children aged one to two

Within this age group potential responses are diverse and may depend on whether or not other attachment figures, such as grandparents, are present. Much like infants, children within this age group pick up on the atmosphere at home and respond primarily to being separated from their main attachment figure. As such, during hospital admissions or periods of in-patient rehabilitation, it is important to maintain daily telephone contact with your child, possibly even at the same time each day. Modern forms of communication, such as Skype, can be helpful. Most of the time, your child will only listen to you for a few seconds before they will want to play with the telephone. However, these brief moments are incredibly valuable for the parent-child relationship and your child's sense of security. Visits should take place as often as possible. Do not worry about the possibility that your child may become frightened in a hospital environment. Many children do not think twice about matters that worry adults. Dealing with visiting times in a straightforward manner will have a beneficial impact on your child.

Depending on your child's language development, which is highly variable in this age group, it may not be possible to explain the nature of your illness as such. However, that does not preclude you from telling your child that mummy or daddy is ill: young children have the ability to recognise emotions in other people, especially their caregivers. To your child, this ability constitutes an important source of information about their environment. When unsure about something, young children literally search for an answer in their mummy or daddy's face. Children are able to sense parental fears or restlessness and may, in turn, respond with restlessness, crying, sleeping difficulties or refusal to eat themselves.

Case example: Two-year-old Lisa suddenly refused to eat and her mother found it difficult to cope with her constant whining. There was nothing her mother could do right. After a consultation session, her mother decided to tell Lisa about her illness. She said: "Lisa, mummy is ill. She is sore here" and pointed to her breast." The doctor will have a look to see what's wrong and examine it." You could use a doll, for example, in order to demonstrate things. Sometimes children will then want to take a look for themselves. Trust your instincts when deciding whether you are ok with this; this may depend on your attitude towards nakedness and physicality. Tell your child "I don't like this" if you do not like it.

Again, the manner in which you interact with your child is important. It helps to have this conversation when you are calm and not in a rush. When you have to leave to go for a check-up, for example, you could tell your child that daddy or a neighbour will look after them. You might say ''I'll be back tonight and put you to bed.'' if you are certain that this will be the case.

9.4 Children aged three to six years

Within this age group responses can vary greatly depending on the situation and the child's temper. Children often have a good understanding of illness and potential loss through personal experience. Children within this age group are very scared of being separated from mummy or daddy. They have a rough concept of time. As such, you should be very precise when referring to time. Only say ''I'll be back in an hour'' when you can guarantee that this will be the case. Children find it extremely unsettling and suffer unnecessary anxiety when their parents are running late. You might want to provide your child with an alarm clock and demonstrate where its hands will be on your return.

The following responses are common within this age group: The child withdraws from the attachment figure or suddenly does not want to leave the flat. It is not unusual for children aged three to six to regress developmentally. Young children may suddenly need to wear nappies again and nursery aged children may return to sucking their thumb. Underlying this regression may

be a desire to return to a time when things were good, when illness was not an issue.

Sometimes children begin to complain of ailments themselves. Three-year-old Paula claims, for example, that she has bad animals in her stomach, just like her mummy, and that she is therefore unable to eat. To put this into context: Paula's mother has significant fluid retention in her stomach, and as a consequence, her stomach has grown noticeably, to the extent that she could no longer carry Paula. Paula sensed: something is not right and that is a problem. Older nursery-aged children can sometimes become aggressive and deliberately destroy toys. Difficulties falling asleep are common. These are usually caused by non-specific anxiety. As mentioned above, children often behave differently outside of their home environment. As such, it is important to involve nursery-school teachers and keep them informed about important events, such as planned hospital admissions or periods of in-patient rehabilitation. Ask teachers or nursery-school staff to contact you if they notice any changes in your child's behaviour.

It is not necessary or helpful to provide nursery-aged children with detailed explanations regarding the situation in general, or risks and prognoses in particular. Children within this age group have an attention span of approximately five to fifteen minutes, and as such, it makes sense for you to focus on the essentials. In the first instance, children may need to know about specific changes to their daily routine. Remember: your child is faced with a difficult situation and will require a great deal of attention and affection. If your child falls within this age group, call your illness by its proper name, regardless of how difficult this may be for you.

Example: Mrs Müller has two children, four-year-old Lara und seven-year-old Tom. Both of them are aware that their mother is ill, but they do not know that she suffers from cancer. Whilst out shopping they meet Susanne, who lives next door and who goes to nursery with Lara. When Susanne spots Mrs Müller, she loudly asks ''Will you die from cancer soon?'' Mrs Müller is shocked, as is Susanne's mother, and

she is embarrassed and feels guilty. Lara and Tom look at their mother with wide eyes. Lara begins to cry and says: ''Mummy, is this true? Do you have cancer and are you going to die?''

9.5 Children aged seven to twelve years

From the moment children go to school for the very first time, they tend to develop a level of independence and detach themselves from their parental home. At this age, children are generally able to comprehend the seriousness of the situation. Difficulties at school are common within this age group: Performance may deteriorate, although the opposite may also be true. Children may attempt to cheer up their unwell parent by excelling at school.

Sometimes children do not allow themselves to experience pleasure in their day-to-day life. They believe that they are no longer allowed to laugh, a misconception that is also common in adult partners and family members. However, it is vital for children to experience fun and cheerfulness, to visit friends and to continue to engage in all other activities they enjoy, despite the difficult situation. Children aged seven to twelve years closely observe their unwell parent and are guided by their behaviour. For example, if their father says: ''Mum needs to pull herself together and stop crying'' children may take this message to heart and behave in exactly this manner. They will pull themselves together and try hard not to cry. Sometimes children in this age group respond by taking on an extremely caring role, which may prove to

be a significant burden to them. They make cups of tea for their unwell mother who is lying in bed, they ''mother'' her and do not leave her side. The belief ''I can help'' provides children with a sense of importance and security amidst all the uncertainty they face. Do not let your child take on too much responsibility; Do not let them develop feelings of guilt when they are not in the mood to help out or when they resent having to be considerate of their ill parent's needs at all times.

Feelings of guilt are common amongst this age group: ''It's my fault mum is ill because I've not been good'', ''If I don't behave well mum will have a relapse''. Girls in particular are prone to this way of thinking. Children who experience those thoughts often do not dare to be cheeky, disobedient or sad. The opposite may be true also, as the following case example will demonstrate:

A very distressed 36-year-old woman sought professional help because the situation at home appeared to escalate. Her eleven-year-old son Lukas engaged in various refusal behaviours, his performance at school deteriorated, he became increasingly aggressive and shouted at his seriously ill mother, telling her she should hurry up and die because she would eventually die anyway. It soon became apparent that Lukas was very aware of his mother's life threatening condition. His mother dismissed his fears because she was in denial about the threat her illness posed. She tried to keep the truth at bay at all costs. His father did not provide any meaningful support either. Lukas' death wishes for his mother may reflect an attempt to exert some control over a situation that had escalated.

School aged children often do not know how to approach the topic of cancer in a school environment, i.e. they do not know if they should raise the matter at all, and if so, whom they should confide in and how much information they should share.

Case example: Mark is ten years old and suddenly no longer wants to go to school. His parents are very distressed and struggle to understand the reasons behind his school refusal. A conversation with Mark during a consultation revealed that he did not know how to respond to his classmates when they asked him why his mother was in a wheelchair. I asked Mark whether it would be helpful for me to visit his school in order to carry out a joint lesson with his teacher, focusing on the subject of illness and cancer. Mark declined this offer, even though he thought this idea was ''quite good''.

When I asked him whether he had any alternative suggestions, he responded in a swift and confident manner: ''Yes, I'd like to talk to the other children myself, but the problem is that I don't know much about cancer.'' I used a text book and a series of pictures and diagrams in order to enhance Mark's understanding of cancer, its origins and the type of cancer his mother suffered from. One week later, his parents reported that he successfully delivered a presentation on cancer and was now known to be an expert on the subject. This greatly improved his confidence and he was happy to attend school again. Of course, not all difficulties can be resolved as promptly as this, but occasionally fast and easy solutions do exist.

Can I get cancer, too? Have I inherited it?

Children may be pre-occupied with this question, but this may depend on your child's personality and their general attitude towards health and illness. It is important to provide children with some answers that are specific to their individual situation.

For children aged seven to twelve the following points are important:

- Be specific about changes to daily routines. This may enhance even older children's sense of security. For example: ''Granny will take you to your ballet lessons for as long as I'm too tired to do this.''

- Provide your children with details regarding your illness, its treatment and likely outcomes. Children in this age group are thirsty for knowledge. Biology books etc. may help provide relevant explanations.

- Illustrate specific bodily changes. ''Chemotherapy makes me lose my hair, and that's why I might be bald and wear a wig soon. My hair will grow back though.''

- Explain in detail why you need to attend check ups. Children do not understand why additional treatment, such as hormonal therapies, may be necessary. They may worry that things are being kept secret from them if they are not provided with a coherent explanation.

- Explain to your child that cancer is not contagious and discuss the subject of heritability, possibly with the help of your doctor. Children are usually excited at the prospect of questioning a doctor.

- Talk to your children's teachers about your condition. If you have a good relationship with them, you may also

want to provide them with details regarding the course of your illness, including any planned periods of in-patient rehabilitation.

- Do not dramatise setbacks. Most of the time they will pass.

- Help your children overcome feelings of guilt. Your illness is nobody's fault.

- If you ask your child to carry out major domestic chores, tell them when this will come to an end. Children may be burdened by the prospect of having to look after younger siblings for months on end.

- Do not pressurise your children: "If you do 'such and such', mummy will recover more quickly." This leads children to believe that their behaviour can affect your illness. If your illness progresses they are quick to blame themselves.

- Provide your child with explanations regarding medical equipment or instruments, however, only do so if your child asks for this information and appears interested. Do not take children along to treatment sessions. Certain conversations that occur during these appointments may be extremely distressing. However, you may wish to offer your child a tour of the treatment unit.

9.6 Teenagers and youths aged thirteen to eighteen

Puberty is a time of conflicting emotions, and having a parent who suffers from cancer may exacerbate this experience.
Teenagers face a particularly difficult situation: They are on the verge of becoming independent adults, but are "forced to return home" by their parent's illness, especially when younger siblings are around. Teenagers quickly sense that something is wrong. However, they may be too self-focused to ask questions. Parents can find it difficult to initiate conversations, especially when there is pre-existing conflict. Children within this age group typically worry that they may fall ill themselves. Younger children may share this worry, too, and this can be problematic in the long-term. Teenagers undergoing puberty are highly focused on the subject of the human body, especially body parts that have a sexual meaning, such as breasts. Matters may be even more complicated when a girl's mother is diagnosed with breast cancer, for example.

Case example: Sixteen-year-old Natascha initially seemed to cope well with her mother's illness. However, she subsequently began to examine her breast several times per day. Eventually, she complained of pain and her concerned mother took her to the doctor. The doctor did not detect any abnormalities, however, it only took several days for Natascha to complain of pain in her breast again. During a consultation, it became clear that she had developed a "non-specific fear" of having breast cancer herself. She was extremely scared, struggled to sleep and did not wish to burden her mother with her worries.

The following responses are common in teenagers:

- Aggression directed at the affected parent or the entire family
- Depression
- Difficulties at school
- Eating disorders
- Psychosomatic complaints, including headaches or stomach/leg pain, for example
- Drug use
- Withdrawal from friends
- Lack of interest in hobbies
- Behaviours characterised by extreme rejection

Some helpful pointers for conversations with teenagers:

- Do not wait until you find the right opportunity to talk. Take initiative. Teenagers are usually open and ready to engage in a conversation when parents say: "I need to talk to you about a difficult subject that affects all of us."

- Here, the following applies (as it does with other age groups): Your child's anxiety will be minimised if you avoid keeping secrets and openly address illness within the family.

- Parents should generally assume that their teenager knows as much about cancer as they do, however, this may not apply to their specific type of cancer.

- As such, they should take time to explain the nature of the illness and its treatment.

- Although teenagers understand a lot and like to give the impression that they understand everything, parents should avoid over-loading them with too many "if's and but's".

- Most teenagers are able to access the internet these days. They tend to research matters online, but are often completely unable to cope with the information they find. At this stage, it may be helpful for them to have a conversation with their parents or professionals.

- A conversation with a doctor may help teenagers organise information. This may provide them with a sense of security, which, in turn, may reduce anxiety.

- When teenagers only have one parent, they may fear that they will end up all alone, and it is vital to address this fear and to identify specific solutions.

10. Special family circumstances

Certain circumstances may complicate children's ability to cope with a diagnosis of cancer. Children in this situation carry a particularly heavy burden and professional assistance may be indicated from the very beginning. Particularly difficult circumstances include:

Patchwork families:
A situation that is not uncommon: A father who has two children marries a mother who has a daughter. The daughter does not get along with her stepfather and her mother is diagnosed with cancer. As such, she increasingly relies on her stepfather for care.

Adopted families:
There is a higher risk of cancer-related behavioural disturbances in children who have been adopted. However, this does depend on the age of the child at the time of adoption. In this group of children, loss-related fears are activated more readily.

Families who already struggle with other pre-existing physical or psychological illnesses:
Children in this situation carry a heavy psychological burden even prior to their parent's illness. As a consequence, they require a high level of psychological support right from the start.

Single parents:
Children within this category feel especially threatened given that they often lack a significant other who is able to look after them. They tend to rely on their primary caregiver who cannot be around much because of their illness. During the acute phase of the illness, children are concerned that their parent will die. Financial worries may be present and cause additional worries. The unwell parent tends to share these fears and worries. Who will look after my child if I die? Parents are often plagued by feelings of guilt about leaving their children behind.

Having lost a parent to cancer in the past:
Unfortunately, this situation does arise and affected children tend to experience significant anxiety right from the start. The unwell parent should seek psychological advice and support from an early stage.

Parents who both suffer from cancer:
In addition to seeking counselling, it is important to discuss the subject of heritability with your child. Initial conversations should also include a discussion about who will look after your child in case of an emergency.

Parents who struggle financially:
Financial strain in the context of an already difficult situation may distress children more than one might assume initially. Investigate whether you can access some form of financial support. This may depend on the country you live in. In Germany, being eligible for the "Härtefonds der Deutschen Krebshilfe e. V." (a one-off payment of 250.- Euros) due to financial difficulties facilitates access to other charities.

11. Discussing the subject of death

Discussing the subject of death is certainly one of the most difficult tasks parents have to face. Even professionals, such as doctors, nurses and psycho-oncologists who lack experience in this matter may struggle with this task. It is important to discuss this subject with your children, regardless of their age, especially when your illness progresses and cure is no longer possible.

Adults who lost a parent during their childhood often talk about how badly they were affected by their parent's silence and reluctance to discuss death.

Even at an old age, some adults remain distressed by the fact that they did not have the chance to say good-bye to their mother or father. Adults who, when they were children, were told that their parent would die soon, describe feelings of intense sadness, but generally seem to cope much better with the resulting loss. They were provided with an opportunity to bid farewell to their dying parent.

Children have the ability to deal with the subject of illness, death and dying in a much more adaptive and straightforward manner than adults. They show fewer reservations and, from an adult point of view, sometimes treat individuals who are dying in a rather callous and heartless manner. For example, ten-year-old Christiane asks her mother: "Can I have your golden necklace when you're dead?" It is important to be well prepared when discussing the subject of your nearing death, for example by talking things through with your partner, friends, a minister or professionals. Your own thoughts and beliefs about death and dying and about a possible after-life play a significant role when discussing the subject of death with your child. Your faith and life experience have shaped who you are and will influence the conversation. How much does your child know about death and dying? Perhaps this question may help you initiate the conversation.

Key points discussed in the sections above also apply to conversations about death: If possible, be mindful of your child's experiences. When dealing with younger children, a children's book may be a great way to facilitate a conversation. However, be careful not to hide behind the book. Tears and feelings of sadness form part of any such conversation and should not be suppressed. Suppressing such feelings may lead children to believe that sadness is not tolerated, and they may consequently attempt to protect their parents by suppressing their feelings altogether.

The following case example illustrates how a conversation about death and dying may be initiated: As discussed above, Mr Engler was incredibly relieved when the psychologist supported his decision to openly discuss the seriousness of his wife's illness and the possibility of her death with his son Saymon. During a consultation, ways in which he

could initiate the conversation were discussed (see below), and the importance of using language Saymon is familiar with was emphasised. The psychologist encouraged Mr Engler to share with his wife the ideas that were discussed during the consultation. Ideally, Mrs Engler would agree with the plan of action. The psychologist also encouraged him to discuss with his wife when they might feel ready to have this conversation.

Later that day Mr Engler said the following:

''Saymon, mummy and I need to talk to you about something very important. Can you come and see mummy in bed for a minute?''

The boy sensed the seriousness of the situation, stopped playing and came along to the bedroom.

Mother: ''Come, sit next to me.''

Father'' ''You know that mummy is very, very ill and I've been feeling very nervous recently.''

Saymon: ''Yes, and grandpa seems to be in a bad mood all the time. Nothing seems right anymore.''

Father: ''Saymon, we feel that you should know what's going on, otherwise you might be scared and you might not know why. That's why we want to talk to you.''

Saymon: ''Yes?''

Mother: ''Saymon, you know that I suffer from cancer and have spent a lot of time in hospital. The doctors tried their best to cure me, but unfortunately, it didn't work out.''

Saymon: ''What does that mean, mummy? You'll be fine, won't you?''

Father: ''No, Saymon, mummy won't recover, she will die soon.''

Saymon begins to cry: ''No, I don't believe you.''

Father: ''Unfortunately, it's true, Saymon, and it's really, really difficult for all of us. We don't want it to happen either, but mummy won't recover from this.''

The family spent a lot of time crying during and after this conversation. Ultimately, however, having this conversation provided an enormous relief for the entire family: They all had the same level of information and could stop to pretend. Saymon was relieved that his parents spoke to him in such an open manner: ''Finally I understand why grandpa always looks so sad, he isn't mad at me.''

12. When should you seek professional help?

You may wish to seek professional help if:

- You have some questions that you are unable to answer by yourself.
- You experience conflicting feelings and opinions in relation to having a conversation with your child.
- You do not know how to talk to your child.
- You and your partner disagree about the level of information you should share with your child.
- You feel unable to cope.
- You do not know whether your child's behaviour is a consequence of your illness.
- You become increasingly worried about your child and do not know how to interpret their behaviour.
- Your child asks for additional help and support.
- You would like some reassurance that you are dealing with matters in a child-appropriate manner.
- You require further information

13. Service – Websites

www.kinder-krebskranker-eltern.de

www.bremerkrebsgesellschaft.de

www.krebskompass.de

www.hilfe-fuer-kinder-krebskranker-eltern.de

www.inkanet.de

www.bianca-senf.de

www.aktionpink.de

www.allesistanders.de

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