

What you encounter when your child has cancer



You have just been told that your child has cancer and your world has been turned upside down. You have so many questions and emotions, whilst you also need to take care of all sorts of practical arrangements. You are worried about your sick child and you want to give him or her all your love and attention. Your partner and any other children that you may have also need you. How can you divide your time and attention? How should you deal with family and friends and what about school and work? And when are you supposed to find time for yourself?

This booklet provides answers and suggestions from parents who have experienced the same thing.

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The diagnosis



When you first hear that your child has cancer, the most common reaction is a state of shock. You are effectively paralysed and can barely comprehend what the doctor is saying.

This is followed by disbelief. "This can't be true". "He looks healthy!" "She was playing tennis yesterday". "Other people get cancer, not my child". "They have made a mistake". "That doesn't run in our family." Disbelief and denial are very normal and even necessary reactions. They soften the blow and ensure that you don't break down completely. Next, the reality sinks in slowly but surely: "Our child has cancer. Our child might even die".

Everyone responds differently. You might do nothing but cry, or you might clam up entirely. You might experience outbursts or rage. There is no right or wrong way to respond and all forms offer a healthy way of expressing deep sorrow. The people around you might not know what they should do when someone becomes angry and they may try to calm you down or tell

you to get a grip. They might feel uncomfortable. It is not helpful to bottle up your emotions. So cry if you need to cry, scream if you want to scream.

Who can help

Don't hide your fear or sorrow, talk to someone about it. This will help you gather your thoughts and look at things from a different perspective. You will only be able to cope with the situation once you have acknowledged the full severity of the situation. Friends and family are often more than willing to listen, but there are also other people who can help you. You can always ask the social worker or psychologist in the hospital for help. They have a lot of experience in helping families with a child who has cancer. Other parents who have gone - or are going - through the same thing can also offer support.

We (The Dutch National Childhood Cancer Association) can help you with this. We offer private Facebook groups and (on-line) meetings. Support workers are also on duty in the Princess Máxima Center and a number of shared care centres. Nobody understands better what you are going through than our support workers, because their child has had cancer too. They are there to support you and to answer your questions.

Staying afloat

At some point, you will realise how sick your child actually is. You will subconsciously draw on past experiences to keep yourself afloat. Try to remember what you did at the time to keep your head above water; this might help. Please remember that you - like other parents - will somehow have unprecedented strength to cope with this uncertain path together with your child.

Hope

You do not know for certain whether your child will get better or not. That makes it extra hard. Fortunately there is hope. Whatever happens, cherish every glimmer of hope. Hope will keep you going. Hope will allow you to hang in there and be there for your child. Hope springs eternal. There is always something to hope for. You hope that your child will get better. When things aren't going well, you hope that your child will not die. Or you hope to

have as much time as possible together to share precious moments. Never give up hope.

There will be days when you want to give up. Seeing your child so sick, being afraid of death, the side effects of the treatment, your family knocked off balance. This is hard for any parent. Sometimes you will feel like you are at the end of your tether: exhausted, frustrated, angry and about to lose all hope. This is not surprising. Try not to worry. Hope is resilient and will return.

Faith is similar to hope. You may seek comfort and assistance from God and find strength and hope in your faith. Even if you are not religious, you can still pray and seek pastoral care. The opposite can also happen, you may lose your faith. You may place your hope and faith in the treatment team, in the love for your child or in their inner strength.



We kept telling ourselves that:

- we wanted to make the best of every day
- our child was missing his normal life and that it was best for him to keep the days as normal as possible
- it was impossible that all the children on the ward would die
- that it was a hospital, not a funeral home



Guilt, anxiety and anger

You may feel guilty that your child has cancer. "If only I had taken better care of myself during the pregnancy". "Why didn't I take him to the doctor sooner?" Nobody could have prevented your child's illness, not even you. The doctor will tell you this too.

You are probably scared of what might happen, what the future will look like. This is normal, but try not to let this fear paralyse you. You can tackle this fear by trying to live in the moment. You cannot fear the present.

Knowledge can also reduce your anxiety. Write your questions down and ask the treatment team to answer them. They are there for you.

Anger is also a normal response. Find a way to express your anger and frustration, however embarrassing or difficult that may seem. Yell into the wind, hit a pillow, go for a run, kick a tree. This relieves pressure and reduces tension.

Be well-informed

Being well-informed about the disease and your child's treatment is one of the best ways of keeping yourself afloat. You also need good information in order to make considered decisions about the treatment. Your child's assigned doctor is the best person to give you this information. You decide for yourself how much you want to know and at what stage.



Further information

- Booklet about the diagnosis of your child
- Diary with medicine charts
- www.kinderkankernederland.nl
- www.prinsesmaximacentrum.nl



Questions that you can ask:

- What is the exact diagnosis?
- What is the prognosis?
- Which examinations will my child need to have?
- What exactly do these examinations involve?
- Are these examinations really necessary?
- Are there other, less invasive, ways of obtaining the required information?
- What does the treatment involve?
- Will the treatment proceed according to established (national or international) guidelines?
- Will my child be hospitalised, and if so, how long and how often?
- Will my child be given medication? If so, which, in which dose?
- How do these medicines work?
- Will my child need to have an operation?
- Will my child need to have radiotherapy?
- Will my child be given immunotherapy?
- What are the side effects of medicines, operations and/or radiotherapy?
- Is there a risk that my child will be infertile or less fertile when they grow up?
- Is it possible to store sperm cells or ovarian tissue for the future?
- Is there an alternative to this treatment?
- If the disease is rare and the treatment is not clear, who can I contact for a second opinion?

Internet

If you search the internet, be sure to check the source of the information carefully. A lot of information on the internet is unreliable or has no scientific basis. Please also realise that the treatment of cancer in children differs from the treatment of adults.

Diary or blog

Writing offers a way for you to organise your emotions and thoughts. Reading what you have written allows you to distance yourself from events and gives you a better overview of everything that has happened. A diary in the form of a blog is also a handy way of keeping your loved ones informed.

Contact with other parents

It can feel good to speak to other parents of a child with cancer. They understand what you are going through and they know the ropes. You will feel less alone knowing that other parents have the same concerns as you do. You will see that they manage to keep themselves afloat despite everything and that offers hope. They can tell you about the treatment, the side effects and how they coped with this and they can give you tips. You may find other parents to chat to on the ward, but you can always contact the Dutch Childhood Cancer Association too.

Informing your child

When your child is diagnosed with cancer, they have already had all sorts of examinations. The child already knows that something is wrong. When you have a quiet moment, for example together with the doctor, tell your child what is going on and what lies ahead.

Prepare your child for the examinations and treatments; a very useful tool is the beaded "Kanjerketting" (Bravery-Cord). Be honest about the fact that a treatment can be unpleasant or even painful. Use words that your child can understand. If you find this difficult, ask the pedagogical employee whether she can help you.

Give your child the chance to talk about his feelings and don't hide your own emotions. Your child can tell how you are feeling. Speak about your anger, fear and sadness and don't be afraid to let them see you cry. Crying together can relieve stress.

You, your child and the assigned doctors form a team together. Your child is more likely to cooperate and will accept the treatment more readily if he feels like a member of the team. Be honest with your child about what is going to happen and let him make (simple) decisions for himself. This will give him a sense of responsibility for his role in the team. It's great if your child can tell himself: "Together we will make sure that I get better."

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Further information

- Booklet "Praten met je kind(eren)" *Talking to your child(ren)*, available from our service desk in the Máxima Center or via the webshop on www.kinderkankernederland.nl
- www.kanjerketting.nl



Your family

As normal as possible

Now that your child is sick, everything changes, including the daily routine. But it is that routine that helps your child(ren) to feel secure. Of course you can't keep everything the way it was, but try to stick to the normal routine if at all possible. For example, eating dinner at the table at a specific time, watching your favourite television programme together, playing sports or going to yoga at the regular time and seeing friends and family regularly. Your child is allowed to do fun things. Laughing, having fun, celebrating birthdays or going to a party. A sombre mood in the home will not help anyone.

Whether intentional or not, your sick child will receive extra attention. It's understandable that you will be more flexible regarding setting boundaries, however remember that structure is important to your child. This builds trust and security. The boundaries that you set will depend on your child's situation. Trust your instincts (and not those of others) and try to be clear and consistent above all. Of course you can spoil your child a little, but don't go overboard.

Love and attention

All children need love, attention and security, and sick children need this

even more. Show your child that you love them. Take time to listen to their stories and questions. Try to support your child to the best of your ability and enjoy the good times spent together.

Your child may be dealing with other issues than you are. Not just his treatment, a bald head or nausea, but also school, sports, games, friends and keeping up with their peers. He or she is still a child and needs all the things that healthy children need too: parents, siblings, friends, and a little bit of extra love and attention.

Keep communicating

Of course you don't stop talking after the diagnosis, you will continue to communicate with your child throughout the treatment. You will notice that your child "matures" quickly and will have lots of questions. If you have been open and honest with your child from the outset, they will feel more at ease asking you questions and they will be able to express their emotions more easily. Your child's moods will vary, sometimes as a result of the medication. Your child can experience difficult moments of sadness, anger or frustration. Show them that you are always there for them - including the bad times - and that they can come to

you with any questions. Your child will feel supported and that is what he or she really needs.

Older children

Older children sometimes find it hard to speak to their parents about their disease and their emotions. Just when they were starting to become independent and learning to fend for themselves, they suddenly find themselves completely dependent again. They often blow off steam by speaking to other adolescents with cancer, a nurse, a teacher or a sports coach. Try not to feel insulted or hurt. Your child is doing what is best for them at that moment. Being a parent also means letting go of your child with love and confidence. Your child needs you more than ever, but it is sometimes hard to admit at this age. At this age children tend to focus more on their peers. They make their own decisions about their care and treatment, which you may not always agree with. Try to respect your child's decisions.



Further information

- Booklet "Praten met je kind(eren)" *Talking to your child(ren)*, available from our service desk in the Máxima Center or via the web shop on www.kinderkankernederland.nl

Self-care

Now that your child has cancer, a lot will change for you too. Try to find a healthy balance between caring for your child and caring for yourself. Taking better care of yourself is also better for your child.

Try to eat regular, healthy meals, because you need the extra energy. Your loved ones often want to help, but they don't know how. Ask them to do the shopping or take turns cooking for your family.

Getting enough sleep is also important for your energy levels, though you may experience trouble sleeping. The nights in the hospital can be particularly restless, so it is a good idea for you to take turns with your partner or another person that your child is close to. This allows you to get enough rest to support your child.

Caring for a sick child also means that you have less time to exercise. A walk, even just a short one, a quick cycle, or other exercises all help you to stay fit. Fresh air is also good for you. Give yourself some space to unwind, have a cup of coffee with someone or go to the hairdresser. Don't be afraid to ask for help, for example asking someone to look after your child(ren), tend the garden or do the washing.

Asking for help may take some effort, but you will receive a lot in return. Do you feel you need professional support? You can speak to a social worker in the hospital and your general practitioner can help you too.

Of course there will be days that you feel miserable, scared, tired or depressed. It is best to allow those feelings. Let others take care of things and take a break. Let off some steam. Cry. Have a chat with a friend, or not if you don't want to. Feel sorry for yourself. Have a breakdown. By the next day you will have pulled yourself together and feel ready to tackle things head on again.

Siblings

Of course brothers and sisters, or siblings, also feel the tension in your family and that will evoke a whole range of emotions in them. They can feel lonely, anxious or guilty. Often they will also feel responsible for their parents and their sick sibling. Some siblings will become angry and rebellious, others will become jealous that their sick sibling is getting all the attention. Others will attract as little attention as possible and will withdraw. All in all the siblings don't have an easy time. They also need love and attention, honest information, and a familiar daily routine.



Further information

- Booklet "Praten met je kind(eren)" *Talking to your child(ren)*
- Book "Een raar gevoel" *A weird feeling 3-8 years*
- Booklet "Brussenspinsels" *Sibling Guidebook* from approx. 10 years

The relationship with your partner

You should actually be focusing more on your relationship right now, but you don't have the time or energy. If you are taking turns being with your child, you only have time to discuss practical matters, but not a real conversation, not to mention spending time together.

You and your partner are both dealing with this situation in your own way. That can sometimes be tricky. You might not feel supported or you might feel as if you have to do things on your own. You start to feel annoyed and love seems like a distant memory. However, remember that your partner is also having a tough time and he or she is just expressing that in a different way. Give him or her the space they need. Try to make time for each other to discuss your emotions and needs. You can't feel each other's sadness, or remove it, but you can be

there for each other. By offering your understanding, warmth and love and by giving the other space. Try to do things together, even if it is just a fifteen minute walk or a cup of coffee.

When you are on your own

If you don't have a partner, then you are responsible for everything. You need to be extra strong. Make a clear and precise list of your needs and what is important to you. Any other children that you have will also need you and

you need time for yourself. Time to relax and recharge. You cannot do everything on your own. Don't be afraid to ask for help and to accept any help that is offered, to you, your sick child and your other children.

Try to find people who can support you. A good friend who is there for you. Friends and family who will go to the hospital with you, or perhaps take over some of the care at home. Neighbours who are willing to help with your other children. The social workers in the hospital or your general practitioner can help you to arrange support.

Your loved ones

Family and friends

Your loved ones will probably ask a lot of questions: how things are going, whether they can visit, what they can do to help, etc. Sometimes it feels good to tell your story more frequently. However, all that attention also places demands on your time and energy. The time and energy that you need to care for your sick child, your family and yourself.

What can be helpful:

- Try to manage your own time.
- Tell people when it is the best time to contact you.
- Reach out to people at a time that suits you.
- Write regular blogs or e-mails about what is going on.
- Ask someone to act as a contact person.
- Don't be afraid to ask for help, people really want to help.
- Let your loved ones know exactly what they can do, for example the washing, the garden, shopping, vacuum cleaning, going to the pharmacy or babysitting.
- Ask a close friend or neighbour to coordinate the people who want to help.

Your work

Working and caring for your child – and your family – is a tough combination. Not only do you have less time, your head may not be in the game either. However, it is important to sit down with your employer as soon as possible to discuss the options: carer's leave, flexible working hours, working from home, (temporarily) reducing your hours or taking sick leave. The decision that you reach together will be unique to your situation. Work may provide a welcome distraction and may even give you energy. Whatever you decide, follow your heart.



Information and assistance

- Visit www.kinderkankernederland.nl for more information and practical tips about work and income.
- We regularly organise a Walk-in Consultation on Parents & Work at our service desk in the Máxima Center. Maaïke Wetting, expert in employment law and due to personal experience, is happy to answer all your questions and offer practical advice. Check the current dates on www.kinderkankernederland.nl.
- Social workers in the hospital can also help you get started.



Your child's (children's) school

School is important for a child, even for a sick child. School is not just about learning, but also about social and emotional development.

- In the midst of all the uncertainty, school offers a sense of security and structure. It is the only thing that is still normal, a part of the life they had before the disease.
- School makes certain demands (school grades) and this improves self-confidence.
- School means friends, social contacts, remaining part of the group.
- School offers hope and future prospects, even for children who cannot be cured.

With a bit of luck, your child will be able to go to school as normal and follow all lessons, perhaps with some modifications. There is no need for them to fall behind and certainly no need for them to be treated differently because of the disease.

The school relies on you as the parent for information to help them to mentor your child, any other children that you have and their classmates. You can explain what disease your child has and what the treatment will involve, what your child is and isn't allowed to do, what your child does and does not know, how any siblings are doing and what information you are willing to share with classmates and their parents. This requires good and open communication.

Schedule regular, preferably weekly, meetings to share information and make or modify arrangements. Having these meetings pre-scheduled makes it easier for you to contact the school if problems occur between meetings.



More information and teaching materials

- www.kinderkankernederland.nl
- Book "Wat nu? Mijn leerling heeft kanker!" *What now? My pupil has cancer!*, verkrijgbaar via www.kinderkankernederland.nl
- Teaching kits: www.kinderkankernederland.nl

After the flower bead (end of treatment)



Receiving the flower bead is a celebratory moment that you have all looked forward to. Yet you still experience uncertainty whenever your child coughs or has a bruise: is it really over?

Getting back to normal life is easier said than done. This experience has changed all of you. You may emerge feeling stronger than before, but months or even years of stress can also leave you feeling exhausted. In the same way as you feel after a really bad flu, your body – and also your mind – needs time to recover. Even if you feel happy, you may subconsciously and unintentionally sometimes also feel angry or rebellious about everything. It almost feels as if you are only now realising everything that has happened. It is completely normal to feel this way, because you have been through an intense period.

The same applies to your partner and your child(ren). You are all trying to find a new equilibrium and just want to be a normal family once more. Siblings may demand extra attention, because they feel that they missed out on this and your child who was sick will try to restore his old position. That isn't always easy, because you will probably always be

extra worried about this special child. Your child may have difficulty walking, may struggle to concentrate, may not be eating properly yet or may have difficulty sleeping. Your child may seem mature for his age and thus have a different outlook on life. Or your child may think: "Why not experience everything that life has to offer?" They may even become reckless, because they feel invincible. Your child may also experience self-pity, avoid others and become subdued. It is a good idea to ask your general practitioner for help if your child exhibits any of these extreme reactions.

Things may turn out differently than you had hoped. You may have lost friends along the way or hit a road block at work. Your relationship is strained or didn't survive the stressful period. Despite their best efforts, your child may need to repeat a year at school or may face a long rehabilitation process. Perhaps your child can no longer participate in his or her favourite sport as a result of the treatment, or your child may need

to reconsider their education or career choice. Nonetheless, you may still be able to draw some positive things from this period. You appreciate the little things, feel an intense closeness with your family, built new friendships and know what is truly important in life.



Further information

- Booklet: "Bloemenkraal, eind goed, al goed!?" *The flower bead: all's well that ends well?!*

If your child cannot be cured

When you are told that your child cannot be cured, you face a difficult and uncertain time. "How long do we have?" "Will my child be in pain?" "How will we cope?" These are questions that sometimes cannot be answered.



Further information

- www.koesterkind.nl
- Book: "Koesterkind. Ons kind wordt niet meer beter" *Cherish the Child. Our child cannot be cured*
- Book: "Verbonden met jou" *Connected to you*
- Booklet: "Praten met je kind, als je kind niet meer beter wordt" *Talking to your child once you know he or she is not going to get better.*

Do not lose heart and do what is best for your child and for you. Your child may have a special wish to fulfil, or your child may just want to carry on going to school for as long as possible. Try to enjoy the time that you still have together as much as possible.

The Dutch Childhood Cancer Association is here for you in these difficult times too and offers support and information.

Further information

For parents

www.kinderkankernederland.nl

Diary

via the Princess Máxima Center

Information booklets on diagnoses

via the Princess Máxima Center

Praten met je kind(eren) *Talking to your child(ren)*

available from our service desk in the Máxima Center or via www.kinderkankernederland.nl

www.kanjerketting.nl

App Kanjerketting *BraveryCord* for iOS en Android

Bloemenkraal; eind goed, al goed!?

The Flower bead: all's well that ends well?! available from our service desk in the Máxima Center or via www.kinderkankernederland.nl

Magazine "Attent"

Attent available from our service desk in the Máxima Center or receive a free copy with membership of the Dutch Childhood Cancer Association

For children and adolescents

"Chemo-Kasper" *Chemo Caspar* 4-12 years available from our service desk in the Máxima Center or via www.kinderkankernederland.nl

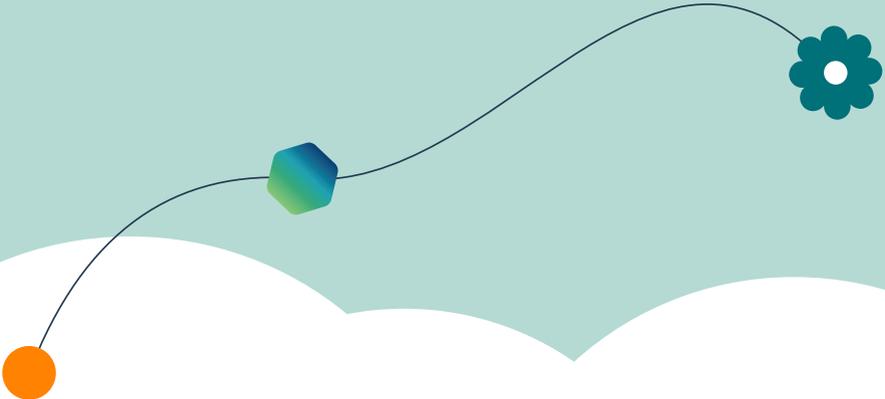
"Radio-Robbie" *Radio Robbie* 4-12 years available from our service desk in the Máxima Center or via www.kinderkankernederland.nl

Immuno-Lisa *Immuno-Lisa* 4-12 years available from our service desk in the Máxima Center or via www.kinderkankernederland.nl

"Prinses Lucie" *Princess Lucy* 4-12 years available from our service desk in the Máxima Center or via www.kinderkankernederland.nl

Book "Een raar gevoel" *A weird feeling* 3-8 years available from our service desk in the Máxima Center or via www.kinderkankernederland.nl

"Brussenspinsels" *Sibling Guidebook* 12-18 years available from our service desk in the Máxima Center or via www.kinderkankernederland.nl



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