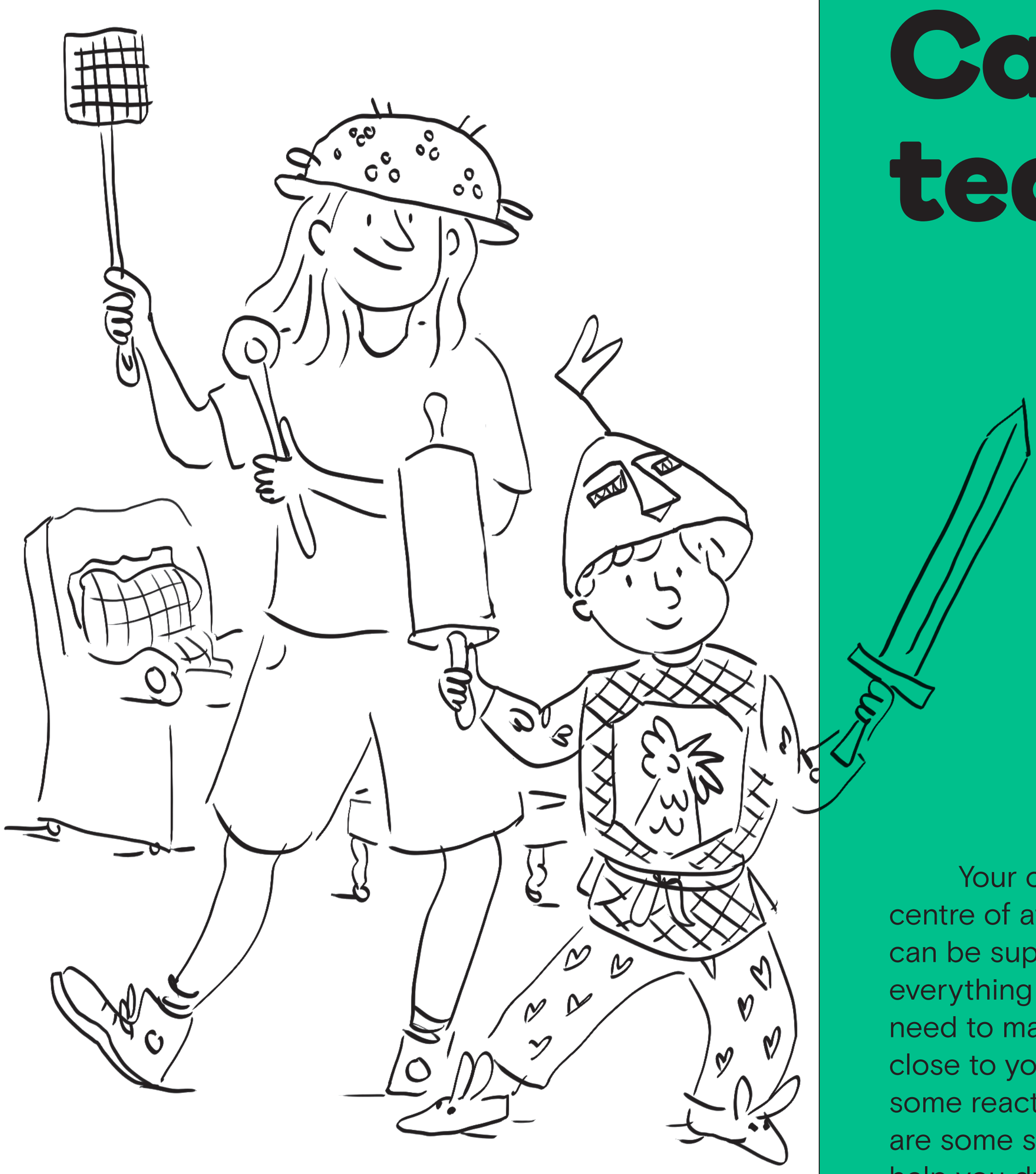
Tips from fellow parents and patients

No one expects childhood cancer to enter their family life. In the beginning, this can feel overwhelming. While everyone copes with such hardship in different ways, luckily, there are some universal “hardship laws”. All those who have weathered the same storm, no matter how different their situations, had to deal with the same struggles. This is a precious and powerful thing to know. We hope that you will find some solace in the experiences of other parents and patients. Their advice, tips and shortcuts may offer you both comfort and practical support. You may even gain some precious time by reading this booklet.

We have organised the tips and tricks by theme. Under each theme, we first mention the “priority tips” which are helpful at the beginning of the treatment. The next tips may be useful either in the beginning or later, when you start finding your way.

Overview



Calling the team

Your child's illness will bring you into the centre of attention from friends and family. This can be supportive, but also challenging. Along with everything else you are dealing with, you may also need to manage the emotional reactions of those close to you. While people may have good intentions, some reactions may be unhelpful or insensitive. Below are some suggestions on how you can help others help you during this period.

Updating friends and family

Your child's health is a private matter, so it is your and your child's decision whether or not to share the news with others. However, your child's absence and potential physical changes may draw the attention of your friends and family, leading to worries and questions. Being transparent about what is happening can prevent misunderstandings, rumours, and uncomfortable situations.

Certainly, answering questions and communicating the same information repeatedly, especially difficult news, can be a burden.
To avoid this to some extent, you could consider communicating in a centralised way by setting up a WhatsApp, Signal or Telegram chat group (with or without the option to reply). This can give you control over when, how and to whom you talk. It may also save you time and energy.

Some families also choose to create a dedicated social media page or blog about their child's cancer journey. Although an online community can be supportive, think twice before doing so. Even if your page is private (closed to the public), your online presence will leave a permanent trail in the virtual world. This could backfire later if you or your child change your mind. Circulating pictures about your child's illness, for example, could become confronting when your child has switched back to a "normal" life.

Holding off to hold on

When you have set up a communication channel, people may send you messages asking about updates or wishing you well. Although you may appreciate their support, some parents have also found it overwhelming. To hold on during this long journey, you'll need to hold off from time to time. Here are some friendly ways to do so:

- When you don't feel like responding. It's lovely to hear from people when you have a hard time, but it's even more lovely when they add: "No need to reply." If you feel the same way, let your friends and family know that you love hearing from them, but apologise in advance that you may not always be able to respond. The mental burden of "being unable to reply" shouldn't add to your stress.
- When you don't feel like talking. When someone asks you a question in real life, and you don't feel like talking, tell them that you would like to talk about something else. Don't feel guilty about it. This is perfectly ok. You don't have to discuss your child's illness with everyone all the time.


DO NOT DISTURB
UNABLE TO REPLY

Tell me what I can do

Ideally, friends and family will offer concrete help such as “Shall I pick up the other children from school on Wednesdays?”, so you don’t have to come up with tasks for them. However, many people will only offer vague help, so you may need to suggest specific tasks. Below are a few ideas for tasks you can ask for, and who you can ask. Support from the team can make a huge difference, so be shameless and delegate with steely intent.

→ **A close family member or friend**

Don’t hesitate to ask your “framily” to take turns and alternate guarding at your child’s bedside. To take good care of your child, you also need time to take good care of yourself. Try to sleep in your own bed for a while, go for fun activities with your other children or treat yourself. For more information, see below: “Taking care of yourself”

→ **A person you trust**

Give a reliable person the keys to your home and ask for help with household chores such as doing the laundry, cleaning or running errands.

→ **A great cook**

Ask for prepared meals (in single portion containers) that you can take to the hospital, or go for cooked dinners for the whole family at home.

→ **A parent of a friend of the siblings**
Other parents can help by taking your child's siblings to their extra-scholar activities, for example.

→ **A natural public relations talent**
You can ask to animate a chat group with the latest information on your child's treatment. This way, you don't have to find the words yourself or repeat the same information over and over again.

Handling less helpful hands

No matter how well-prepared you are, some people may be a burden rather than a joy. How to handle their well-meant but unhelpful reactions without feeling bad about it?

→ **People who know of a great magical cure**
Some people will tell you everything about incredible, alternative therapies they have heard of. Thank them for their help and let it rest. Don't go into discussion. If your curiosity is aroused, talk about it with your doctor. And whatever you do, make sure that additional supporting therapies don't interfere with your child's treatment, so always ask the medical team first.

→ **"Whatever-I-can-do-to-help" people**
These people mean it well, but the "whatever" can be daunting. As we noted above, coming up with tasks is a task in itself. Express your gratitude and tell them you will think about it. If you come up with a task, don't hesitate to ask. Usually, people are happy to help.

Share the KickCancer "Framily Etiquette"

Your friends and family — or "framily" — may feel confused, upset and maybe even afraid to say something wrong. To avoid isolation and break the ice, you could send them the KickCancer "Framily Etiquette" by scanning the QR code below and sending the link. This quick guide contains some friendly tips on how your friends and family can be truly helpful.

KICKCANCER FRAMILY ETIQUETTE

→ **Tip 1. Be honest, but follow our lead**
Some people tend to behave differently around someone who has cancer, such as talking overly warm and uplifting, or being solemn or very busy. Just be yourself, as we know you. Simple phrases like "It's good to see you" and "How do you feel today"? are always fine. They allow us to be both honest and not have to go through all the ups and downs of the past weeks. If you want to know more and dig deeper, please take your cues from us. For example, if we want to talk about "changed looks" because of the treatment, we'll start talking about it ourselves. We know it's not easy for you to know what works or not, so we have given some examples below.

Instead of saying:

- "I feel so sorry for you." (This turns us into an object of pity, which feels a bit discouraging.)
- "If anyone can beat this, it's you." (Our chances of surviving cancer are based on a range of factors, but "character" is not one of them.)
- "Everything happens for a reason." (No, we just got unlucky, and will have to deal with it.)
- "What doesn't kill you makes you stronger." (This is not necessarily true; not all suffering results in more strength.)

It is better to say:

- "I am sorry this happened to you. I wish you didn't have to go through this hard time." (This acknowledges that we are still active participants in what is happening, instead of helpless victims.)

- “This sucks. I wish I had a better way to say it, but I know there aren’t any words in the world that can make it feel better. I want you to know that you will always have me, and I am not going anywhere.”

→ Tip 2. Offer concrete help

Our world has been turned upside down, and often we don’t know where to begin when people offer help. You can make it easier for us by making specific and practical offers, such as cooking a meal, helping with housework, walking the dog, or collecting the other children from school. Your help doesn’t have to be a grand gesture; small practical things already mean a lot. If you don’t know how to help, you can ask us of course. Surprises are also welcome.

→ Tip 3. We need to talk about it, but not the whole time

Don’t avoid “the subject”, but let’s talk about mundane things too and have a laugh now and then. Our cancer is not the only thing worth talking about (but we know it’s a difficult balance to strike).

→ Tip 4. Don’t expect (instant) replies

We love hearing from you, but we may not always have the energy or time to respond.

→ Tip 5. Cancer is not a battle, but a submission

It’s better not to say that we need to be strong and brave and fight against cancer. Surviving cancer depends on its type and stage and the availability of the right treatment, not on our fighting skills. Cancer is not a character test with recovery as a reward for the brave only. We must submit to medical science and hope for the best.

→ Tip 6. Your emotions

If you’re too upset to comfort and help us, we totally understand. You can still send us cards, messages, or other small signs of support.

→ Tip 7. Your medical opinion

Please don’t give your medical opinion about the treatment if we don’t ask for it (unless you are an expert in the matter, of course).

→ Tip 8. Showing your affection is the most important thing

Don’t be afraid to say something wrong. Being there, showing that you care, and doing your best are the most important things. And if you think you said something wrong, it helps to be open about it. For example, you could acknowledge your slip of the tongue and make a joke about yourself trying your best but failing terribly. This usually takes the heat out of the room.

At home in the hospital

You and your child will spend a lot of time in the hospital together. We hope the tips below will help you to turn the hospital from a place associated with illness into a place that keeps your child well (and your family in one piece).

Prepare everything you need

Leaving for the hospital can be a rush, so having things prepared in advance can be reassuring. For example:

→ **A suitcase with permanent basics (to refresh after each stay):**

○ Underwear.
○ Sleepwear and slippers.
○ T-shirts for a few days.
○ Toiletries (toothbrush, toothpaste, samples or small containers of shampoo and shower gel, soothing cream, and lip balm).

→ **A bag with personal highlights:**

○ Cutlery, cups, and plates (microwave-proof).
○ Your favourite tea bags, mugs, and a small coffee maker (if allowed).
○ A picnic blanket to stay warm or play on the floor.
○ Toys, children's books, games, DIY kits.
○ Something relaxing for you too (books, magazines, crosswords).
○ A diary or notebook you can fill in together with your child.
○ Decorations for the room (see below).

Ask about rules and communicate your needs

To make your hospital stay easier, it is important to understand the rules and communicate your needs.

→ **Room rules**

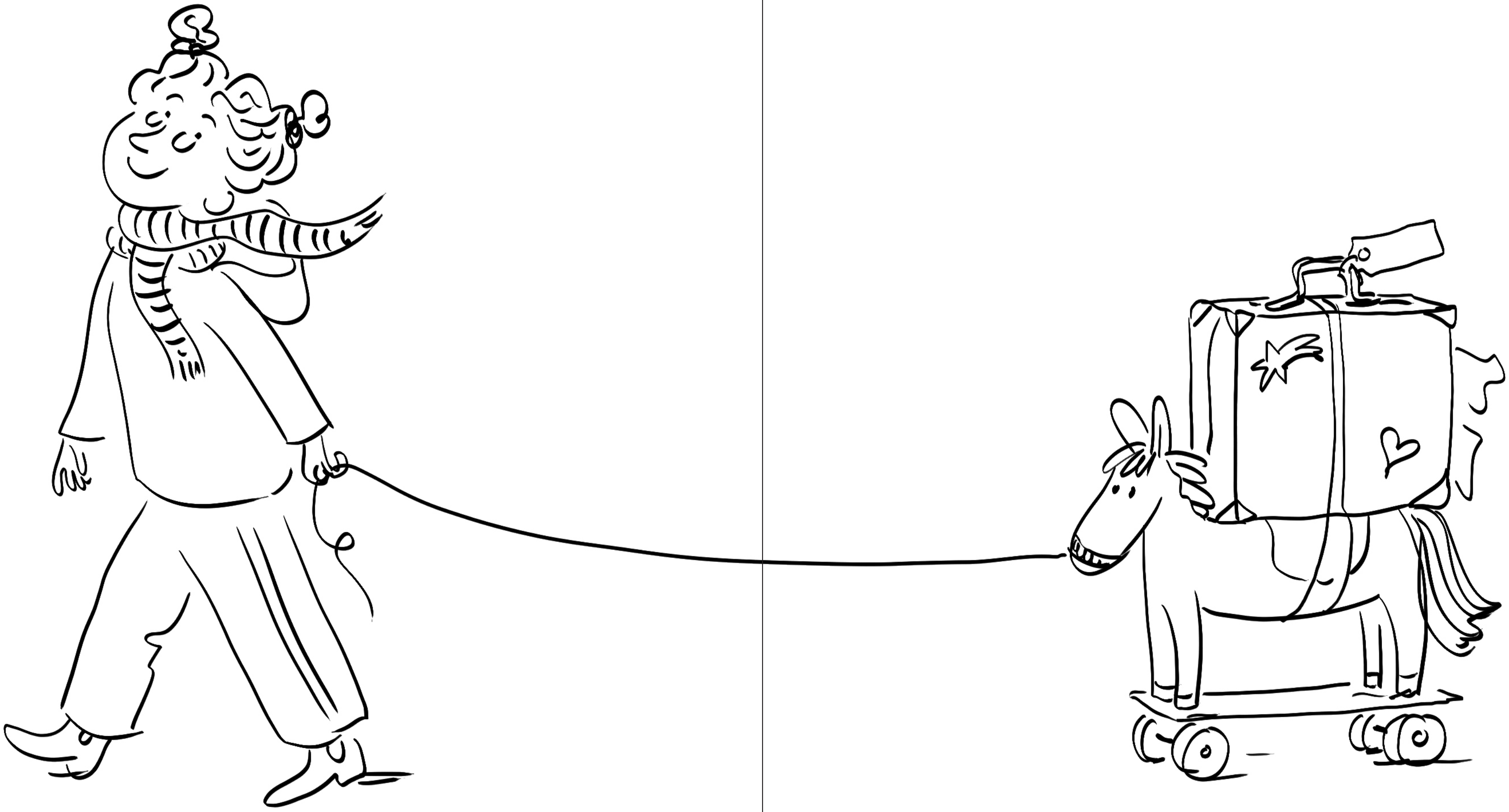
Ask the hospital staff about the room rules. Who can visit and when? What can you (not) bring and (not) do?

→ **Let the nurses know**

If you or your child need to sleep a little longer because you are tired, let the nurses know.

→ **Nurses are gold**

The nurses are there to look after your child. Let them handle the necessary care tasks so you can take a little break. Also, don't hesitate to tell them if you feel overwhelmed or have any difficulties. Nurses can provide a listening ear, give advice, and offer a social connection that you may not have expected to find in a hospital.



Cheer up your hospital stays

After a couple of weeks, you will start finding your way a bit better. So why not take a deep breath and sparkle up your child's hospital stays? Now you are here, you can as well make the best of it. Every moment you go through with your child is unique, how hard it may be, and it will never come back.

Here are some ideas to pimp (or even cherish) your hospital stays:

→ **Relaxing hospital activities**

Ask the care coordinator or animator about the activities they organise for children and their parents in the paediatric oncology unit, or the hospital's neighbourhood. Visits from clowns, DIY workshops, music classes and massages can lighten up your child's day. Some parents have admitted that — when scheduling longer treatment stays — they take into account the visiting days of the hospital clowns (but shush, this is a best-kept secret).

→ **A bit of home in the hospital**

Decorating your hospital room can become a meaningful ritual with your child. It can help soothe the sadness of every new hospital stay, allow your child to take back some control of their environment, and make the room feel a bit more like home. When you change rooms during different stays, your decoration can help keep the room atmosphere consistent, which can be comforting. Your personal decoration may also trigger nice conversations with the medical team and create a small spiral of joy. Prepare a "standard" decoration package that you can always take with you. Some ideas include:

○ Family photos and tape (supplied in the support kit).
○ A flag line, light garland, or banner.
○ Drawings or letters from friends.
○ Your colourful bed linen and pillows (if allowed).
○ Posters.
○ Etc.

→ **A joyful arrival ritual**

Perform the same joyful ritual with your child each time you embark on a new hospital journey. It can be the room decoration process explained above, but also the same board game you play every time you arrive, or watching the next episode of a TV series, or a movie that you only watch together in the hospital. You decide!

Bring your favourite food

If you and your child love hospital catering, you can skip this part. However, if you prefer to bring your own comfort food (and if your medical team and dietitian agree), below are some ideas for easy dishes (all hospital units have a microwave,

sometimes even an oven):
○ Lasagna or other gratinated dishes.
○ Soups and stews (potatoes, lentils, vegetables, meat).
○ Couscous and pasta.
○ Bread, raw vegetables and spreads (hummus, tapenades...).

Secret tip: track the best bakeries in the hospital's neighbourhood and treat the whole family.

→ HUDERF:
- Delicia, Av. Houba de Strooper 234, 1020 Laken (950 m).
- Boulangerie Saint Pierre, av. Secrétin 5, 1090 Jette (1000 m).
- Patisserie Chanson Jette, av. Guillaume De Greef 55, 1090 Jette (650m).

→ Cliniques Universitaires Saint-Luc:
- Boulangerie Les Délices de Mon Moulin, rue de l'Eglise 98A, 1150 Bruxelles (1,8 km).

→ Hôpital de la Citadelle (CHR):
- Boulangerie patisserie Gerard, rue Sainte Walburge 5, 4000 Liège (550 m).
- Boulangerie coopérative Chez Matteo, rue du Palais 32, 4000 Liège (1,1 km).

→ CHC Montlégia:
- Boulangerie Maréchal, Rue du Coq 83, 4000 Liège (2,1 km).
- Boulangerie coopérative Chez Matteo (address see above: 3,6 km on foot, 15 min by bus 88 or 7,3 km by car).

→ UZ Anvers:
- Payet Bakkerij, Hazeschransstraat 31, 2650 Edegem (2,1km).

→ UZ Leuven:
- Brood en Banket Gielis, Brusselsestraat 106, 3000 Leuven (1,7 km).
- Patisserie Zuut, Vismarkt 2, 3000 Leuven (2,1 km).

→ UZ Gent:
- Bakkerij Broko, Zwijnaardsesteenweg 470, 9000 Gent (650 m).
- Bakkerij Frimout, Zwijnaardsesteenweg 278, 9000 Gent (800 m).
- Bakkerij Aernoudt, De Pintelaan 1, 9000 Gent (1 000 m).

Making friends in the hospital

Many people may not fully grasp what you are going through, and you may feel misunderstood even by your closest friends. Talking to other parents in the hospital kitchen or playroom can help. You may suddenly feel a bond with strangers because you share the rare experience of having a child with cancer. Speaking to fellow parents about your difficulties can relieve some of your stress. You could even make jokes about those clumsy comments from

well-meaning friends or your neighbour’s silly magic medicines stories. You may never have guessed that the hospital would become your new community, but it will, and this can be very comforting at times.

Bringing friends to the hospital

Encourage your child to stay in touch with siblings and friends through online play dates. If possible, schedule video calls as a welcome break between more difficult moments. They can chat or play games online (you could even join in!). If hospital rules permit, bringing your child’s siblings along is even better. Children who are ill often enjoy having company around. They like to talk about mundane things, rather than seeing their illness as the only thing worth discussing.

Your medical odyssey together

A happy mess

When you first learn that your child has cancer, everything will be turned upside down. There is no magic trick to deal with such hard news. All parents have to accept that their life is in shambles, especially in the very beginning. What to do?

→ **Accept the mess**

Try not to plan too much in the beginning. You will need to rearrange your plans anyway, which will only add stress to an already difficult period. Once your child's healthcare team has defined the first treatment steps, you will understand better what is feasible or not. Until you have a medical treatment plan, it will be a mess. Taking it day by day is the best you can do.

→ **Laughs and love**

But, it can be a happy mess if you find some humour in the situation and feel the love of the people surrounding you. Laughs and love will help you and your child relieve stress, recharge your spirits, and see things a bit more clearly.

Understanding the next steps with a treatment calendar

After the first chaos, the medical treatment plan will bring back some structure. You will have a better view of the next few weeks and the different milestones. With your child, you can create a "treatment calendar" that includes all the medical milestones: hospital stays, tests, surgery, and so on. Knowing what to expect may help your child and the siblings feel more at ease.

→ **Include the fun**

Don't forget to add birthdays and parties to the calendar!

→ **Make it look nice**

Cut paper sheets, draw, glue stickers, and so on. Ensure that the calendar looks cheerful and give it a central place.

→ **Mark the progress**

Cross out each day that has passed. Seeing progress will give everyone a bit of courage. Siblings or visiting friends can also cross out the days so that your child's progress becomes something shared by the team.

→ **Celebrate milestones**

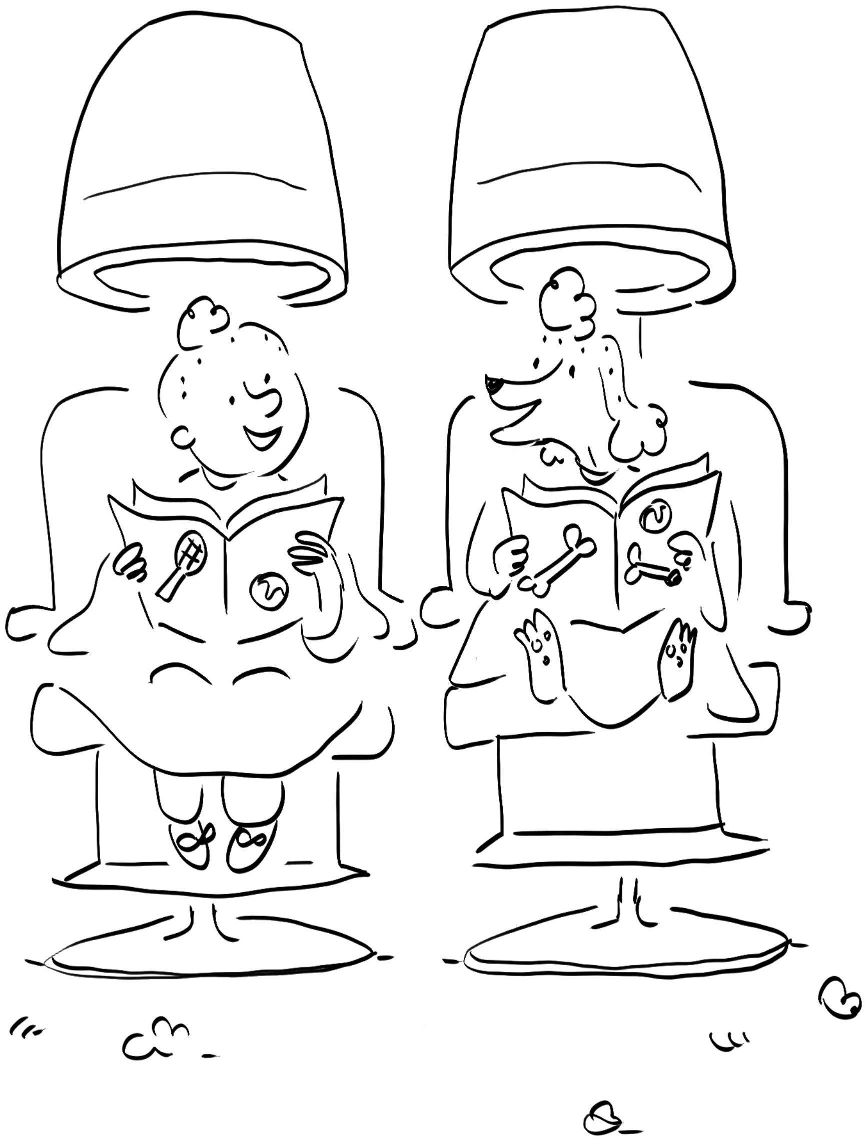
If your child is up to it — and if you have some energy left — you could organise a family activity when your child has passed a milestone. Shouts of joy or rallying cries will be all part of it.

→ **Digital calendar to share**

If your child agrees, you can also create a digital version of the treatment calendar to share with the larger family, friends, school, dance class, music academy, scouting, or sports team so they feel involved and can follow your child's medical journey.

The really bad hair day phase

During chemotherapy or radiotherapy, it is likely that your child's hair will fall out. If you anticipate this, it will be less difficult for your child to cope with. Discuss what works best for your child: a shave or a short haircut. The aim is to avoid situations where locks of hair fall out at once, which will feel very uncomfortable. Some families have turned the "haircut day" into a fun activity at the hairdresser with siblings or friends. You could see it as a once-in-a-lifetime chance to play around with crazy haircuts before shortening all the hair.



Friending those medical monsters

Now, how to deal with that parade of pills, needles and scans? These mischievous medical monsters are totally unpleasant but also necessary friends to make your child better. Helping your child to accept them will make the treatment easier for everyone. Here are a few ways to do this:

→ **Explain**

Explain why pills, needles, and scans are actually your child's best friends on their road to getting better.

→ **Pleasant prospects**

Promise a nice activity after a medical intervention so that your child will focus on the fun prospect. This doesn't need to be "big"; playing a game together is already great.

→ **Surprise bag**

Prepare a surprise bag with small (homemade) gifts, coupons for fun activities, drawings or letters (from friends and family). After every examination, unpleasant treatment, or nasty medicine swallowed, your child can pick something from the bag. Check with your hospital whether they also provide small gifts, so that it doesn't become too much.

→ **Paediatric psychologist**

Consult the paediatric unit's psychologist for further advice and assistance; they have a lot of experience and are there to help.

Eating is king

All parents struggle with children not wanting to eat (enough of) the "right" things, but making ill children eat is a different kettle of fish. Side effects of cancer treatment include nausea, sickness, taste changes, loss of appetite, trouble swallowing, diarrhoea and constipation. Here are some tips to overcome the food hurdle:

→ **Let your child choose**

Eating is often difficult enough, so let your child choose. Keep checking what your child likes because chemotherapy might change the taste, and periodic nausea is obviously not a good appetiser.

→ **Ask the dietitian**

Don't hesitate to ask the dietitian for tips if you are worried about your child's eating behaviour.

→ **Keep eating fun**

In all circumstances, try to keep eating fun, even if you would like your child to eat more. For example, have a snack party every last evening of longer hospital stays with chips, crackers, cheese, vegetables, dips, smoothies, and so on.

Taking care of your child(ren)

Your role as a parent

Parenting naturally has its ups and downs, but having an ill child turns this into a more difficult balancing act.

→ **Trust your gut feeling**

As a parent, you know your child better than anyone else. If you think something is wrong (while you have been told everything should be okay), or if your child is in too much pain, always notify your doctor.

→ **Continue parenting as usual**

Remain a parent to your child, and be firm if necessary. Empathy is important, but so is setting boundaries. Try to stick to your usual parenting habits. If your child has to say 'please' and “thank you” at home, keep up with this habit in the hospital too. Consistency will make your child feel safe (throwing out all the rules would suggest that something is really wrong).

Things to look forward to

→ **Good times together**

Try to plan something fun for your child (and the whole family) now and then. Don’t worry, this can be very basic: things they like to eat, a movie night, playing a game together or a festive dinner at home.

→ **Healing through humour**

Jokes can be great helpers in the face of helplessness. Humour works, especially with older children. Laughing together about silly things can sometimes make difficult subjects easier to discuss and digest.

A break away from home and hospital

Everyone needs a break now and then, especially families in your shoes. Some organisations offer nice, tailor-made holidays adapted to the specific care needs of ill children, without compromising on cosiness. Look at www.childrencancer.be or ask your hospital’s social worker or unit animator (they usually know more about it). Here is a list of interesting organisations you can check:

- A.E.C. (FR – Liège)
- Casa Clara (FR+NL)
- Chateau Cousin (FR)
- Ensemble, pas à pas (FR – HUDERF)
- Koninklijke Villa Oostende (NL)
- Make-A-wish (FR+NL)
- Menno’s Droomvakanties (NL)
- Mistral Gagnant (FR)

- Noctiluca (Kiekafobee) (NL)
- Salus Sanguinis (FR – Cliniques Universitaires Saint-Luc)
- Studio Nona (NL)
- Sun Child (FR – Bruxelles)
- Villa Max (NL)
- Villa Rozenrood (NL)

Supporting the siblings

Cancer is a whole-family diagnosis. It's a shock that also affects the siblings. Brothers and sisters of a care-intensive child obviously also need their parents, even if they are "big kids" who seem to cope. How to support the siblings?

→ **Acknowledge their feelings**

All children respond differently. They may be afraid, miss their brother, sister or parents or feel frustrated at the new, chaotic family schedule. How they feel and behave will depend on their character, age and what they can understand, and may change during your child's treatment. Some children won't find the words to describe their feelings but will change their behaviour, like becoming more withdrawn at school. Free some time to sit down with them. Leave your door wide open so that they can express their worries. Recognise their feelings and reassure them that anger, worries, jealousy or guilt are all normal and okay. This will comfort them.

→ **Be honest**

It's important to be honest with your other child(ren) about the situation and the struggles, even if it is difficult. If you find it challenging to talk with them or if they are hesitant to talk with you (maybe they worry about upsetting you), consider finding a trusted family member or friend to take over.

→ **Involve siblings**

Allow siblings to participate in making decisions about the new family schedule. This will help them feel included and give them a sense of control.

→ **Just you and them**

If you feel out-of-sync with the other child(ren), spending one-on-one time with each sibling can help strengthen your relationship. This doesn't have to be anything fancy, just sitting together or watching TV is already fine. You can also let them suggest things they would like to do with you.

→ **Things to look forward to**

For your other children too, it is important to organise activities they can look forward to. Again, this can be as silly as going to the supermarket and giving them the privilege of choosing the meals for the week or picking their favourite cookies. You don't need to organise something extraordinary; what counts is spending attentive time with them.

→ **Call the team**

If siblings can no longer attend activities due to your child’s illness, “call the team” and ask for support. Can you think of someone who can drive them to their judo class? Just ask for it! There's no harm in asking for help.

Taking care of yourself

We held a survey among parents who were in your shoes before: 100% were tired and stressed. Ok, now we’ve got this off our chest, let’s see what we can do about it.

You deserve a break

With a very sick child, you are back in the shoes of the parent with a newborn: not a second to yourself. So when an opportunity presents itself, grasp it and take a break.

→ **Find out what keeps you going**

Free some time to think, sleep and disconnect, even if it only takes 15 minutes a day (although we know how quietly a day can slip away). A walk in the woods, rummaging in the garden, a lunch with friends, a mindful or mindless activity: self-care looks different for everyone. You know best what works for you to recharge.

→ **Take turns and take breaks**

Once in a while, let a family member or a good friend look after your child. Alternate guarding at your child's bedside in the hospital with your partner or another adult (when allowed). When your child is being cared for by the nurse, school teacher or physiotherapist, take a break and do something you like.

→ **Don't feel guilty**

While your needs may be the last thing on your mind, it's important to recognise that this is a stressful time for you. Taking care of a seriously ill child is a marathon, not a sprint. To be there for your child to the best of your abilities, you will need to take care of yourself too. So when you leave the care of your child in someone else's hands, you are not doing anything wrong, on the contrary. Your batteries must be recharged on time. No child enjoys the care of an over-tired and bad-tempered parent, so see every treat to yourself as a treat to your child.

→ **The joy of a new challenge**

If you have stopped working altogether to look after your child, you may enjoy a small project for yourself. Why not take on a new challenge? Learning something new can be fulfilling and energising. There are many online courses offering (free) cooking, languages and crafts classes. "Don't let what you can't do interfere with what you can do", someone once said. But of course, you can also indulge in an easy TV series if you are totally exhausted.

Sleep is the answer to everything

We know this is all too obvious, but please find some time to sleep. Bad sleep makes bad circumstances less bearable. One extra hour of sleep may win you many hours during the day. If you have time to sleep but are unable to do so, talk to your doctor about it. If you are staying in the hospital and need to sleep in, ask the nurses not to wake you up.

Two parents, different needs

Different people react differently to stressful situations. Reacting differently does not mean you no longer love each other or that your partner is careless, stupid, or irrational. You are just different.

→ **Identify your needs**

Try to talk and think about your different reactions in terms of needs: one parent needs to find out and will ask many questions, while the other prefers to trust the doctor (this is just an example). It's a bit like during pregnancy, but definitely less fun: while one parent may want to know the gender, the other may want to keep it as a surprise.

→ **Accommodate your needs**

Once you have identified your different needs, think about practical solutions to accommodate both your needs as best as possible. Going back to the pregnancy example, one parent can leave the consultation room while the other stays to hear the news.

Home sweet home

Back to your social self?

Not really, for most of us... However, at home, you can plan visits more freely than in the hospital (provided your child's oncologist allows it). You and your child may be yearning for those bonding moments. Consult the booklet Treatment tracker to know when your child's immunity and energy levels will be high enough to have visitors over.

Even if you planned a visit, the day could turn out differently than expected. Don't hesitate to cancel the visit last minute, or shorten it if you see that you or your child become too tired. Visits are meant to make you both feel good; this is the priority.

Beating boredom at home

A sick child won't have much energy to play around, but at the same time, your child (and thus you) may become bored, cranky and fed up with hanging around all day. Keeping your child entertained and cheerful despite the illness can be a daunting task. What to do?

→ **Create a home routine**

Giving your days a clear structure will make everyone feel better. Home routines can be just small things, like taking a shower or listening to a song in the morning, some exercise for both of you, and so on.

→ **Sunlight, fresh air and rosy cheeks**

Even if your child is having a bad day, going outside for a short while will boost their energy level, immune system and vitamin D supply. So wrap up warmly, take some snacks and walk around the block or take the stroller (for elder children, you can use a bike trailer which you can push like a stroller).

Back to school (on your terms)

Schooling can be a lifeline for children during illness. Following classes is a welcome distraction and keeps ill children up to date with their friends and "normal life", which can greatly support them. It will also feel good to prepare for a future beyond illness. In the booklet Getting organised, we provide some practical info on how to organise schooling differently. Below are some additional tips to make the best of schooling during and after your child's treatment.

Informing teachers and classmates (start of treatment)

Give your child’s teachers and classmates basic information about the type of cancer and treatment. You can do this at school, alone or with your child if he/she feels like it (and if the doctor allows it). When you find it too difficult to handle, you can ask someone else or the teacher to explain your situation. A hospital teacher or psychologist can also take your place, or at least help you prepare for this difficult moment.

You can also pass your child’s teacher some educational references on how to talk about cancer in the classroom. Here are a few examples of books and brochures:

- **Hand in Hand (NL) — À deux mains (FR)**
  A guide published by the “Stichting tegen Kanker — Fondation contre le cancer”.
  → https://www.kanker.be/alles-over-kanker/jongeren-en-kanker/dagelijkse-leven/studeren-als-je-kanker-hebt/erover-praten-de
  → https://www.cancer.be/aide-aux-patients/l-cole/en-parler-en-classe
- **Educational kits from Télévie (FR)**
  → https://televie.be/vous-etes/enseignant/kits-pedagogiques/

- **Alles over kanker (NL)**
  Information on going to school and studying while being diagnosed with cancer.
  → https://www.allesoverkanker.be/naar-school-gaan-en-studeren
- **KickCancer (NL/FR/EN)**
  Find many more resources on our website.
  → https://kickcancer.org/patients/resources

Attending school from the hospital or home (during treatment)

Luckily, there are several options for ill children to stay in touch with friends, classmates, and teachers during their treatment. In the booklet Getting organised, we provide four schooling options: attending regular school, hospital schooling, virtual schooling, and homeschooling. What suits your child best will depend on personal preferences and their health condition, which may change during the medical journey.

The social aspect of going back to school (after treatment)

When children feel better after treatment, schooling becomes a priority again. Going back to school is important for their intellectual and social skills, but it also restores a sense of normality by bringing back a well-known, daily routine.

However, it may not be easy to return after a long absence, even when your child has kept contact with school friends and followed some classes. We all know that children and teenagers can be quite harsh and insensitive in their comments and behaviour. Social dynamics in children's groups often change as well, with friends coming and going, so recovered children may have to find their place again in the wolf pack.

How to support your child?

→ **Prepare for the return**

Before returning to school, discuss whether you or your child will tell the class something about the journey you have been through, what feels good to share (or not), and inform your child about possible difficulties that may arise.

→ **Organise a class discussion**

You can organise a class discussion a few days before the return or on the big day itself. If your child feels comfortable doing this, telling their story can be an intense but healing moment. Your hospital psychologist or hospital school teacher can help you and your child prepare for this.

→ **Anticipate changes in appearance**

When your child looks different due to hair loss or weight loss (or gain) resulting from cancer treatment, ask the school teacher to prepare the class for these changes. Talking about the specific consequences of cancer will have a normalising effect, may soothe unease and nip gossip and bullying in the bud.

Dealing with schooling and slow recovery (after treatment)

Cancer treatment causes various side effects, like concentration problems, fatigue or nausea. Your child may need some time to adapt when going back to school.

How to make it easier?

→ **Lighter tasks to stay involved**

Your child may want to rejoin the group as soon as possible and do the same activities, but this is not always possible. Discuss with the teacher how

to strike a balance between effort and ease. Your child needs to feel involved without being overburdened. For example, he/she could explain the game's rules or keep the score during a gym class instead of sitting on the bench.

→ **Combing school with treatment**

It is possible that your child will be allowed to go to school again while still receiving medical treatment. In that case, inform the school staff about the activities your child is not allowed to do at the moment, such as gym classes. The hospital team can help to assess which activities are not appropriate for your child right now.

→ **Sick classmates**

When one of the classmates is (slightly) ill, it is better to be aware of it. Depending on your child's immunity level, you can then decide whether to keep him/her at home. Ask the school teacher to tell other parents to inform the school about possible contagious illnesses, or to report them directly to you.

Tips for teenagers

If your child is a teenager, you can read through this section (and the previous ones) together. Teenagers are not just big children, so here are some specific tips for them.

Getting organised

→ **Talking with your teachers**
Are you stressed about schoolwork? This is very normal. Try to communicate clearly to your schoolteachers what you are concerned about. They will certainly help you out.

→ **You need a break!**
Don't set the bar too high for yourself. Stop and take a break when you feel that it all becomes too much.

→ **Focus on the main subjects**
Put together a package of subjects or lessons that you really want to follow. Review them regularly. Don't worry; focusing on the main subjects is more than enough.

→ **Hospital teachers to the rescue**
Don't hesitate to contact the teachers at your hospital (or ask your parents). They will be happy to help you.

Healthy in your head

→ **A different perspective**
If you have a lot of worries or feel stuck in your head, you can arrange a talk with a psychotherapist (or ask your parents to do so). This has helped many people before and is a normal thing to do. Talking with someone outside your family, with a different perspective, may give you new insights. It can comfort you and clear up the sky.

→ **Find the right therapist for you**
If you don't like the therapist you have talked with, please tell your parents. It's important that you feel comfortable because this makes talking much easier. Look for a therapist who feels right for you.

Food, sports, and your looks

→ **Try out new recipes**
Do you have trouble eating? Why not open a cookbook or search the internet to try out new tastes and recipes, or watch a cooking programme?

→ **Every move counts**
Although it can be tough, try to keep exercising. Every little bit helps. You can ask your physiotherapist to give you extra training exercises to complement your physio sessions.

→ **You are still you**
Your looks may change during medical treatment: losing weight because you can't or don't

want to eat, hair falling out and growing back again, swelling because of the cortisones. Although there's not much you can do about it, remember that this is temporary. You are always still you. Try to take care of your body and continue to like it; you will need it. If this is really hard for you, consider talking about it with someone.

→ **Keep smearing**

A tip for teenagers who get cortisones: keep smearing to avoid stretch marks. A product like Bio-Oil can do the trick.

After treatment

→ **Social life**

When your treatment ends, you may feel excited to resume your social life. However, it's important to first discuss with your doctor what is (not) recommended. Just because your treatment is over does not mean that your body is completely ready for "normal life" again. For example, if your immune system is still weak, meeting (too many) people right away is not a good idea.

Here are some ideas for seeing people back in a small group:

○ Take a walk or bike ride and bring a picnic.
○ Plan a cosy campfire night and spend time together around the fire pit.

- ○ Try geocaching via a geocaching app.
- ○ Organise a board game afternoon with friends.
- ○ Pick your favourite movies for a movie night.
- ○ Cook a yummy recipe and enjoy it together.
- ○ Find a sports buddy and rebuild your physical condition together.
- ○ Explore what's in your neighbourhood (a boat ride, mini golf, a scavenger hunt, and so on).

Apart from the above tips, the most important thing is to keep listening to your body. It sounds cliché but you really should! Your body is still recovering from a very tough treatment and that takes time. Three more suggestions:

- ○ It can be hard for your friends to guess what you can or can't do yet. Just tell them what you can handle and what is still too difficult.
- ○ Try to make feasible compromises such as going to the youth movement, but not every weekend. You could start with twice a month and gradually rebuild your former social habits.
- ○ In general, resume everything step-by-step. Going back to "normal life" is, unfortunately, not a light switch you can turn back on, but a gradual process.

→ Your rights

As an ex-cancer patient, you have specific rights that are important to know. One example is the "Right To Be Forgotten" (RTBF). Having a history of cancer can be a hurdle for access to financial credit services, particularly insurance products. This is why Belgium adopted this legislation for cancer survivors (both adults and children). It allows financial companies, in the context of insurances or loan contracts, to collect medical information related to cancer only up to ten years (or less for specific cancers) after the end of treatment, so not after that period.

SHARE WITH THE TEAM!

If you have a great idea that could help other families, please share it with us via
→ patients@kickcancer.org .
We will include your idea in the next edition of MY COMPANION.