Being diagnosed with cancer as a child is one of the biggest challenges a family can face. Unfortunately, there is often little time to digest such unfair and hard news. The diagnosis will immediately turn your daily habits upside down and generate a lot of administrative tasks. This can seem overwhelming, especially at first.

This booklet hopes to guide you in this difficult first phase by sorting out the essential things to do, step-by-step.

First of all

Receiving a cancer diagnosis can be a shock for everyone involved. You may find it hard to believe or feel numb, dazed, and confused. If you feel overwhelmed, which is a very normal reaction, do not hesitate to seek support from the start. You can contact various people for help, big or small. They are ready to welcome you:

- Hospital Social Service. Every hospital has a social worker unit to support patients and their families with administrative tasks mainly. → You can find the contact details of your social worker in the booklet My medical map > My cancer in a nutshell
- Hospital Care Coordinator. Most hospitals also have a “care coordinator” for general questions about patient care. For more information, see below.
- KickCancer peer-to-peer team. If you want to talk to someone who has been through a similar situation, send an email to patients@kickcancer.org.
- Paediatric unit psychologist. You can also consult a psychologist for advice and assistance. Ask your paediatric oncology unit because they have an experienced support team that is ready to help you or your child during the hospital journey. They can also help to identify therapists closer to home.

Helpful people to contact

- To check your rights and benefits
- To ensure your administrative tasks are settled

To make the road to recovery easier for you and your child, you are entitled to various important rights and benefits. You are not in this alone: there are several sources of financial assistance, rights, and benefits available for children diagnosed with cancer, including your hospital's social service, your sickness fund, your health insurance (if you have one), and the government. However, sometimes you need to apply for these yourself, so it is important to contact the appropriate people. By using the checklist below, you can ensure that you have covered all the necessary steps.

People to contact	**Why**
Hospital Social Service	**Rights and administration** We recommend contacting your hospital's social service first. A social worker will explain your basic patient rights and take over some administrative tasks to lighten your paperwork. **Allowance and refunds** It is often also possible to get an allowance, a refund for transport costs, or even assistance with transportation and a parking card (under certain conditions). Your hospital's social services can help you find out what is locally available.
Hospital Care Coordinator	**General patient care** You can also consult your hospital's care coordinator for general questions on patient care. Also called a "nurse coordinator", "liaison nurse" or "Coordinateur de Soins en Oncologie" (CSO), a care coordinator is responsible for well-managed patient care: monitoring treatment plans, educating patients on their conditions and connecting them to relevant healthcare providers (doctors, physiotherapists, dietitians, etc.) both within and outside the hospital.

Hospital Paediatric Oncology Unit

Psychological support and physiotherapy

In most hospitals, a psychologist will visit you and your child in the room during your hospital stay. If you haven't had the opportunity to meet with a psychologist, this is definitely a question you can raise with your child's oncologist. Note that psychological sessions are reimbursed for both patients and their relatives. Cancer patients are also entitled to physiotherapy sessions.

Government Handicap Belgium

Recognition of disability status

Any child with a severe condition such as cancer is recognised as disabled, which entitles your child to several essential rights and benefits: 1. reduced taxes on the parents' income; 2. an increased family allowance; and 3. a disability parking card. For more information, you can visitd handicap.belgium.be and check with your hospital's social service on how they can assist you in the application process.

Sickness fund or mutual assistance

Medical expense reimbursements

Your fund can explain which medical expenses, such as drugs or medical devices, you are entitled to be reimbursed for.

Recognition as a primary caregiver

Your fund can also explain how you can apply for recognition as a primary caregiver, which can open doors to additional benefits. These benefits can vary from one fund to another, so it's better to ask open-ended questions such as “What do you offer in our situation?”.

Health and/or hospital insurance (if you have one)

Additional benefits

On top of the services provided by your sickness fund, your hospital and/or health insurance may offer additional benefits, services, or reimbursements for medical expenses.

School

Medical certificate

You should submit a medical certificate to your child's school within three days of the beginning of their absence, so that their absence is covered and your child remains registered at school (which is mandatory). If your child is a student aged between 18 and 25 years old, this is also a necessary procedure to continue receiving family allowances.

Communication

Although you are not legally obliged to inform the school that your child has been diagnosed with cancer, it is better to involve them from the start. Informing the teachers about your child's condition enables the school team to initiate an open dialogue between your child, their schoolmates and their parents, and yourself. Open communication also allows the school to make the necessary arrangements to support your child in pursuing their education. For more information, see School, a welcome distraction below.

Employer

Additional support

Some employers offer additional support for primary caregivers, like extra days off or financial support, so better check this with your employer.

Hobbies

Continue or resume

If you and your child have some energy left, it can be helpful to think about hobbies too. Consider which activities can be safely resumed given your child's current condition and treatment plan. Hobbies can provide a sense of normalcy and enjoyment during a difficult time.

You are amazing!
Keep going!

School, a welcome distraction

In Belgium, school is compulsory for every child aged between 5 and 18 years. Of course, this obligation can be suspended during periods of illness because it may not be safe, comfortable or advisable for your child to attend school. Your child's absence will be covered by a medical certificate.

There will be a lot of factors to balance during your child's treatment journey. Staying in contact with classmates is good for emotional well-being, helps to keep on track with school and offers some distraction from the hospital world, but fatigue will kick in along the way too. The information in this part is therefore optional. You can school your child during treatment, but only to a reasonable and feasible extent, and always in your child's best interest.

Regular school

Your child's regular school can play a very positive role in the recovery process. Keeping everything as normal as possible can be of great emotional support for your child because routine feels safe and stable. It also feels

good to prepare for a future beyond illness. However, it's important to discuss schooling with your child's doctors first, as they may have recommendations for adjustments such as reduced school hours or accommodations for physical limitations. As with any other illness, your child is allowed to be absent from school for a certain amount of time and can return when they feel better. → For more information, see booklet How to stand the storm > Back to school (on your terms)

Hospital school

All paediatric oncology units offer school lessons in hospitals.

Hospital schooling has several advantages:

- It is available for children between 2,5 and 18 years old.
- The schooling programme is tailor-made in close collaboration with your child's regular school teacher and is attuned to your child's health condition and learning pace.

- It can be organised in small groups in a classroom or individually in the hospital room.
- The schedule is flexible, depending on your child's varying energy levels.

→ You can find more information at www.hospichild.be

Please note that schooling may not always be possible, depending on your child's health condition. For example, if children are immunocompromised, attending school may not be allowed. In this situation, the hospital teachers may propose time slots to work with the children in their own rooms.

Virtual school

Your child can stay in touch with their schoolmates via online video calls but can also attend classes through video services offered by specialised non-profit organisations:

(FR) **ClassContact** for French-speaking schools
(NL) **Bednet** for Flemish-speaking schools

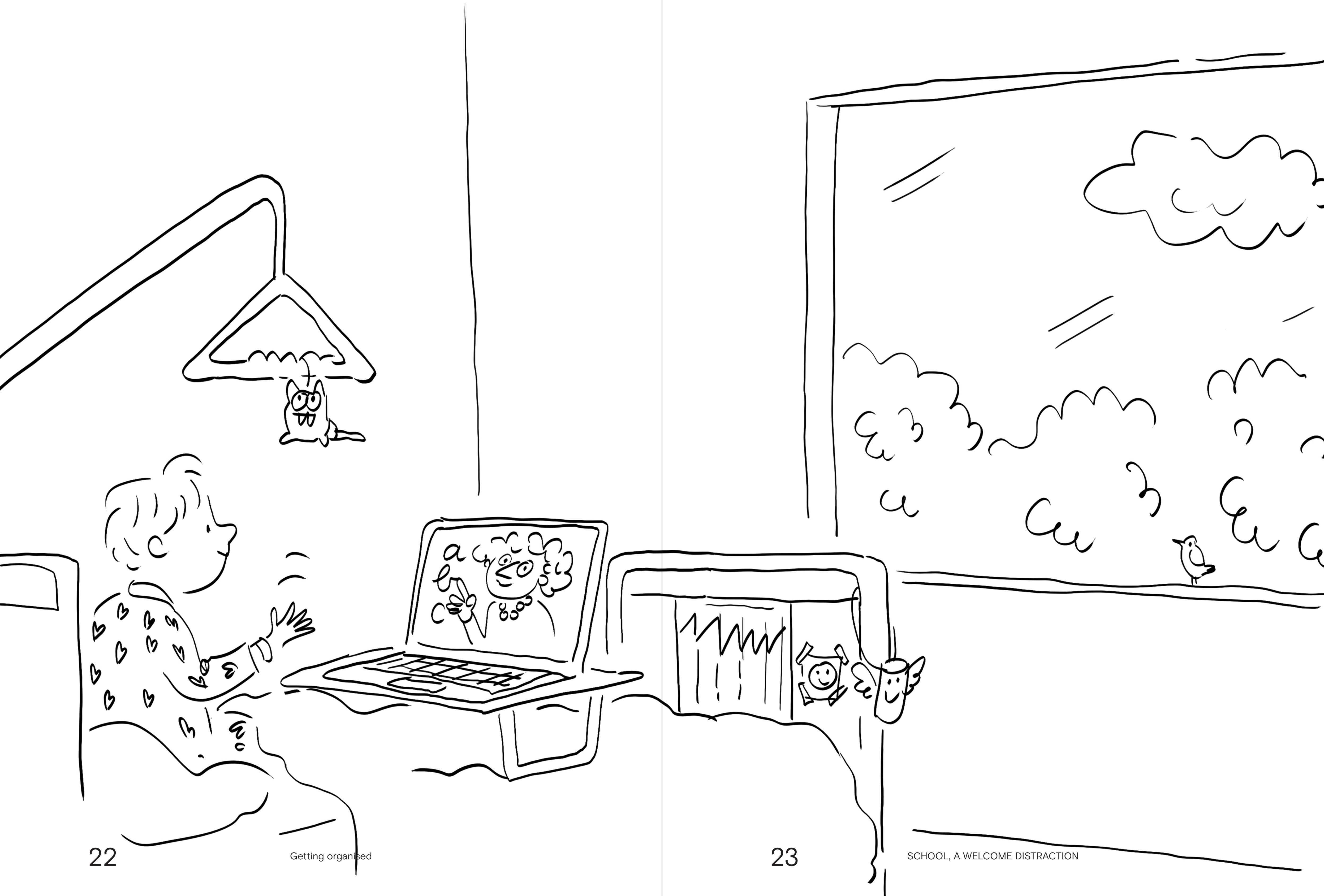
These organisations will equip your child's regular classroom so that your child can attend live classes (a bit like during the Covid pandemic really). Their services are free of charge, but please note that your child's regular school needs to give permission in advance. Sick children appreciate virtual school services because it helps them feel more like they are part of their friends' regular lives. If your child feels tired or unable to concentrate, there is no obligation to connect.

Home school

When your child is physically unable to go to school, homeschooling may be a fine temporary solution:

(FR) For French-speaking children, the non-profit organisation « L'École à l'hôpital et à domicile » is a group of volunteer teachers who organise additional teaching at home. → Visit www.ehd.be for more information

(NL) For Flemish-speaking children, the non-profit organisation "School & Ziekzijn"


a
b
c

is a group of volunteer teachers who organise additional teaching at home.
→ Visit www.s-z.be for more information

Other local associations may also offer homeschooling services. Consult your hospital's care coordinator for more information.

Please note that homeschooling sometimes progresses faster than regular learning thanks to one-to-one contact with teachers. You may then be tempted to shift up teaching to another gear. However, your child's health and recovery should be the top priority. Also, if your child is not feeling well, don't hesitate to cancel the homeschooling sessions, but inform the teachers in advance to avoid unnecessary commuting.

Here are a few more tips:

- Focus on the main school subjects (mathematics, languages, science…).

- End-of-year tests (exams) are not mandatory to pass the year or to finish high school.

- Your child can join the gym class when they feel physically capable.

For more information, you can visit:
(FR) The website of the Administration Générale de l'Enseignement de la Communauté Française de Belgique → www.enseignement.be
(NL) The website of the Vlaamse Gemeenschap → www.vlaanderen.be/nl/onderwijs-en-wetenschap or of the umbrella organisation for Flemish education → https://onderwijs.vlaanderen.be


3 + 2 = ?


healing ?

More support

Here are some additional support possibilities.

Navigating the medical mountain

Your first concern as a patient, or parent of a patient, will be to ensure that you receive the best medical treatment. Your first sources of information will be your family doctor and paediatric oncologist, but it may be difficult to see the forest for the trees. What are all the options for treatment? What do the guidelines say about your child's type of cancer? Which therapies are under development? Is your child eligible for a clinical trial? Finding answers to all these questions is not easy, let alone finding out whether the answers give you the complete picture. Most of us do not have the time, energy or knowledge to skim through the literature to discover all the available options and nuances.

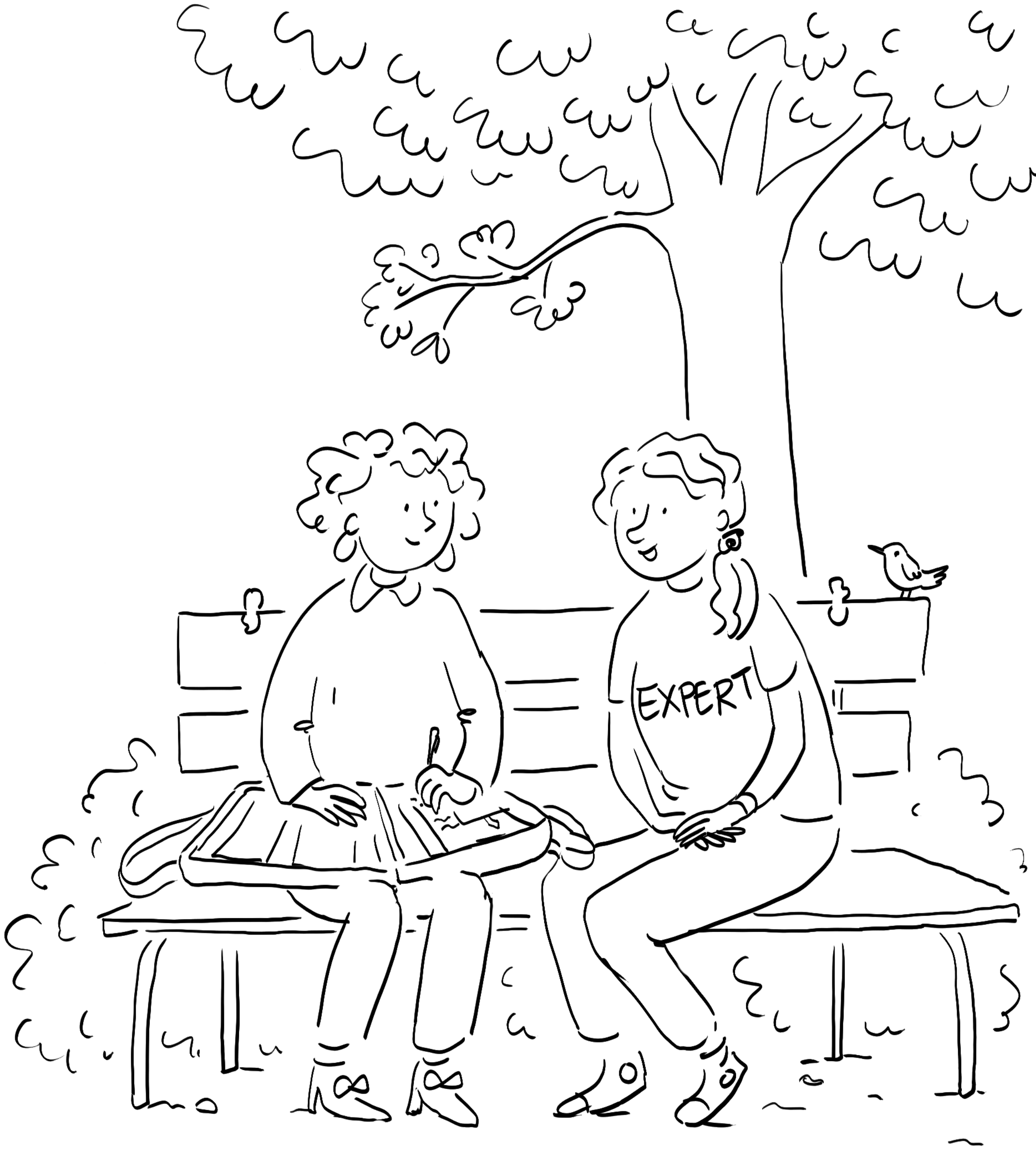
First and foremost, ask your child's paediatric oncologist whether the proposed treatments are "standard of care". If they are, you can be sure that the scientific community considers these treatments the best options for your child.

If the proposed treatments are not "standard of care", there is definitely room for questions to ask your doctors. The team of scientists and physicians from the Anticancer Fund, a Belgian non-profit organisation, can provide you with additional, curated scientific information relevant to your child's situation. Their "MyCancerNavigator" is a free service for cancer patients treated in Belgium. Consulting this online tool can make it easier to take well-considered and informed decisions about your child's treatment.

Peer-to-peer boost

Another challenge is understanding what is happening to yourself, your child and your family and regaining a sense of control over the turmoil of events. Talking to someone who has been through the same thing can be very helpful in this regard. A peer knows the impact of cancer on daily life, will understand you better and may therefore be able to give you comfort and good advice.


EXPERT


EXPERT

To address this need, KickCancer trains former patients and their parents to become “expert patients”. These people have been educated to take an elevated view of their personal experience to help other patients and their parents in an effective and sensible way. Our peer-to-peer guides are not only experience-experts but also know your rights as a patient very well. They are a source of practical knowledge and can provide you with helpful information on a vast array of topics. For example, they can teach you how to identify reliable cancer websites, tell you more about the relevance of enrolling in a clinical trial or how to get a second medical opinion. Connecting with expert patients and their parents can therefore be very useful not only psychologically, but also from a practical point of view.

If you feel like contacting a peer to discuss any aspect of your child’s treatment journey, please don’t hesitate and send an email to patients@kickcancer.org.

Support close to home

Local support initiatives can be very valuable and convenient. Ask the social service of your hospital for an overview of the local associations that offer support. You can also visit www.childrencancer.be to explore local helpful initiatives and services organised by non-profit organisations for children with cancer and their families.