

Taking up an active role in your child's care journey

Medical appointments will be a constant during the treatment journey. These appointments can be both reassuring and confronting. Talking with your child's doctors can provide a handhold, but the medical context can also feel upsetting due to its sterile atmosphere, difficult words and many unknowns. In moments like these, remember that doctors are your partners in this journey, standing by your side.

Our advice is to prepare well for medical appointments. Try to see every consultation with the doctors as an opportunity to ask questions and understand what they tell you. We know from experience — and research confirms this — that informed patients make better decisions and are more likely to accept their treatment. By turning medical appointments into “your” moment, you will also feel more actively involved, empowered and in control.

Finally, remember that as a parent, you are making decisions for your child. Depending on their age and willingness, it is important to involve them in the decision-making process. If your child is in their teens, they might need some privacy to discuss personal matters with their doctor. Please consider allowing them some time (not the whole time) on their own with the medical team.

General tips

- If you don't understand a word, ask for its definition.
- Ask the doctor to repeat something if it is not crystal clear.
- Don't feel embarrassed to repeat what the doctor said to check whether you have understood it correctly.
- Take notes to summarise what the doctor said. You can use them for future reference. For example, reviewing your notes may increase your understanding and even shed new light on what the doctor said during the consultation.
- Ensure that all of your questions are answered before leaving the medical appointment.
- Take your time, even if the doctor seems to be in a hurry.
- Ask the doctor to wrap up the next steps at the end of your meeting.
- You can conclude the meeting by summarising the next steps out loud: "So the next steps are...". This ensures that you have understood everything properly.

How to use this tool?

My appointment assistant is a tool to help you make the most of your child's medical appointments with the healthcare team. It contains two handy tools:

→ Ask-the-doctor checklist

A list with the most important questions for each treatment phase, to discuss with the medical team during each medical appointment.

→ My medical journal

A notebook you can use to keep track of all the information you receive during your appointments.

We have divided the treatment journey into six phases:

1. When cancer is diagnosed
2. Discussing treatment options
3. When the doctors mention a clinical trial
4. Arranging help and support
5. Turning lemons into lemonade
6. When treatment is completed

For each phase, we distinguish between “priority” and “additional” questions:

- **Priority questions** refer to matters that require a clear and comprehensible answer. They will provide you with crucial information, so make sure all priority questions are addressed by the doctor before ending the appointment. They are designed as a checklist, so you can keep track of all (un)answered questions by ticking the boxes.
- **Additional questions** are less crucial. You can ask them if you want to delve deeper. They are also designed as a checklist, so you can keep track of their answers as well.

Before every medical appointment, we recommend reviewing the ask-the-doctor checklist with priority questions for the corresponding treatment phase, so you have these in the back of your mind. In the checklist, you can also highlight the additional questions you want to ask the medical team. Feel of course free to ask other questions as well.

During the appointment, take your notebook and fill in the blank appointment sheet with the date, doctor’s name and subject. The notebook is for writing down the doctor’s answers, while the checklist is for keeping an eye on which questions the doctor has (not) addressed yet. Tick off the

answered questions and pose the ones that are still open.

However, note that all the questions in this booklet are mere suggestions; not all of them will apply to your specific situation. In other words, you don’t have to stick to the list and ask all questions. If you are not sure about a question, ask yourself if you, your co-parent or your child really want to hear the answer.

Good to know: the medical team should be willing to answer all the questions in this booklet (if they apply to your situation, of course). None of the questions are rude or offensive, and you are allowed to ask all of them. The doctors won’t treat you or your child any less if you do.

Lastly, you probably won’t need to ask many of the suggested questions because the medical team will give you the answers automatically. We compiled all the questions to ensure that you know everything you need to know before leaving the consultation room.

1. When cancer is diagnosed

When your child is first diagnosed with cancer, the doctors will need to determine the type of cancer, its sub-type and severity. If the doctor who made the diagnosis is not specialised in paediatric cancer, you better ask your initial questions again once your child has been transferred to the paediatric haemato-oncology unit. The specialists there will listen to all your questions. Your paediatric oncologist will also give you the document [My cancer in a nutshell](#) summarising most of the information you need to move forward.

Checklist with priority questions →

- Level of certainty** — How certain is the doctor about the diagnosis? Does he/she “think” it is the right diagnosis, or is he/she “sure” it is?
- Doctor’s speciality** — Is your doctor a general paediatrician, or is he/she specialised in children’s cancer (paediatric haemato-oncologist)? (You need to know the qualifications of the doctor you are talking to!)
- Next steps** — What is the plan for the next steps?
- Start treatment** — What is the anticipated date of the treatment’s start?
- Preserving fertility** — What are the measures required to preserve your child’s fertility before the treatment begins (if there are some)?

Additional questions →

- 1.1. How long will it take to confirm the diagnosis?
- 1.2. Which tests have already been performed to confirm the diagnosis? Which tests are still required to finalise the diagnosis?
- 1.3. What is the cancer’s stage? What does that mean?

1. WHEN CANCER IS DIAGNOSED

- 1.4. Does my child have a genetic predisposition to cancer?
- 1.5. Do you know the cause of my child’s cancer?
- 1.6. Is this type of cancer rare or common in children?
- 1.7. What is my child’s prognosis (chance of recovery and survival)? (This question is very personal; not everyone may want to ask it.)

2. Discussing treatment options

The questions in this section should be discussed at the beginning of the treatment, but can also be discussed if the treatment has already started (sometimes things must go really quickly). You may also need to revisit them during the course of treatment, as doctors sometimes need to change the initial plan and take new decisions. For example, surgery may no longer be required, or surgery may be required, but radiotherapy can be skipped, and so on. Answering the questions below will help you understand better what is going on.

Hospital and doctors

Checklist with priority questions →

- Best hospital** — Is this hospital the most specialised one in Belgium for your child's type of cancer?

Additional questions →

- 2.1. What is the total number of children treated for this cancer in this hospital annually, and in total so far?
- 2.2. Did you discuss my child's case with other doctors in Belgium or Europe? If so, can you explain this further?
- 2.3. Can you (or another treating doctor) recommend someone for a second opinion and assist in transferring my child's hospital file? (Only ask this question if you want a second opinion.)

Treatment (general)

Checklist with priority questions →

- Proposed treatment** — What treatment does the medical team propose?
- Standard of care** — Is the proposed treatment standard in Europe?
- Decision time** — How much time do you have to decide on the treatment plan?
- Treatment plan** — Can your doctor propose a treatment plan that includes:
 - the total duration of treatment (beginning to end);
 - how the weeks will be organised;
 - hospital stays and outpatient clinic visits;
 - important milestones.
- School and hobbies** — Can your child continue to go to school and pursue hobbies during treatment?

Additional questions →

- 2.4. How long has this treatment plan been used?
- 2.5. How many children have you treated with this plan before?

- 2.6. Are there any alternative treatment protocols available in Belgium or other countries?
- 2.7. What are the common causes of delays in the treatment?
- 2.8. What is the survival rate for children treated with this plan? (This is a personal question not everyone may want to ask.)

If the treatment includes radiation

Checklist with priority questions →

- Duration** — What is the estimated duration of the radiation treatment?
- Anaesthesia** — Does your child need anaesthesia before each radiation session?

Additional questions →

- 2.9. What will be the radiation dose?
- 2.10. What are the possible long-term side effects of radiation treatment?

If the treatment includes surgery

Checklist with priority questions →

- Surgery details** — What exactly does the surgery entail?
- Removal** — Can the tumour be completely removed during surgery?
- Effects** — What are the effects (both permanent and temporary, short- and long-term) the surgery could have on your child's basic functional abilities?
- Surgeon** — What is the name of the surgeon who will perform the surgery? Is he or she an expert in this surgical domain?
- Home arrangements** — Do you need to make special arrangements in your home after the surgery?
- Revalidation** — Which rehabilitation services may your child require after surgery? Does your doctor recommend a specific revalidation programme?

Additional questions →

- 2.11. Are there several possible surgical techniques that can be used?
- 2.12. What if you cannot completely remove the tumour during the surgery?
- 2.13. What complications could arise during or after surgery?
- 2.14. What is the expertise of the surgeon who will operate on my child?
 - Is the surgeon specialised in children or adult surgeries?
 - Is the surgeon specialised in this type of tumour or body part?
 - How many surgeries for this specific cancer does the surgeon perform annually?
- 2.15. How urgent is this surgery? Can I ask for a second opinion? Would you recommend someone for a second opinion (from another hospital or country)?

If the treatment includes radiation and surgery (extra questions)

Checklist with priority questions →

- Order of treatment** — In what order will your child be operated on and receive radiotherapy?
- Mutual impact** — What is the connection between surgery and radiotherapy? How do they impact each other?
- Avoid radiotherapy** — Can you avoid radiotherapy with surgery?

Side effects

Checklist with priority questions →

- Acute side effects** — What are the possible acute side effects of the treatment?
- Preventive routines** — What routines should you implement to prevent side effects (house cleaning, handwashing, additional medicines, diet, etc.)?
- Emergency signs** — What are the signs and symptoms that indicate that you should call the healthcare team or go to the emergency room?
- Emergency numbers** — What are the emergency numbers you should contact, both during and after office hours?

Additional questions →

- 2.16. Did you give us all the possible strategies to prevent long-term side effects of the treatment? For example, can my child prevent or reduce hair loss by wearing protective headgear? (Even though preserving looks is not a priority, it may be very important for your child's peace of mind.)

Monitoring

Checklist with priority questions →

- First evaluation** — When will your doctor evaluate the treatment's effectiveness for the first time?

Additional questions →

- 2.17. How often will you evaluate the treatment's effectiveness?
- 2.18. What kind of testing will you do to monitor the disease and its treatment?
- 2.19. Do other options exist if the evaluation shows that the treatment is unsatisfactory?

3. When the doctors mention a clinical trial

This section is only useful if your child will be included in a clinical trial.

- Interventional trial or not** — Is it an interventional trial (affecting your child's treatment protocol) or a non-interventional trial (collecting information about your child's case without affecting the treatment)?
- Alternative to trial** — What treatment will your child receive if you do not agree to participate in the clinical trial?
- Child's consent** — Will you need your child's consent for the trial? If so, are you, as a parent, obliged to follow your child's wishes? Does your doctor have child-friendly information about the trial?
- Difference with standard treatment** — What is the difference between the clinical trial and the standard treatment regarding:
 - The treatment itself.
 - The possible risks and side effects. Do they differ from the standard treatment protocol?
 - The burden on my child such as 1) additional hospital visits; 2) additional tests or interventions (scans, blood draws, etc). Will some of them hurt or require anaesthesia?
 - The benefits.
 - The long-term follow-up care.

- 3.1. Can you help me understand the clinical trial better:
 - Is it an early-phase or late-phase clinical trial?
 - What is being studied?
 - Is the study randomised? If so, what are the differences between the arms of treatment?
- 3.2. Will you share the final results of the study with us?

4. Arranging help and support

Your child's cancer journey may have a big impact on your family life, work and financial situation. When you feel lost, remember that the entire medical team is there to help you. No one can succeed alone. Once treatment has started, and you are getting a bit more familiar with the whole situation, you may want to look for additional (social or psychological) support. This section explains how you can find the right help within your hospital.

Understanding the hospital rules

Checklist with priority questions →

- Visiting rules** — What are the visiting rules of the hospital?

Additional questions →

- 4.1. Can grandparents, uncles or aunts also look after my child or is this role limited to the parents?
- 4.2. Can the siblings visit their brother or sister in the hospital, and if so, are there specific times set aside for these visits?

Finding the people who can help

Checklist with priority questions →

- More support** — Ask how you can arrange a meeting with
 - the team of psychologists;
 - the social workers;
 - the local patients' organisation.
 (Meeting these three types of experts can be very helpful, as it will give you an overview of who can help and when.)

Additional questions →

- 4.3. Can I / my child / the siblings see a hospital psychologist during our hospital stay? Which psychological support options are available outside the hospital setting?
- 4.4. What types of financial assistance are available? What are other support options (house cleaning, etc.)?
- 4.5. Is there a dedicated housing residence near the hospital for families to stay in during prolonged hospital stays or repeated daily visits? Does everyone have access to this residence, or do specific criteria apply?
- 4.6. Are there specific social activities for the siblings, or is there a dedicated support programme?

5. Turning lemons into lemonade: doing fun things despite everything

We all learn and change over time. While you may want to put all activities on hold at the beginning of the treatment, your and your child's needs may change later on. Some parents discovered that organising small events gave them more energy and courage to deal with tougher moments. If you feel like organising something, here are some questions to help get you started.

- Best moments during chemo** — What are the best moments to plan activities during the chemotherapy cycle (if possible at all)?
- Activities during chemo** — Can your child continue to take part in any physical activity? If so, what activities does your doctor (not) recommend?
- Contact during chemotherapy** — Can your child be in contact with people outside the close family circle during chemotherapy?
- Essential medicines kit** — When you go outside, should you take a kit with essential medicines? If so, which ones?

- 5.1. Can I organise activities with other people during treatment?
- 5.2. Can I invite my child's friends over (or the siblings' friends)? Are there any restrictions?
- 5.3. How can I help friends feel comfortable with my child?
- 5.4. Can my child attend a family or friend's party?
- 5.5. What precautions should I take? Do I need to give guests any instructions?
- 5.6. Can we go on holiday during chemotherapy?

6. When treatment is completed

After completing the treatment, you can finally start facing forward. So first, let's celebrate! You kicked out cancer, what an achievement. However, keep in mind that the coming months may not be so easy. You will encounter many new questions, so we have compiled some of them in this chapter. Also, the doctors won't let you go so easily. Your child will need dedicated follow-up care to ensure things turn out the best way possible.

After the treatment, you will meet with the long-term follow-up specialist from the paediatric oncology centre. This person will give you a summary of your child's past treatment, discuss the possible long-term effects, and propose a follow-up plan. This plan or "passport" will be tailored to your child's specific needs and will include a long-term appointment schedule in addition to regular, mandatory cancer check-ups. The type and frequency of these examinations will depend on the type of cancer your child had, its treatment and any complications that may have arisen. A long-term follow-up plan is therefore not a one-size-fits-all plan, but unique to every child.

It is good to know that your child's "passport" is based on current best practices, so it may be updated as new medical insights arise. Close follow-up with the medical team is therefore highly recommended. Additionally, it is important to share this passport with your general practitioner and any other doctors your child will visit for other health concerns. Knowing that your child has survived cancer will help them fine-tune the medical care plan.

Tip for follow-up care

Keep a medical journal between medical appointments:

- Jot down any questions, signs, symptoms, concerns or other unusual things you notice. It's a good idea to discuss these observations with your child's doctor during your appointment.
- Keep track of any changes in medication (or additional supplements) or medical history.

Remission

Checklist with priority questions →

- Remission** — What is it, and when is someone considered to be in remission?
- Frequency of check-ups** — How often will you need to return to the hospital for check-ups?
- Details of check-ups** — What will these visits involve?
- Grouping of tests** — Is it possible to schedule all the tests for one day?
- Symptoms/signs to monitor** — What symptoms or signs should you monitor and report to the medical team between check-ups?
- Diet** — Do your child's dietary restrictions still apply now that treatment is over?
- Rehabilitation** — Does your doctor recommend a specific rehabilitation programme (if available)?
- Sports** — Rebuilding your child's physical condition is very important for enhancing their recovery. What safe sports and activities does your doctor recommend?

6. WHEN TREATMENT IS COMPLETED

- Back to school** — When can your child return to school?

Additional questions →

- 6.1. Why does my child need additional therapies while in remission? (Ask this if your child requires maintenance therapy.)
- 6.2. How long will it take for my child to fully recover from treatment?
- 6.3. When returning to school, should I inform the teacher about any specific difficulties?
- 6.4. What is (not) allowed regarding my child's social life?

Long-term follow-up

Chemotherapy and radiotherapy can affect the growth of your child's bones, tissues, and organs, potentially leading to long-term side effects. Whether these effects occur or not depends on several factors, including the type of cancer, its location, the type and dosage of treatment received, and your child's age during treatment. While not all patients experience long-term side effects, it's better to be safe than sorry. Therefore, it's essential to closely monitor your child's overall health after treatment, as addressing any potential effects early is crucial.

Checklist with priority questions →

- Follow-up needs** — What are your child's follow-up needs for other health aspects?
- Follow-up specialists and duration** — Which doctors or specialists will continue to monitor your child and for how long?
- Frequency of follow-up visits** — How frequently will you need to return to the hospital for long-term follow-up visits?
- Tests** — Which tests will be necessary to identify and monitor possible late side effects (e.g. heart check-up, monitoring of kidney function...)?

- Contact person** — Whom should you contact if your child experiences any health issues?

Additional questions →

- 6.5. What are the known long-term side effects of the treatment?
- 6.6. Can you give me a written follow-up care plan or survivorship care plan?
- 6.7. Does this hospital have a specialty clinic for long-term follow-up care?
- 6.8. What is the protocol for transitioning to adult care in this hospital?
- 6.9. Does my child have a genetic predisposition to cancer? If so, what is the monitoring plan?

Mental health

Completing the treatment will bring relief, but it won't necessarily be an easy period. Many people start landing on their feet and begin to realise what on earth has happened to them as an individual, parent and family. While you would expect to feel happy that it is all over, this "landing" phase can be difficult. It is normal to ask for help in working through this phase, particularly because those around you may believe it's time to move on. They may expect you, your partner, your child or the siblings to resume your previous lives as if cancer never happened, but that's not so easy. Speaking openly with specialists about your and your child's physical and emotional concerns can be very supportive.

Additional questions →

- 6.10. Who can offer psychological support in our region if we need it?
- 6.11. Are there any family activities available to help us during the "post-treatment" phase?

Fertility

Chemotherapy and radiotherapy can have an impact on fertility for both boys and girls. In some cases, fertility only temporarily decreases and recovers after treatment. However, the decrease can also be permanent, which can lead to infertility.

Additional questions →

- 6.12. After treatment, how long will it take to determine if my child is still fertile?
- 6.13. Will my child be able to have children naturally after treatment?
- 6.14. If my child will have children, will they be at an increased risk of developing cancer?

