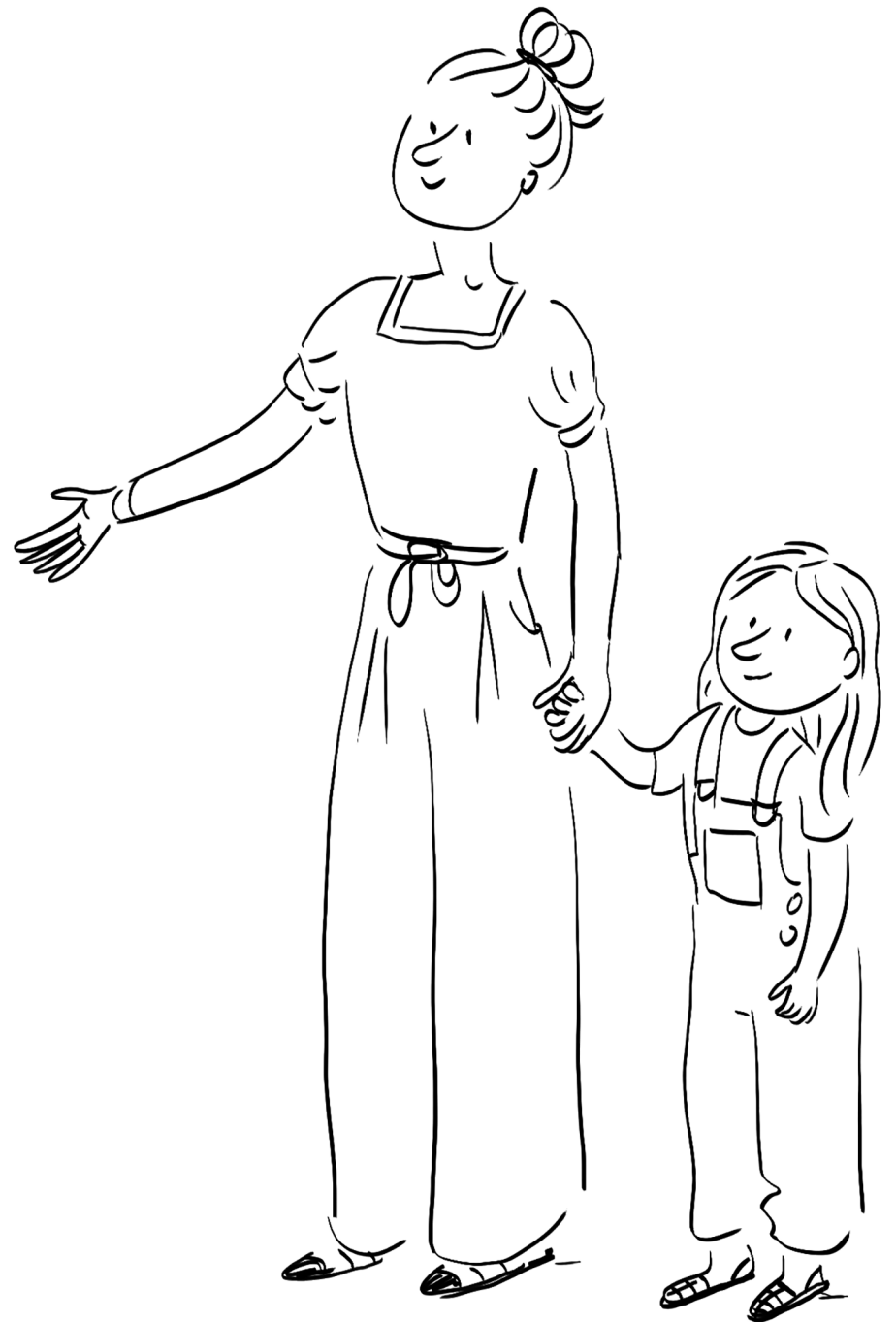


The world of cancer can seem like a different planet, with a completely new vocabulary and unfamiliar procedures. This can be daunting and confusing at first. This booklet hopes to help you grasp the basics, so you can better understand what is going on.

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Glossary of terms

Basics

Tumour

A tumour is a group of cells in the body that continue to divide or multiply. A tumour can be benign or malignant. Only malignant tumours are referred to as cancer.

Benign tumour

“Benign” refers to a “good” condition. A benign tumour does not spread but may grow slowly in one location and cause symptoms such as pressure on the surrounding tissues. A benign tumour is not cancer. However, it is possible for an initially benign tumour to become malignant.

Malignant tumour/Cancer

“Malignant” refers to a “bad” condition. The cells of a malignant tumour continue to multiply, either locally or in other parts of the body, which harms the patient in both cases. In the first case, the multiplying tumour will invade and affect surrounding tissues. In the second case, the malignant cells “metastasise”: they spread to a different part of the body than where they originated. Both malignant cases are called cancer.

Stage/stadium

A malignant tumour can have different stages depending on its type, size and location (local or spread into other tissues or organs). The doctor can determine the stage of the tumour through biological and genomic tests. Knowing the stage helps to estimate how serious the cancer is, the chances of survival and the most appropriate treatment.

Liquid/solid tumour

A malignant tumour can be either liquid or solid. Both cancer types are composed of abnormal cells that multiply uncontrollably. Solid tumours create one or more lumps of cancer cells, like sarcomas. They grow in organs and can occur anywhere in the body. Liquid tumours are cancers that develop in the blood, bone marrow, or lymph nodes. Examples include leukaemia, lymphoma, and myeloma.

Diagnosis and testing

Positive vs negative results

A “positive” test result does not mean “good” news but affirms the presence of the tested parameter. A “negative” result means that the tested parameter is absent.

Medical imaging techniques

○ CT scan

Computer Tomography (CT) uses X-rays to capture detailed cross-sections of the body from different angles. The machine scans (parts of) the body section by section. A computer then combines all these sections into a detailed 2D or 3D image of the body. **Used for:** detecting and examining abnormalities in internal organs, necrosis (dying tissue) in the brain, blood flow and vascular abnormalities (such as clots), fluid retention, getting a clearer picture of the lung tissue, and so on.

○ Echography/ultrasound/sonography

Echography uses ultrasound waves (inaudible) to create images or “sonograms” of the inner parts of the body. Other terms for echography are echoscopy,

ultrasound or sonography. Oncologists often carry out a “liver” ultrasound because many cancers have metastases in the liver. An ultrasound examination often accompanies a puncture or needle biopsy. **Used for:** examining almost all body parts, such as detecting glandular packages or tissue abnormalities in the liver, kidneys, heart, and intestines, or checking for internal fluid retention.

○ **MRI/NMR scan**

Magnetic Resonance Imaging (MRI) uses strong magnetic fields and radio waves (no X-rays) to create detailed images of organs and other body tissues. Sometimes it is also called NMR (Nuclear Magnetic Resonance). **Used for:** more detailed examination of the bones, the spinal cord, the brain, internal organs and sometimes the heart. **Important:** for younger children (< 6 years), anaesthesia is often necessary because they need to lie still for 20 minutes.

○ **PET scan**

Positron Emission Tomography (PET) uses a tracer, which is a small amount of a slightly radioactive sugary substance (FDG), to detect abnormalities in the body. The intake of this tracer makes infections and malignant tumours visible. A PET scan is often combined with a CT scan. **Used for:** detecting metastases (spreading of cancer cells) or checking how the patient responds to therapy.

○ **RX/radiography**

Radiography (RX) uses X-rays to create a flat 2D image of the body. In most cases, the radiologist makes two pictures: one from front to back (face) and one from left to right (profile). Bones and other dense tissues, rings, buttons and bra hooks absorb much radiation and appear white or transparent on the X-ray against a black background. Air and soft tissues such as lungs, skin, and blood let more X-rays pass

through and appear dark or grey. **Used for:** searching for swollen lymph nodes around the heart, diagnosing pneumonia, checking for bone fractures or other bone abnormalities, determining bone age (which gives an idea of growth potential), and so on.

Examinations and tests

With children, doctors will usually carry out the tests below (except for blood tests) under anaesthesia (like MEOPA or midazolam).

○ **Biopsy**

A biopsy is a small sample of tissue taken from the body to examine more closely under the microscope.

○ **Blood sample**

A blood sample examines hormonal and metabolic parameters such as glucose levels, cholesterol, and salts. This allows doctors to assess the liver, thyroid and kidney functions. A blood count of the sample consists of counting white and red blood cells, and platelets.

○ **Bone marrow puncture/aspiration**

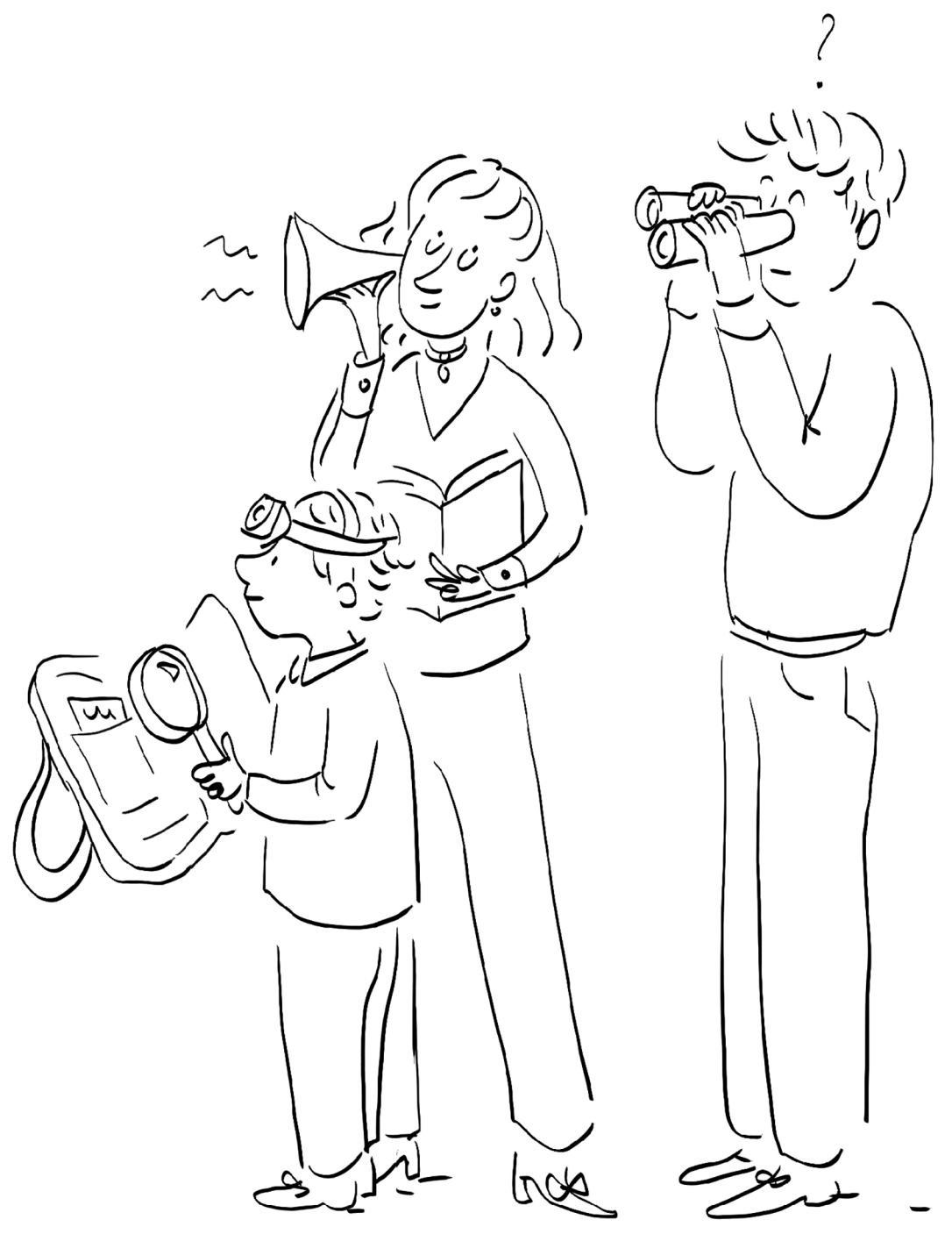
During a bone marrow puncture, the doctor uses a hollow needle to extract some bone marrow for examination. This technique is mainly used to examine whether the bone marrow produces normal amounts of blood cells.

○ **Bone biopsy**

When bone particles are removed during a bone marrow puncture, this is called a bone biopsy. The sample is then examined in the lab.

○ **Lumbar puncture / spinal puncture**

During a lumbar puncture, a needle is inserted in



the lower back between two spinal vertebrae to remove a sample of “cerebrospinal” fluid from the spinal canal.

Cancer therapies

When discussing various treatment options with your child’s oncologist, you will encounter some of the terms below.

Types of therapies

○ Curative therapy

Curative therapy is intended to cure or at least “bring the patient into remission”, which means “slowing down the disease”.

○ Supportive therapy

Supportive therapy eases side effects such as pain, bleeding, and nausea. It can be provided at any stage of the disease. For more info about its different types, see further below.

○ Palliative therapy

Palliative treatment does not cure the disease. Instead, it aims to improve the patient’s comfort and quality of life and can sometimes extend life. Palliative treatment can slow down the disease, ease symptoms such as pain, and prevent complications caused by the tumour, such as infections and bleeding.

Most common therapies

○ Chemotherapy

Chemotherapy uses drugs (cytostatics) to destroy cancer cells or at least stop their growth. The patient can take these drugs orally or by injection (using a needle) or infusion (using a catheter) into the bloodstream. In some cases, chemotherapy drugs

can be taken locally, for example, by injecting them into the cerebrospinal fluid.

○ Neoadjuvant chemotherapy

Neoadjuvant chemotherapy is given before surgery or radiotherapy to shrink the tumour. It is also called “inductive” chemotherapy.

○ Adjuvant chemotherapy

Adjuvant chemotherapy is given after surgery or radiotherapy to destroy any remaining cancer cells. It is also called “consolidation” chemotherapy.

○ Immunotherapy

Immunotherapy is a treatment that stimulates your natural defences (immunity) to attack and destroy cancer cells.

○ Radiotherapy

Radiotherapy or “radiation therapy” uses ionising radiation to kill cancer cells while sparing healthy cells as much as possible. There are different types of radiotherapy:

- **Conventional radiotherapy** uses X-rays or photon beams in high doses to destroy tumour cells. Photons are the basic units that make up all light. They don’t have mass, so they can pass through the body and will not stop inside the tumour, which may affect surrounding tissues. With photon radiation, oncologists can minimise, but not eliminate, the radiation dose on neighbouring tissues and organs.
- **Proton therapy** uses proton beams to destroy tumour cells. Protons are basic particles found in all atoms. Their properties allow doctors to better adapt radiation to the tumour’s size and shape. Unlike photons, protons have a mass, so they can be stopped at a certain depth inside the body. This better spares surrounding tissues, making

proton therapy more precise than conventional radiotherapy.

- **FLASH radiotherapy** is a novel technology that uses a single ultra-high dose rate. Compared with conventional dose-rate irradiation, FLASH irradiation is 400-fold more rapid so that it can be delivered in fewer doses and a shorter period.

○ **Resection**

Resection is the surgical removal of a part of a tissue or organ. In this context, the removed part is the tumour.

○ **Stem cell transplantation**

When the bone marrow produces abnormal amounts of white blood cells, they are called “cancer cells”. The ill-functioning marrow needs to be replaced by a healthy one through bone marrow or stem cell transplantation.

Less common therapies

The therapies below are less common but helpful to mention.

○ **Cancer vaccines**

Unlike conventional vaccines that prevent you from becoming ill, cancer vaccines are designed to cure when you are already ill. Cancer vaccines do so by teaching the immune system to recognize and attack cancer cells. Doctors also call them “therapeutic vaccines” to distinguish them from preventive vaccines.

○ **Gene therapy**

Gene therapy cures diseases at the genetic level. It repairs or replaces a defective gene causing the disease with a functional, healthy copy of that gene.

○ **Inhibitors**

Inhibitors are a form of targeted therapy. They inhibit the signals that allow cancer cells to grow. Different types of inhibitors act on different signals from cancer cells.

Supportive therapies

Cancer patients often require supportive care alongside their main cancer-curing therapy. Supportive medication reduces suffering from side effects and helps to better bear the treatment. It can be used for both prevention and cure. Preventive supportive medication wants to prevent complications, while curative supportive medication wants to cure complications, such as an infection.

The most common supportive therapies:

○ **Antiemetics**

Antiemetics are drugs for nausea and vomiting. You can take them orally or by infusion. Antiemetics are used curatively or preventively together with chemotherapy to avoid side effects. They can vary in mechanism, strength and dose. For example, the stronger the chemo, the more antiemetics may be needed.

○ **Antibiotics**

Antibiotics are drugs that fight infections caused by bacteria or other microorganisms. During cancer treatments such as chemotherapy, the number of white blood cells often drops significantly. This temporarily weakens the immune system, which increases the risk of infections. In case of an infection, you may need to take antibiotics several times a day, orally or by infusion. Antibiotics are also used preventively when your immune system is simmering.



○ **Broad-spectrum antibiotics**

When your blood shows abnormally low concentrations of neutrophils (a type of white blood cell), your resistance will be virtually non-existing. When you have a fever in such a “neutropenic” period, the doctor will immediately give you broad-spectrum antibiotics by precaution. These antibiotics treat a broad spectrum of bacteria or germs and are extremely important to help your body fight the infection.

○ **Corticosteroid therapy**

Corticosteroid drugs are synthetic hormones that closely resemble cortisol, a hormone naturally produced by your adrenal glands. Cortisol controls many bodily functions, such as the immune system and blood pressure. Corticosteroid drugs are used to treat cancer, temper your immune response and reduce inflammation (for example, after a bone marrow transplantation). They also reduce nausea during chemotherapy, or can even improve your appetite. However, corticosteroid drugs also have several side effects, such as mood changes, muscle weakness, increased growth of body hair, a puffy face, and sleeping difficulties.

○ **Vitamins and minerals**

Taking vitamins and minerals can give you a boost during heavy therapy and prevent you from developing deficiencies. For example, you will need calcium tablets and vitamin D preventively during corticosteroid therapy.

○ **Laxatives**

Laxatives are used against constipation or hardened bowel movements. They can be given preventively to avoid harder bowel movements or curatively in case of a bowel obstruction problem.

○ **Ointments and creams**

Ointments and creams can have a pain-relieving (analgesic), moisturising, or restorative effect. Examples are skin-anaesthetising EMLA or Rapydan ointments to reduce puncture-related pain. Other examples are Dexeryl cream, which keeps the skin from drying out, and haemorrhoid ointments to soothe fissures or lumps inside and around your bottom (anus).

Treatment lingo

○ **Alopecia**

Alopecia is partial or complete hair loss (head, eyebrows, eyelashes, beard, underarm hair, pubic hair). It is a side effect of some chemotherapy drugs (on the whole body) and radiotherapy (only on the body part under treatment).

○ **Blast cell**

A blast cell or “blast” is an immature blood cell. Different types of blast cells develop into different types of blood cells. For example, lymphoblasts develop into lymphocytes and erythroblasts into erythrocytes. In the case of “leukaemia”, the number of blast cells has become too high due to their uncontrollable growth.

○ **Cell**

A cell is the smallest part of an organism (living being) that contains all its genetic information or DNA. Each cell contains metabolism processes, which are vital to the organism’s growth.

○ **DNA**

Each living cell contains DNA or deoxyribonucleic acids, which are large molecules that contain all its genetic information. DNA carries the instructions for

the structure, function and behaviour of the cell and is essential for all known life forms.

- **Fertility**

Fertility is the ability to conceive children. Some cancer treatments can harm fertility, so it is important to discuss this beforehand. Together with your doctor, consider the risks and perhaps freeze reproductive cells.

- **Karyotype**

The karyotype or “karyogram” is a microscopic picture of the chromosomes (DNA carriers) at a specific stage of cell division. By studying the karyotype of one cell, you can find deviations in the number or shape of the chromosomes. In the karyotype of a tumour, you can also see deviations which refer to its malignant or benign characteristics.

- **Metastasis**

A tumour growing in healthy tissue is called a “primary” tumour. Sometimes tumour cells escape and spread through the bloodstream or lymphatic system to other body parts. They may further develop there into secondary tumours. This spreading of cancer cells to other body parts is called “metastasis”.

- **Mutation**

A mutation is the permanent modification of a gene. We all inherit genetic mutations, but they may also originate during our lifetime. Mutations can also occur in tumours, making them either more malignant or more benign.

- **Neutropenia**

Neutropenia means a lack of “neutrophils”, which are the white blood cells that protect us from infections. Neutrophils are essential for our immune system: they help fight diseases and protect us by

destroying bacteria, viruses and fungi. A deficiency of neutrophils leads to increased susceptibility to infections, especially bacterial ones.

- **Organ**

An organ is a set of tissues within an organism with one or more functions. Examples of organs are the skin, the intestines, the kidney, the liver, the bone marrow, and so on.

- **Prognosis**

A prognosis is a likely course or outcome of a disease. It estimates the chance of recovery and recurrence. Of course, every situation is different. A prognosis depends on many factors, such as the type of cancer, the stage of the disease at diagnosis, and so on.

- **Stem cell**

Stem cells are the mother cells of all other cells. For example, almost all your (white and red) blood cells developed from the “haematopoietic” stem cells in your bone marrow.

- **Tissue**

A tissue is a cohesive group of similar cells. For example, muscle tissue consists of muscle cells. The term histology refers to “tissue research”.

End of treatment

- **Follow-up (FU)**

After your therapy, you need to see your doctor regularly for control tests. This follow-up examination is necessary to evaluate your health and well-being after treatment.

- **Remission**

Remission means that medical examinations show no abnormalities. No more cancer cells are detected in your body anymore. However, to be considered completely cured, an additional period needs to pass.

- **Relapse**

Relapse means that the cancer cells reappear after a period of remission.

- **Predisposition**

Genetic or hereditary predisposition means you have an increased risk of developing a particular disease or disorder because of hereditary factors. However, this does not mean that you have or will ever develop the disease or disorder.

Interpretation of blood results

How come my child's blood results are good despite the red numbers?

Don't panic when a blood test shows red numbers. Red indicates that the results don't fall within the range of healthy blood values, but this is quite common among cancer patients. It doesn't imply that your child is doing badly; the result may even be very good.

What are the different blood cell types?

All humans have three types of blood cells which perform different tasks in our bodies:

○ Platelets (thrombocytes)

Platelets are important to stop bleeding. When you have a wound, platelets create blood clots that halt the bleeding.

○ Red blood cells (erythrocytes)

Red blood cells (erythrocytes). Red blood cells transport oxygen to all the cells of your body. If the cells in our organs don't get enough oxygen, they cannot work properly and you will become tired.

○ White blood cells (leukocytes)

White blood cells are your immune cells. They are very important in fighting all kinds of infections. They protect your body from foreign harmful substances such as viruses, bacteria and fungi.

When is a blood transfusion needed?

During a blood transfusion, you receive extra blood via an infusion. A transfusion may be necessary when you have a shortage of red blood cells or platelets. Usually, the blood comes from a blood donor, but sometimes it can be your own blood.



Why are neutrophils important?

Neutrophils are a type of white blood cells that are essential for your immune system. They help fight diseases and protect you by destroying bacteria, viruses, and fungi. A lack of neutrophils is called 'neutropenia'. This deficiency leads to an increased susceptibility to infections, especially bacterial ones.

What is the function of the liver?

The liver has several essential functions. A doctor can detect whether your liver is disturbed by testing and analysing your blood.

A healthy liver

- regulates the sugar, fat and protein metabolism;
- helps to stop internal bleeding;
- makes bile, which is needed to digest fats;
- breaks down certain endogenous hormones;
- detoxifies toxic substances;
- stores iron, sugars, fats and specific vitamins;
- contributes to the production and breakdown of red blood cells.

What is the function of the kidneys?

The kidneys consist of millions of tiny filters. Your blood constantly flows through these filters, which remove excess waste and water. Various tests can assess your kidneys' purifying function by measuring two critical parameters: the creatinine concentration and Glomerular Filtration Rate (GFR):

- **Creatinine** is a degradation product of the muscles. Your kidneys continuously filter creatinine from your blood and excrete it via urine. Therefore, the concentration of creatinine in the blood is a suitable parameter

for the functioning of the kidneys. If your blood contains too much creatinine, your kidneys are not working as they should.

- **The Glomerular Filtration Rate (GFR)** can be estimated from the creatinine value in the blood. The GFR number indicates how much blood your kidneys can filter per minute. In a healthy person, this is more than 90 millilitres per minute. The GFR value decreases when you get older.

What are electrolytes?

Electrolytes are substances in your blood and other body fluids that carry an electrical charge. They help your cells to absorb nutrients and get rid of waste products. Electrolytes keep your body fluids balanced and ensure that your muscles function properly. Examples of electrolytes are calcium, chloride, potassium and sodium.

Context of paediatric cancer



Paediatric cancer is a rare disease, which has an impact on how it is treated and cured. This section tells more about the context of children's cancer.

All paediatric cancers are rare

There are about 16 main types of paediatric cancer, such as leukaemia, brain and spinal cord tumours, neuroblastoma, lymphoma, rhabdomyosarcoma, osteosarcoma, and so on. Furthermore, each type is divided into additional subgroups, adding up to about 60 different subtypes of paediatric cancer in total. In general, all these paediatric malignancies are different from adult cancers (even when they have the same name, they may belong to a different subtype). Therefore, each paediatric cancer requires dedicated scientific attention and unique treatment.

International standards of care

Most children with cancer are treated according to the same international "standards of care". These standards describe the safest and most effective treatments based on the most up-to-date scientific knowledge. They are agreed upon by specialised European and international medical expert groups who base their recommendations on the results of clinical studies (Clinical Trial Groups).

Clinical trials

Clinical trials are a form of research that allows doctors to improve treatments and reduce their side effects (or "late effects"), thus improving patients' survival rates and quality of life. There are two types of clinical trials: therapeutic and non-therapeutic. Therapeutic clinical trials test a new treatment on patients and evaluate the results. Non-therapeutic

trials don't treat patients but study factors that help to understand cancer and its impact better. A new treatment must go through the three phases of a clinical trial to be sure that it works and is safe. There is a fourth additional (optional) "late-phase" clinical trial during which standard treatments (current best) are tested against promising alternatives. You can only take part in a clinical trial if you sign a written consent with all the information you have been given about the study (informed consent).

Clinical trials for children

Because childhood cancers are rarer than adult cancers, much less is known about appropriate treatments and long-term impacts. Clinical trials and international scientific collaboration are, therefore, standard practices in cancer treatment for children, adolescents and young adults. Even at diagnosis, most young patients are eligible for treatment in late-phase clinical trials. Participation in such trials is strongly encouraged by paediatric haemato-oncologists and is even considered part of the standard of care. When no "open" late-phase clinical trials are available, patients are treated according to the treatment protocol internationally considered the best (most efficient and least toxic) by the most recent, late-phase (closed) clinical trials.

Arms of a clinical trial

Clinical trials involve several "arms" or groups of randomly selected patients. Each arm receives a different treatment. "Experimental" arms receive the new experimental treatment, while "control" arms receive the current best "standard" treatment. Doctors will compare the medical outcomes of both arms to evaluate the effectiveness of the new experimental treatment.

Online resources



How to identify reliable online resources?

When diagnosed with cancer, most patients will naturally search the web for additional information (even when advised not to do so). Unfortunately, the web is full of wrong information, which can endanger the quality of a patient's treatment. Some websites offer miraculous cures without side effects, calling themselves medical experts and trying to convince you through false testimonies from "happy" patients. Unfortunately, they are based on pseudoscience and are mostly too good to be true. Under all circumstances, your health physician should remain your most important source of information.

Below are a few questions that can help you to detect misleading or inaccurate information online. Please be alert if you can't answer these questions or find product marketing cues.

- Is the purpose of the website clear? (e.g. education, product marketing.)
- Who is responsible for the content of the website?
- Does the website represent a well-known and respected organisation?
- Is the website published by a reliable source (e.g. a university, medical facility, government, company, or society)?
- Is the information impartial and one-sided? Be wary of "ideological" sites (e.g. anti-vax, conspiracy theory websites, etc.). Most of them present information in a very pushy way and mimic objectivity, which can be very misleading.
- Do you find evidence on the website from high-standard, peer-reviewed scientific journals supporting the claims? You can find such journals on PubMed, a free database for medical research
→ <https://pubmed.ncbi.nlm.nih.gov>.
- Has the website been updated recently?

Trustworthy resources

You can find a list of websites providing quality-approved scientific information about paediatric cancer here: → <https://kickcancer.org/patients/resources>. These websites have been analysed and verified by expert patients, the Anticancer Fund, the Belgian Society for Paediatric Haemato-Oncology and KickCancer.



