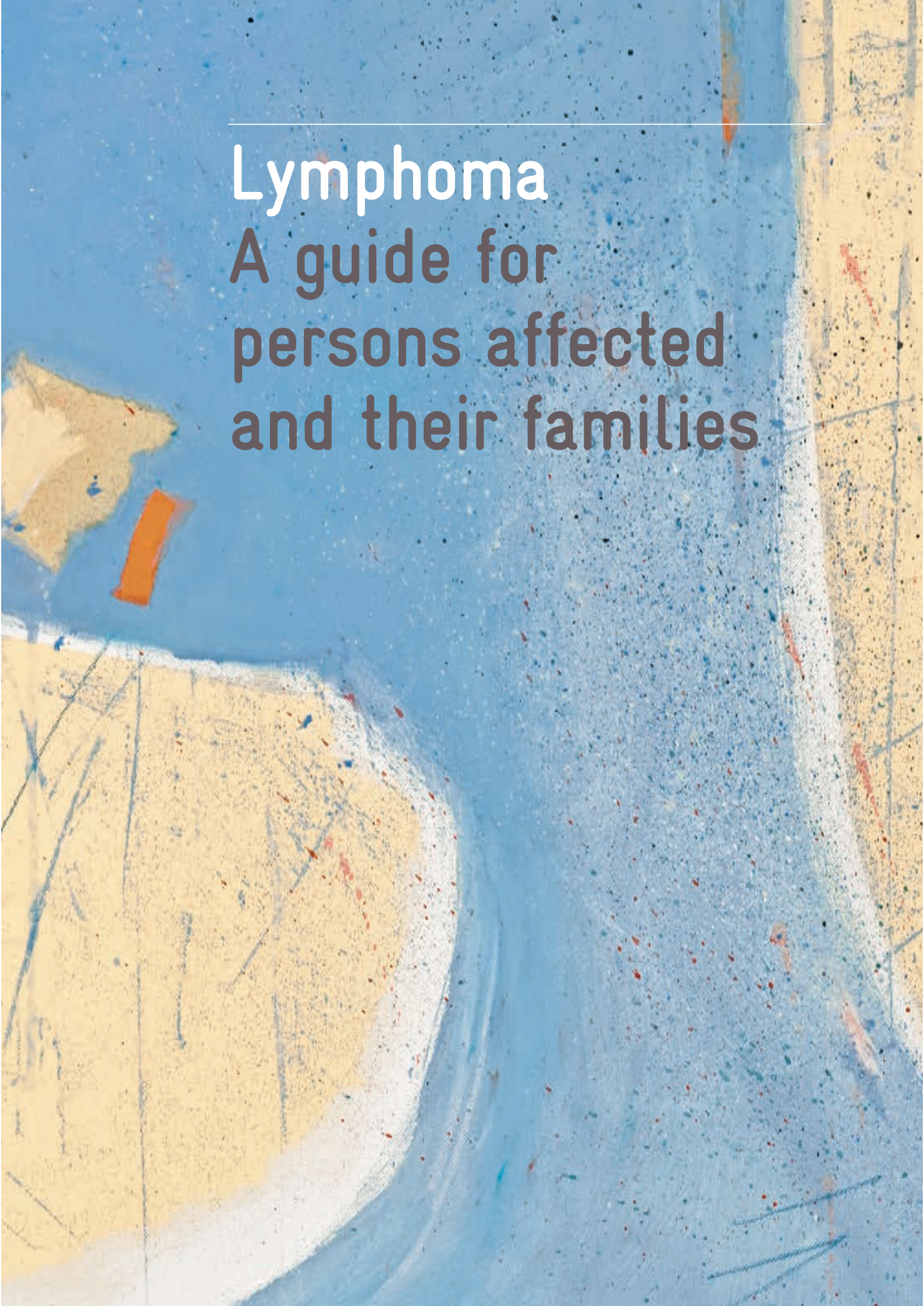


Lymphoma
A guide for persons affected and their families

Imprint

Text and editing
Mathis Brauchbar, Adrian Heuss, Prof. Andreas Lohri, Rosmarie Pfau
Prof. Christoph Mamot, Kantonsspital Aarau (DLBCL - Diffuse Large B-Cell Lymphoma)
Prof. Andreas Lohri, Kantonsspital Baselland, Liestal (HL - Hodgkin Lymphoma)
Dr. Christian Taverna, Kantonsspital Münsterlingen (FL - Follicular Lymphoma)
Dr. Michael Gregor, Kantonsspital Luzern (CLL - Chronic Lymphatic Leukaemia)
Prof. Dr. Emanuele Zucca, Ospedale Regionale, Bellinzona (MZL - Marginal Zone Lymphoma)
Prof. Mario Bargetzi, Kantonsspital Aarau (MW - Waldenström's Macroglobulinemia)
Prof. Christoph Renner, Onkozentrum Hirslanden, Zürich (TZL - T-Cell Lymphoma)
PD Dr. Felicitas Hitz, Kantonsspital St. Gallen (Rare Lymphomas: E - Extranodal involvement, BL - Burkitt's lymphoma, PML - Primary mediastinal B-cell lymphoma, HIV-associated lymphoma)

Design and production
Continue AG, Basel / Christine Götti, Therwil

Translations
Sophie Neuberg (F), Marco Altrocchi, Ellis D'Elia (I), ITC Global Translations USA, Inc. (E)

For further copies please contact
lymphome.ch – patientennetz schweiz, Weidenweg 39, CH-4147 Aesch
Tel. +41 (0)61 421 09 27, info@lymphome.ch

© 2020 – 1st edition (E), lymphome.ch – patientennetz schweiz
Note: «lymphome.ch patientennetz schweiz» is the new name of «ho/noho»,
the former Swiss patient organisation for lymphoma patients and their families.

We would like to thank all those who have supported us in the preparation of this guide.
The following companies have made the production of the guide financially possible:
Amgen Switzerland AG, Celgene GmbH, Janssen-Cilag AG, Mundipharma Medical Company,
Roche Pharma (Schweiz) AG and Takeda Pharma AG – Many thanks!
The companies had no influence on the contents.

This brochure may not be copied or translated without the prior consent
of lymphome.ch patientennetz schweiz.

Sources
For references please contact: info@lymphome.ch

About the collages in this brochure
Christine Götti is a trained graphic artist and painter, lives in Therwil (BL) and works in Bottmingen (BL). In 1999 she was diagnosed with lymphoma. After numerous chemotherapy series, operations, and finally a stem cell transplantation, she is currently living relatively free of ailments.

Christine Götti has chosen the technique of collage for the pictures created especially for this brochure. For example, she uses gauze (as a medical element) and she works strongly with contrasts – large and small, warm and cold. Contrasts that also characterise life with the disease. With her paintings she wants to delight the viewers with colours and shapes – and let them immerse themselves in a harmonious tension for a short moment.

www.christine-goetti.ch

Lymphoma
a guide for persons affected and their families

4 Dealing with side effects

5 Work, care, support and assistance

6 Frequently asked questions

7 Patient rights and insurance

Part II The most common lymphomas

8 Diffuse, large B-cell lymphoma

9 Mantle cell lymphoma

10 Hodgkin lymphoma

11 Follicular lymphoma

12 Chronic lymphatic leukaemia

Dear reader,

You are probably reading this brochure because you or one of your relatives has been diagnosed with lymphoma. Perhaps you simply want to find out about lymphoma diseases. Whatever the reason for reading this brochure, we as authors are committed to promoting understanding of this disease. There are many forms of treatment for lymphomas, and often a cure is possible.

In addition to medical information on lymphomas, this brochure also contains information on treatment options, health insurance and social insurance law, the services offered by patient organisations and much more.

We are proud to present the third edition of this lymphoma brochure. Many things have been updated since the last edition. There are new therapeutic options for most lymphoma types. We do not want to go into too much detail about the treatments; you should discuss them with your doctors. But we will try at least to describe the latest therapeutic approaches in a little more detail. These texts were written by physicians who have often dealt with the respective diseases. This brochure describes the most common lymphomas (except multiple myeloma, information on which can be found at www.multiples-myelom.ch).

I would like to thank all those who were involved in this edition: Rosmarie Pfau, the President of Lymphome Patientennetz Schweiz, the Swiss Patient Organisation for Lymphoma Patients, Christine Götti, who illustrated the brochure with her pictures, the eight experts for the additional chapters, Adrian Heuss, who revised the texts, and last but not least the sponsors, without whom this third edition would not have been possible.

The information in this brochure is also available on the Internet on the Swiss Patient Organisation for Lymphoma Patients website (www.lymphome.ch).

Prof. Dr. med. Andreas Lohri
Oncology and Haematology
Onko-Praxis Bethesda
CH 4127 Birsfelden

Dear Reader,

You have recently found out you have lymphoma, or you are affected indirectly, as a relative or friend.

We have compiled this brochure to help you, your family and your friends to better understand your lymphoma disease and to make sure you are not alone when you first start dealing with the lymphoma diagnosis.

You may feel overwhelmed by feelings of anxiety and uncertainty so soon after the lymphoma diagnosis. If you or someone close to you has received this diagnosis, you should not despair. From my own experience, I can tell you that many fears can be put into perspective if you are well informed about the disease and its associated symptoms, the treatment options and possible therapy side effects.

It is absolutely natural that confronting a cancer diagnosis triggers existential fears on many levels. Deal with this fear and look for «your» strategy for living with the disease and the associated uncertainties.

Perhaps you have already started treatment or you have been discussing the most suitable therapy scheme for you with your doctor. Whatever point you are at the moment, I hope that the information in this brochure will answer some of your questions. It is possible that further questions may arise while reading. Do not hesitate to clarify your questions with your doctor, as this brochure cannot and should not replace those conversations.

It is possible that you may not feel able to read the booklet from cover to cover at the moment. That doesn't matter. Just concentrate on the chapters that are relevant for you today.

This guide is intended to guide you through your treatments. However, the purpose of this brochure is not to recommend a particular form of treatment, as your personal situation will be assessed by your attending physician and her/his team throughout the treatment phase and the necessary steps will be discussed with you.

I hope that this brochure will help you to cope well with the therapy phases and the possible side effects associated with them, and I wish you much courage and confidence for what is to come.

Rosmarie Pfau
President of lymphome.ch
patientennetz schweiz

1 Basic information

1 Managing the disease

1.1 Uncertainty after diagnosis

Cancer is one of the most common causes of death in our population and many people believe that the diagnosis of cancer is synonymous with imminent death. However, this is not the case. Almost half of all people with cancer can be cured. Many forms of lymphoma are curable as well.

It is very important that those affected do not feel that they are alone. Therefore, do not keep a diagnosis to yourself, instead, confide in your relatives or close friends; talk about your fears and anxieties – this will help those around you to deal with the fact better.

Relationships between people can change greatly after a tumour diagnosis. Life in relationships or in families can suffer greatly from this. The quality of life of those affected, their self-esteem and satisfaction in the relationship with their partner are often considerably impaired. Neither anger nor withdrawal help with these changes, only open dialogue. When problems are laid out in the open, people can get closer, focus on what is important, and a relationship can become stronger.

« Almost half of all people with cancer can be cured. There are many forms of lymphoma that are curable. »

«If only I hadn't smoked! If only my diet had been healthier!» Such self-reproaches can arise after a diagnosis. There is no reason to rob yourself of energy with negative thoughts, because nobody can know for sure what caused the lymphoma.

1.2 Knowledge instead of fear

Knowledge is one of the greatest weapons for conquering fear: You can counter your anxiety by getting information – about the disease itself, treatment options and the chances of success. Your primary contact person for specific information is your attending physician. He or she is best informed about the course of the disease. Books, the Internet, sharing experiences in self-help groups and the regional cancer leagues can provide further information. As an informed patient, not only can you effectively counter your anxiety, but you can also understand why your doctors suggest a particular treatment. In this way you can decide together with your doctors which therapy should be used. You will stand behind your decision and start your therapy with confidence and hope.

Participating in a self-help group can help you understand and process your own fear. You'll find that other people affected have as many ups and downs as you have.

Coping with fear is a process, with alternating feelings of hopelessness and confidence. You will take many small steps over a long period of time. It is important to be patient, and not to despair when old fears reappear.

Participating in a self-help group can help you understand and process your own fear.

1.3 Open discussions are important

It is very important that you – whether you are a patient or a family member – talk about fears and insecurities. Know that you can be of great help to each other and that you can bear the burden of the disease together if you are open and honest with each other. Clarifying practical matters also helps to prevent misunderstandings: What kind of help would you like to receive as a sick person in everyday life? To what extent do you want to be relieved of everyday tasks? Maybe conflicts arise because you feel superfluous. Everyone is unfamiliar with the situation and it is therefore always important to discuss the needs and wishes of each individual.

> Instead of fear, hope, the courage to live and the will to survive can develop.

1.4 When conversations are difficult

If you find it difficult to talk about your illness, a support group can be very helpful. Talking and listening in the group helps you to understand and process your own fear. You will find that other people with cancer have as many ups and downs as you do and that it is possible to live well with the fact that you have cancer. Many patients report that they first learned to talk about their disease by talking to other patients. More on this topic in section 5.5.

1.5 Conscious living

A lymphoma diagnosis changes lives. The disease is a drastic experience. What was previously important now seems unimportant – and vice versa. Those who manage to overcome their fear and replace it with hope often see the disease as an impetus to a more conscious life.

The aim is not to repress the illness and the fears associated with it. It is rather a matter of accepting and coping with the disease. Instead of fear, hope, the courage to live and the will to survive can develop.

Tips for dealing with fears

Cancer is often a long-term burden that is associated with fear and stress. Feelings of anxiety and fears can occur time and again: Fears of expectation in diagnosis, fear response in the case of short- or long-term drug therapy, fear and uncertainty regarding the consequences. You should be aware that these are normal fear responses.

In order to reduce anxiety to a tolerable level, here are a few approaches that have proven effective in dealing with stressful situations.

Remain realistic

Try to remain realistic despite all your fears. Observe and describe inwardly what is happening around you. Do not reinforce fear responses with frightening imaginary situations.

Stop brooding

Take your mind off things, distract yourself.
Read a book, put on your favourite music, talk to friends, go to the cinema, do something that you enjoy, maybe something you've wanted to do for a long time but haven't taken the time to do.

› **Lift your spirit**

Setting goals that have nothing to do with the disease gives a boost. These goals can be professional, family related, or a leisure activity. You are not simply a tumour patient, but a person with a wide range of wishes and needs, characteristics and abilities. When fear overcomes you again, think about your goals and imagine how you will feel when you have achieved them.

Think about yourself

If you are feeling anxious, consider doing something that is good for you. This makes you feel relaxed and satisfied instead of afraid and uncomfortable.

2 Medical information

2.1 Diseases of the lymphatic system

The term lymphoma actually refers to an enlarged lymph node (colloquially called a lymph gland). In medicine, malignant diseases of the lymphatic system are called malignant lymphomas. For simplicity's sake, we will call them lymphomas here. In the vernacular, one also speaks of lymph node cancer. This term can be misleading because a malignant lymphoma can attack individual organs without affecting the lymph nodes. Depending on the place of origin, one speaks, for example, of a lymphoma of the bone, the lung or the stomach.

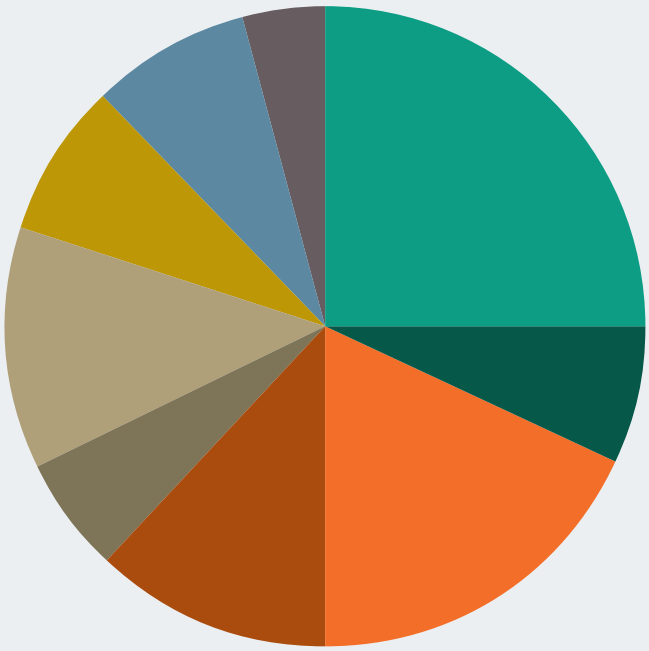
In 1832, the British physician Sir Thomas Hodgkin described a cancerous disease of the spleen and lymph nodes for the first time. However, it was later recognised that only about 10 percent of cancers of the lymphatic system can be assigned to the disease Hodgkin had described. The other 90 percent were therefore grouped under the

Indolent and aggressive lymphomas

Since indolent lymphomas show few symptoms at the beginning and as these lymphomas grow slowly, they are often only discovered at an advanced stage. The treatment of these lymphomas is often determined individually. The beginning of the treatment can also only be determined individually.

In aggressive lymphomas, the enlarged lymph nodes can be painful. Often, other symptoms such as weight loss or night sweats develop. Aggressive lymphomas must be treated quickly. In many cases treatment leads to a cure.

Classification and frequency



- Large cell B-cell lymphoma (A) 25%
- Marginal zone lymphoma (I) 7%
- Follicular lymphoma (I) 18%
- Chronic lymphatic leukaemia (N) 12%
- Sheath cell lymphoma (N) 6%
- Multiple myeloma (N) 12%
- T-cell lymphoma (N) 8%
- Hodgkin lymphoma (N) 8%
- Rare lymphomas <4%

  Burkitt's lymphoma (A) <1% / hair cell leukaemia (I) 1% /
  Waldenström's macroglobulinemia (I) <1% /
  Extranodal involvement (N) <1% /
  Primary mediastinal B-cell lymphoma (A) <1% /
  HIV-associated lymphoma (A) <1%

(I): is mostly indolent
(A): is predominantly aggressive
(N): not clearly assignable

collective term «Non-Hodgkin lymphomas». Today, the World Health Organization (WHO) classifies more than 60 different lymphoma types.

Even today there are still no common names for many types of lymphoma. You try to group them together. The group of indolent lymphomas (indolent means «causing little pain») includes lymphoma types that progress slowly but steadily, usually over years or decades. Aggressive lymphomas progress faster, cause symptoms within a few weeks and can lead to serious problems if not treated on time.

2.2 The lymphatic system

The lymphatic system (also known as lymphoid system) is not a single organ, it pervades practically the entire body and is part of the body's own defence system, the immune system (see diagram on p. 26). The spleen, bone marrow, the lymph nodes and lymph vessels form the basic anatomical structures. These structures are populated by lymph cells (lymphocytes), which can reach the whole body via blood and lymph vessels. These lymph cells, which belong to the white blood cells, are responsible for immune defence.

The lymphatic system has two main functions

1. Defence against bacteria, viruses and toxins that threaten the human organism. For example, if the hand or arm is inflamed, lymph nodes in the armpit can swell and hurt. This is a sign of an ongoing immune reaction. Or: When influenza viruses attack lymph cells, the lymph cells produce antibodies that trigger fever as a «side effect».

What is cancer?

The human body develops from a fertilised egg cell. Through the division of cells and their specialisation, body shapes and organs are created. This development requires a finely tuned process. Cells know when to divide and when not to divide. Some organs consist of cells that renew themselves quickly, and other cells have a long life span. Cancer occurs when cell growth gets out of control. The cells divide and multiply uncontrollably.

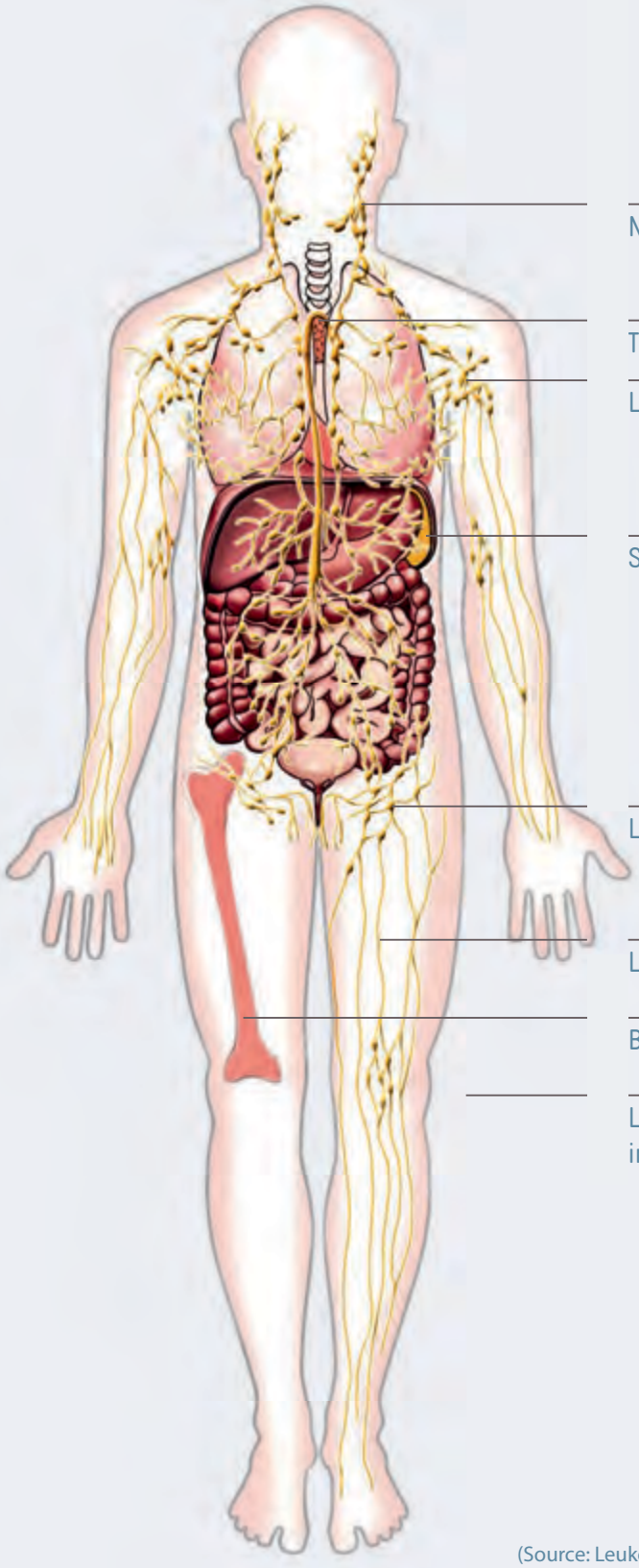
Cancer is an umbrella term for malignant diseases.

It is a collective term for hundreds of diseases of all organ systems, because cancer can develop in any tissue. Usually, cancerous tissue initially develops in one part of the body. Later, however, it can form offshoots in other parts of the body, which are called metastases (in the case of lymphomas, however, one does not speak of metastases, since the lymphatic system is distributed throughout the entire body). Lymphomas can occur in different organs at the same time; for example, the lungs and liver can be affected.

If a cancer is not treated, it leads to death.

Today however, many cancers can be cured, especially if they are detected early. Certain types of cancer can be cured even in advanced stages. This also includes some types of lymphoma.

The lymphatic system



Neck lymph nodes

Thymus

Lymph nodes in the armpits

Spleen

Lymph nodes in the groin

Lymphatic vessel

Bone marrow

Lymph nodes
in the back of the knee

(Source: Leukemia & Blood Foundation, New Zealand)

2. The distinction between foreign and one's own tissue. Certain immune cells guard and recognise their own body tissue and defend against foreign ones. If, for example, an organ is implanted in a human being, it is rejected by the recipient's body. This rejection reaction is controlled by the immune system. With the help of drugs that suppress this rejection (immunosuppressants), organ transplants have nevertheless become possible today.

2.3 Development of lymphomas

The immune system consists of different cell types. The most important in relation to lymphomas are the B and T cells.

- B cells produce biological defence substances, the antibodies. Antibodies can recognise foreign tissue or pathogens such as bacteria and viruses, and subsequently trigger an immune response.

- T cells can bind directly to foreign substances and then produce cell-destroying substances such as interferon or interleukin.

There are billions of these T and B cells in the body. They protect and monitor the body. But they have to be renewed constantly. This is done by dividing the cells. This cell propagation takes place according to a precisely prescribed pattern. Which cells are allowed to divide when is strictly controlled. If this process is disrupted, the immune cells may proliferate uncontrollably. As a result, lymphoma can develop.

2.4 Causes of a disease

«Is it my fault that I have lymphoma?» Many patients ask themselves this question. The answer is: «No» However, there are certain risk factors that can increase the likelihood of developing lymphoma. Most of these factors cannot be influenced.

- The fine regulation and repair mechanisms of cell division begin to become more unreliable with increasing age and malformations result. With increasing age, therefore, the probability of developing lymphoma increases. Hodgkin lymphoma is an exception: Hodgkin lymphomas are often detected in patients around the age of 30.

«Is it my fault that I have lymphoma?» Many patients ask themselves this question. The answer is: «No»

- In rare cases, a pre-existing viral infection leads to cancer (Epstein-Barr virus, HIV, HTLV-1 and hepatitis B and C).

- The rare MALT lymphoma of the stomach (MALT stands for mucosa-associated lymphatic tumour) is caused by the Helicobacter pylori bacterium. This bacterium also causes stomach ulcers. Fortunately, it's becoming increasingly rare.

- In the USA it has been found that farm workers directly involved in the spraying of certain agrochemicals are more likely to develop lymphoma.

- Under long-term therapy with drugs that suppress the immune system (immunosuppressants), lymphomas can occur more frequently. Drugs such as these sometimes have to be taken for life after organ transplants.

- Rare hereditary diseases also result in an increased incidence of lymphomas.

2.5 Frequency of lymphomas

Lymphomas are responsible for about three percent of all cancers. In Switzerland, more than 1700 people fall ill each year – men are affected slightly more frequently than women.

Lymphomas have become more common in recent decades. Very little is known about the reason for this increase, although research in this area has been going on for decades.

2.6 Symptoms of lymphoma

Lymphomas often grow unnoticed for a long time. When the first symptoms appear, they usually do not directly indicate lymphoma. A cold or an infection can be a sign of lymphoma, but of course not every cold is due to lymphoma. If signs of influenza persist for longer than one or two weeks and do not subside, a visit to a doctor is advisable in any case.

« When in doubt, swollen lymph nodes should be shown to a doctor. »

In some cases, swollen lymph nodes are the reason for the first visit to the doctor. Lymph nodes generally do not grow more than one to two centimetres in size, even when there is an infection. With a lymphoma, however, they can grow to over ten centimetres. With indolent lymphomas, they hardly hurt at all, but large lymph nodes on the neck can look unsightly or be troublesome in the armpit. In aggressive lymphomas, the enlarged lymph nodes can be painful. However, such pain can also occur with harmless infections or inflammations. In case of doubt, swollen lymph nodes should be shown to a specialist.

Many patients experience symptoms such as weight loss, nausea or heartburn, tiredness, paleness, general fatigue, itching of the skin, headaches, night sweats or inexplicable fever, called B-symptoms.

Enlarged lymph nodes in the abdomen or an enlarged spleen can cause a feeling of fullness. Some patients have pain in their bones, especially in their back and legs. In a small percentage of patients with Hodgkin lymphoma, the lymph nodes may hurt after alcohol consumption (also known as «alcohol pain»).

2.7 Assessments and diagnosis

The doctor will carry out a series of examinations and assessments in order to trace the causes of the symptoms. The first step is to clarify with the help of a tissue examination (biopsy) whether it is a malignant lymphoma or whether there is another cause. If the lymphoma diagnosis is confirmed, the aim is to find out what type of lymphoma it is and how far the lymphoma has spread in the body. Assessing a lymphoma can take two to three weeks. It is often necessary to wait for certain findings before further examinations are carried out. Thorough clarification is essential for further treatment. Emergency treatment is only rarely necessary.

The importance of prognoses

After the doctor has determined the type and stage of lymphoma, a prognosis for the further course of the disease can be made. However, prognoses are delicate because each person reacts individually to drugs and therapies, so that even with the same treatment, the course of the disease can vary.

Although statistics are important for your own course of disease, their significance should not be overestimated. Do not let prognosis information unsettle you. Many aggressive lymphomas have a good prognosis.

The examinations include:

- Questioning the patient (anamnesis): The doctor will ask about symptoms, previous illnesses and the patient's social environment, as this information can provide important clues for further treatment and care.

- The physical examination / biopsy: The doctors carry out a thorough physical examination. The enlarged lymph nodes are measured as size and weight are important for calculating subsequent drug doses. A biopsy is usually performed to remove cancerous tissue, which can then be examined.

- The blood test: Based on the blood count, the activity of the liver enzymes and the level of minerals in the blood, important clues can be obtained about the activity of a lymphoma.

- Imaging techniques: Knowledge of the extent of the disease determines the form of treatment. If the lymphoma is localised, therapy can usually be carried out more easily and therefore has fewer side effects. Lymphomas are therefore divided into stages (staging). Thanks to various imaging techniques, affected lymph nodes and organs can be reliably detected. In the vast majority of cases today, the most important initial examination is a PET-CT examination (positron emission tomography). In this examination, sugar metabolism is measured, as it is particularly active in tumour cells. This very precise examination makes it possible to detect even smaller affected lymph nodes. Computed tomography (CT), ultrasound and magnetic resonance imaging (MRI) are required for specific problems.

« Thanks to various imaging techniques, involvement in lymph nodes and organs can be reliably detected. »

Stage classification of lymphomas

The stage classification helps determine which treatment is necessary. Depending on the type of lymphoma, other decision criteria such as age, general condition, heart and kidney function, etc., are also taken into account.

- **Stage I** – Only one lymph node area or only one organ and no other lymph nodes are affected.
- **Stage II** – Several lymph node areas are affected, but at most a limited area of an organ outside the lymph nodes (example: individual nodes in the liver). The affected areas must be on the same side of the diaphragm.
- **Stage III** – The tumour is detected on both sides of the diaphragm (example: neck, chest and abdomen).
- **Stage IV** – There is extensive involvement of organs or bone marrow.

In Hodgkin lymphoma, each stage is additionally divided into A or B categories:

- **A-symptoms** – Absence of the three typical B-symptoms. However, this does not mean that there are no complaints at all.
- **B-symptoms** – Weight loss of more than ten percent of body weight within six months; pronounced night sweats, unexplained fever above 38°C for more than three weeks.

3 Lymphoma treatment

The chances of recovery from lymphoma depend on the type of tissue and how advanced the tumour is. Some lymphomas are curable, i.e. the cancer does not reappear after treatment. Other lymphomas respond to treatment, but relapses must be expected. The course of the disease must also be observed very closely after the treatment.

« In most cases, several methods of treatment are used. »

The choice of treatment depends on three factors:

- the lymphoma type
- the stage (spread) at which the disease is at present
- the individual patient: Age? Are there any additional diseases? What is the general condition?

Even if lymphoma has been diagnosed, it does not mean that treatment must be started immediately. If it is a slow-growing, indolent lymphoma that causes little discomfort, the doctor may suggest waiting. The patient is examined at regular intervals and treatment is only initiated if the patient's condition worsens. This procedure is called «watch & wait». The fact that therapy is not always started immediately is often very difficult for those affected. As a patient, one assumes that something must be done about such a diagnosis.

Usually, several treatment methods are used to achieve an optimal result. Every treatment can be accompanied by side effects and every patient reacts differently. Cancer treatment often leads to unwanted side effects. In the following chapters, besides various therapy options, side effects are also listed.

3.1 Surgery

The removal of a lymph node (biopsy) is necessary in order to be able to identify the type of lymphoma through microscopic examination of the tissue. Surgical intervention is therefore used to diagnose lymphomas and only in exceptional cases for therapy (e.g. removal of intestinal lymphoma in case of intestinal obstruction).

The visit to the doctor

Several specialists are often involved in the diagnosis and treatment – surgeons, radiologists, oncologists, radiotherapists, family doctors. They work together as a team. However, sometimes it is difficult for the patient to find out who is responsible. It is therefore important that you appoint a doctor of confidence. In combination therapies, this is often an oncologist. In the case of radiotherapy, the radiotherapist may temporarily be the main reference person. Your family doctor will always remain a contact person.

A good relationship with your doctor is very important during this time. It should be characterised by trust and openness. Prepare yourself for the visit to the doctor. Write down all the questions you have about your illness on a piece of paper, and take it with you to the doctor's appointment. For more information, see section 6.1 and the brochure «Questions about my lymphoma».

Second Opinions

Your doctor will take the time to answer all your questions. During the personal consultation you can ask questions tailored to your situation, dispel uncertainties, address fears and stressful feelings. If you are sufficiently informed, you can also help in making important decisions. An individual consultation takes time and mutual trust. Do not let yourself be put under pressure and do not put yourself under pressure. If you still have questions after an initial interview and do not feel confident enough to make a decision, make another appointment.

If you are not sure whether the proposed treatment is right for you, contact another specialist and ask him or her for an assessment. Obtaining a second opinion is a legitimate claim (see section 7.4). You can get a specialist's details either from your doctor or through the contact points which you will find at the end of this brochure.

3.2 Radiotherapy

Radiation therapy uses high-energy rays to destroy cancer cells and is used to treat lymphoma as lymphoma cells are very sensitive to radiation. Often, chemotherapy or immunotherapy is also carried out to increase the chances of success. Radiotherapy is usually carried out from Monday to Friday for two to four weeks. Although newer irradiation devices can irradiate affected tissue in a very targeted manner, healthy tissue is also affected. The side effects have become less severe, but are often unavoidable. Depending on the area of irradiation, these include inflammation of the mucous membranes in the mouth, oesophagus and intestines. If thyroid tissue is irradiated, a disorder of this organ can occur later.

In special cases, radiotherapy can be applied directly to the tumour cell. To do so, radioactive particles are bound to antibodies that attach themselves to the cancer cells (see section 3.5). A helpful, informative and free brochure on radiation therapy is available from the Swiss Cancer League (see section 17.2).

3.3 Chemotherapy

Older drugs used to treat cancer are called chemotherapeutic or cytostatic drugs. They reach the most remote parts of the body through the bloodstream using intravenous infusion or in the form of tablets. They inhibit cell division. However, they cannot accurately distinguish between healthy cells and cancer cells. As such, side effects occur. Over the years, some 50 different drugs have been developed. The choice of chemotherapy depends on the type of lymphoma in question. Often, several cytostatic drugs are combined to improve the effect. Possible side effects include nausea, diarrhoea, hair loss and infection with fever. Effective medication is available for nausea and vomiting. For longer treatments, a drug entry (Port-a-Cath) can be implanted (see glossary).

Treatment with chemotherapeutic drugs often takes several months. A chemotherapy cycle takes two to three weeks. The drugs are usually administered on the first or from the first to third day of a three-week cycle. For example, the drugs of the ABVD scheme are given as an infusion every two weeks (ABVD stands for the four cancer drugs adriamycin, bleomycin, vinblastine and dacarbazine). Chemotherapy is often combined with other treatments, such as monoclonal antibodies (see section 3.4). A helpful, informative and free brochure on drug-based tumour therapy (chemotherapy) is available from the Swiss Cancer League (see section 17.2).

Chemotherapeutic agents inhibit cell division and thus destroy cancer cells. The treatment regimes used depend on the type of lymphoma and the severity of the disease.

3.4 Antibody therapy

Contrary to chemotherapeutic drugs, antibodies act very specifically on cancer cells and have less effect on healthy body cells. The antibody rituximab, which is directed against B cells, plays an important role in the treatment of B-cell lymphomas. In 1998, it was the first antibody against cancer to be approved in Switzerland.

Therapeutic antibodies are usually administered by infusion. During the process, they are distributed throughout the body and attach themselves to the surface of targeted cancer cells.

How do therapeutic antibodies work and how are they used?

The antibodies rituximab and ibritumomab attach themselves to a specific protein (CD20) on the surface of healthy B-cells, but also of cancer-affected cells. This destroys the vast majority of these B cells. Cells called lymphatic stem cells remain undisturbed. After the treatment, healthy B-cells develop again from these stem cells.

The advantages of antibody therapy are its good efficacy coupled with relatively few side effects. Antibodies can be administered over years and thus improve the prognosis.

What are antibodies?

Antibodies are an important part of our immune system: When bacteria, viruses or other pathogens invade our body, our immune system forms defence proteins, which are called antibodies. Antibodies thus protect the human organism.

Modern medicine makes use of this targeted mechanism of action: Antibodies can be produced in the laboratory. They recognise structures that are located solely on cancer cells, and that are not or rarely on healthy body cells. When the antibody binds to the cancer cell, the cell can be killed directly or an immune reaction is triggered and the activated immune system can kill the cancer cell.

3.5 Radioimmunotherapy

Radioimmunotherapy (RIT) combines the advantages of radiation and antibody therapy. In this form of therapy, the antibody is connected to a radionuclide, which is a source of radiation (for example, radioactive yttrium-90). This combination of active substance binds to the B cells. With the help of the radionuclide, the marked cells can now be specifically irradiated – the surrounding tissue is better protected. RIT is an outpatient procedure and is performed only once.

3.6 Treatment with tyrosine kinase inhibitors (TKI)

TKIs are small molecules that are taken in tablet form. They can enter the tumour cell and block pathological cell signals. Blocking these signals can destroy the tumour cell. In non-lymphocytic forms of leukaemia, TKIs have led to an amazing improvement in prognosis. TKIs, for example ibrutinib, are also effective against lymphomas. Ibrutinib inhibits B-cell receptor signals. Up to now, TKIs have been used primarily in chronic lymphatic leukaemia and indolent lymphomas.

3.7 High-dose chemotherapy and blood stem cell transplantation

In special situations, high-dose chemotherapy with blood stem cell transplantation is necessary. This treatment is used for some lymphomas as part of the initial treatment. It can also be effective when a lymphoma does not respond well to chemotherapy or when a relapse occurs. With the high-dose chemotherapy there is then a second chance of a cure.

The dose of chemotherapy is so high that the bone marrow would take weeks or even months to recover from it. Many patients would not survive this. Before high-dose therapy, blood stem cells are obtained, frozen and returned to the blood after chemotherapy. The blood stem cells find their way into the bone marrow and quickly begin to form new blood cells. It then usually takes only one to two weeks until the blood values are back in a safe range. The risk of infection is therefore greatly reduced.

When obtaining blood stem cells, it is now technically possible to obtain a preparation that practically only contains blood stem cells. The risk of contamination by remaining tumour cells is thus reduced to a minimum.

The blood stem cells come mainly from two sources:

1. From the patient (autologous transplantation): Before high-dose chemotherapy, healthy blood stem cells are taken from the patient's blood and then reintroduced. This treatment is mainly carried out on patients up to 65-70 years of age.

2. From a family member or from a donor (allogeneic transplantation). This treatment is mainly performed on younger patients. Only rarely is it possible in people over 60 years of age.

3.8 Therapy in old age

More than half of lymphoma patients in Switzerland are over 60 years old – and this trend is rising. With older patients the question often arises as to the extent of treatment to carry out. The decision for or against treatment primarily must be based on the general condition of the patient and the accompanying diseases – not on age. This is because older patients have good chances of recovery if the treatments can be carried out consistently.

« Elderly patients have good chances of recovery if the treatments can be carried out consistently. »

To achieve results in this age group equivalent to those in younger patients, the state of health must be carefully assessed before treatment. Supporting measures such as the additional administration of blood growth factors that reduce the risk of infection are frequently used.

Growth factors

Blood growth factors represent a significant advance in the treatment of aggressive lymphomas. They can alleviate the often strong chemo- and radiotherapy induced side effects on the haematopoietic system. The administration of growth factors can significantly shorten the recovery time of the white blood cells, so that the next treatment cycle can be carried out in a timely manner.

3.9 Treatment of young adults

The questions and problems of young adults affected by cancer differ significantly from those of older people. Young adults want to achieve goals and realise dreams that older cancer patients have often already realised. While the healthy friends of cancer patients live their lives, the diagnosis of cancer for a young adult puts the natural development of the patient to a severe test: Students can no longer keep up academically, some lose their independence because they have to live in their parents' house again. Relationship issues, questions of self-esteem, marriage, fertility, pregnancy, education and career are all different for them. Additional problems arise for young adults with small children.

Desire for children, fertility

Many chemotherapies impact the fertility of men and women. With certain therapies, menstruation may stop altogether in women and sperm creation may be permanently stopped in men. The extent to which healthy cells are damaged depends, among other things, on the dose of medication, the radiation and the irradiated body region.

In the worst case, you will not be able to have children naturally after the treatment (sterility, infertility). In young people especially, the risk of infertility plays a special role if the patient and partner still want to become parents.

At the time of your initial diagnosis and before you start treatment, your doctor should inform you about the risks and consequences of treatment on your desire to have children. During this consultation, your doctor will also explain which early measures you can take to fulfil your desire for a child after treatment.

There are various procedures for this, called fertility maintenance measures. These are different for women and men. Before the start of the measure, ask your health insurance company about the coverage of costs. Such measures can also be useful if children are not yet an issue for you.

Fertility preserving measures for women

In women, it should be decided which measures are appropriate depending on the stage and dose of the treatment. It is possible to freeze eggs or ovarian tissue (cryopreservation). Taking hormones may also help as they can protect the ovarian tissue. However, this positive effect of hormones on ovarian tissue and pregnancy rates has not yet been sufficiently investigated in studies. Which method is suitable for you also depends on your age, physical condition, and the time until the start of treatment. Different methods can also be combined with one another. A period of two weeks must be allowed for the oocytes to freeze because they still need to mature. Freezing the fertilised oocytes more often leads to success. The more well-developed cells can be obtained, the more likely you are to become pregnant afterwards. Eight out of ten fertilised oocytes survive freezing and thawing. The chance of pregnancy depends on the age of

the woman and can range from a few to eighty percent. The success of freezing unfertilised oocytes depends heavily on the freezing method and therefore on the experience of the reproductive medical centre.

Ovarian tissue with still immature eggs is frozen, especially when time is short and/or the patients have no partner. This ovarian tissue is stored during the treatment and is retransplanted when the tissue remaining in the ovary no longer functions. An operation is necessary for this procedure: With a laparoscopy under general anaesthesia, your doctor usually removes the tissue on an outpatient basis. However, it is currently unclear how likely this method is to be successful.

Fertility preserving measures for men

Regardless of the stage of your disease, your doctor should inform you about the possibility of freezing sperm before starting therapy and offer it. This method has existed for many years and is possible through a simple sperm donation. If you want children in the future, you can resort to the frozen sperm cells. A small number of healthy sperm is sufficient for artificial insemination. They can also be taken directly from the testicular tissue and frozen. However, an operation is then required. Often no anaesthesia is necessary for this. However, post-operative bleeding or infection can also occur during this procedure. The success of freezing depends on how many fertile sperm can be obtained and frozen.

Patient guideline DKG, DKH, AWMF, Hodgkin lymphoma
(1st edition, December 2013)

See also section 17.3, «Internet links»

What are the important questions to ask my oncologist?

- What is the likelihood that I will experience sterility after my treatment is completed?
- Where is the nearest facility for freezing semen?
- Where can I freeze ovarian tissue?
- Where can I get advice?
- What is the risk of having cancer cells in the ovary at the time of cryopreservation?
- How much time do I need for in vitro fertilisation with the aim of precautionary freezing of fertilised oocytes before cancer therapy has to be started?
- How safe is pregnancy after cytotoxic treatment?

Source:
The brochure Options for Fertility Protection in Germ Cell-Damaging Treatments
Endokrinologikum Ulm

Desire to have children after cancers

The treatment of your lymphoma is complete and you and your partner are now thinking about becoming parents.

Depending on the type of cancer treatment, it is important that you use reliable contraception for at least three to six months after completion of cancer treatment. This period of time will ensure that all traces of the cancer drugs have disappeared from your body. You also give your body the opportunity to recover from the strenuous treatment. In this way, you and your partner have time to process all the stresses and strains associated with cancer. If necessary, you can get professional help together – e.g. from a couples' counselling centre

or a psycho-oncologist. Some experts even advise women to wait at least one or two years after the end of cancer treatment before becoming pregnant, because then the risk of relapse is reduced and the woman can recharge her batteries sufficiently to cope with the stresses and strains of pregnancy.

There's no such thing as the perfect time. Decide for yourself what is medically justifiable and psychologically sensible.

DKH Blue Guide, «Kinderwunsch nach Krebs»
(«Wanting Children After Cancer»)

For many of your questions you will also find answers at the addresses listed in sections 17.2 and 17.3.

3.10 Complementary and alternative therapies

Many lymphoma patients use other forms of treatment in addition to conventional medicine. They deliberately seek forms of treatment that are less aggressive and cause fewer side effects. Complementary medical treatments are in addition to scientifically-based therapies and aim to promote the self-regulating forces in the body. As such, they offer great support in dealing with the disease. In any case, it is important to discuss complementary therapies with the treating physician. Contact your doctor or health care professional.

« In any case, it is important to discuss complementary therapies with the attending physician. »

A fundamental distinction is made between complementary therapies, which supplement scientifically based therapies, and alternative

therapies, which are offered instead of conventional medicine. Complementary therapies include, for example, treatment with mistletoe extracts as offered in anthroposophical medicine. In Switzerland, this treatment is covered by health insurance companies. However, most complementary medicine methods are not covered by the basic health insurance, but only by the supplementary insurance.

Numerous other options are also offered: Food supplements such as trace elements or vitamins, energetic approaches such as kinesiology, the polarity method, the craniosacral method, respiratory therapies, and traditional Chinese medicine with acupuncture and acupressure. Art or painting therapies, eurythmy, relaxation techniques, visualisations and meditation can also have a positive and supporting effect on the individual state of mind. The effect of these treatment forms on the healing process has not been scientifically proven. They can, however, contribute to a significant improvement in well-being and help to get through the illness phase better.

Alternative therapies are repeatedly offered with the claim that they alone can fight lymphoma disease. The effect of such alternative therapies has not been proven. Alternative therapies do not represent a real substitute for scientifically based forms of therapy. On the contrary: There is a risk that the immune system will be stimulated in an undirected way and that, in the worst case, the disease process will be accelerated.

Among the numerous forms of therapy that are offered as a supplement, there is a helpful brochure from the Swiss Cancer League that can be obtained free of charge (see section 17.2) as well as the brochure «Komplementäre Behandlungsmethoden bei Krebserkrankungen (Complementary treatment methods for cancer diseases)» from the Krebsgesellschaft Nordrhein-Westfalen.

Be careful with promises of healing

If alternative methods are offered with the promise of a cure, if the promise of a cure is even connected with the advice to completely renounce a «harmful» orthodox medical treatment, such a recommendation should be rejected. Such offers are mostly dubious and belong to the realm of charlatanry. They have not been scientifically studied. Their claims and effect on lymphoma have not been proven. While a patient relies on these promises, important time for serious treatment is lost and the cancer progresses unchecked.

Participation in clinical trials

It is possible that your doctor will suggest that you participate in a trial. New forms of treatment are being tested in trials. This allows reliable findings to be obtained on the effectiveness of therapies. The treatments of lymphomas in particular demonstrate that thanks to such trials, treatment results have improved continuously. Those who take part in a trial are therefore not taking any risks, but can often benefit from new findings in medicine at an early stage.

There are four different types of trials:

- In Phase I trials, substances that have been effective in cell cultures or in animal experiments are for the first time tested in humans in order to find out which dose is optimal and which side effects occur. Of course, in a phase I trial, too, attention is paid to efficacy, but not focused on it.

- Phase II trials are conducted to determine whether the dose found in Phase I is effective for a specific type of tumour, for example lymphomas. Usually such a trial involves relatively few patients. If a new substance is effective, it will be further tested in a phase III trial.
- Most of the trials carried out by the Swiss Group for Clinical Cancer Research (SAKK), for example, are what are called therapy optimisation studies. They are carried out with the aim of providing patients with the most promising therapies as early as possible. These are often conducted as Phase III trials. This type of trial is an important instrument for the controlled introduction of new, promising therapies.
- Phase IV trials are conducted after the introduction of a new drug. The main aim here is to identify side effects that may not have been noticed during the development phase or that may only occur years after taking the drug.

Strict controls on trials

Before trials are started, the trials protocols are subject to rigorous control by ethics committees and Swissmedic, the Swiss agency for the evaluation of medicinal products. These institutions also monitor the trial while it is being run. In order to document that the patient has been adequately informed about the possible advantages and disadvantages of participating in a trial, as well as about rights and obligations. Patients must also sign an informed consent form.

Important to know

Participation in a trial is voluntary. The decision to participate is made solely by the patient after detailed information by the treating physicians. When deciding whether or not you should participate in a trial as a patient, there are possible advantages and disadvantages that have to be weighed against one another (see table). Participants can withdraw their consent to participate in the trial at any time without giving a reason.

Advantages of participating in a trial:

- Trial patients are treated by proven specialists in the field of lymphomas.
- They gain access to innovative drugs that are not yet available outside clinical trials.
- The monitoring of the state of health in a clinical study is more closely monitored than in normal medical care.
- If the treatment tested in the clinical trial proves to be superior, trial patients may be among the first to benefit.
- Even if patients often do not benefit directly from participating in the trial, they are helping others by supporting cancer research.

Disadvantages of participating in a trial:

- New and little studied treatment strategies may have unknown side effects and risks.
- As the treatment strategies have not yet been sufficiently investigated, their benefit is not certain, i.e. trial participants may have no benefit of their own or the benefit may be less than if they were treated with the standard treatment.

- Since health monitoring in a trial is much more closely meshed than in standard care, trial participants usually have to see a doctor more often. In some cases, examinations are also carried out that would not be carried out in standard care and may be associated with additional inconvenience (e.g. more frequent blood samples).

  For detailed information on clinical trials, please refer to SAKK's information brochure «Krebsbehandlung im Rahmen einer klinischen Studie» (Cancer treatment in the context of a clinical trial). Ask your doctor if you need more information or are interested in participating in a clinical trial.

3.11 After therapy: Follow-up checks, aftercare

In the follow-up care of lymphomas, the timely recognition of relapses is the main focus. In addition, special attention is paid to any late effects of the therapies. Aftercare should be provided throughout the life of the patient. The examinations are usually carried out at intervals of three, six and twelve months in the first year after therapy, every six months in the second, third and fourth year, and annually from the fifth year onwards. During each follow-up examination, a detailed survey about possible signs of illness and a thorough physical examination are carried out. Further examinations may be necessary depending on the type of cancer (see chapter on the individual lymphoma types).

Vaccinations

The question is often asked whether lymphoma patients should be specifically vaccinated. Not all people have the same risk of contracting a disease or developing a dangerous complication. Patients with blood diseases often have a reduced immune system, partly due to lymphoma, partly due to chemotherapy and radiotherapy. This results in an increased susceptibility to infections in this patient group. These persons are therefore recommended to be vaccinated with seasonal flu vaccines (according to the general recommendations of the authorities).

In patients after a stem cell transplantation, vaccination can only take place when the number of white blood cells has risen sufficiently. Due to numerous restrictions, many vaccines can only be given one year after transplantation. However, the question of vaccination is important for patients whose spleen has been removed either because of the disease or for diagnosis. Patients without a spleen should be vaccinated against pneumococci (pneumonia). Somewhat more controversial is the recommendation regarding vaccinations against meningococcus (meningitis) and the haemophilus bacterium. These are also often recommended. In any case, you should always seek medical advice about the new recommendations.

Further information can also be found on the Internet at:
www.bag.admin.ch/infekt/impfung/d/index.html
or by calling the vaccination hotline on 0844 448 448.

4 Dealing with side effects

4.1 Side effects of chemotherapy

Causes of side effects

Chemotherapy involves the use of cytostatic drugs – active ingredients that prevent cells from dividing and are distributed throughout the body via the bloodstream. Cancer cells divide particularly frequently so that the cytostatic drugs slow down their growth. However, cytostatic drugs also attack healthy cells that are frequently renewed, for example, bone marrow cells. The cells of the mucous membranes and hair roots are also affected. This can lead to hair loss or damage to the skin and nail roots. A medical consultation is always held before chemotherapy. The possible benefits and side effects are discussed in detail and weighed against one another. In lymphomas, the aim of treatment is, whenever possible, a definitive cure. Such therapies can be intensive and numerous side effects must be accepted.

Side effects of chemotherapy may include:

- Reduction of white blood cells (leukocytes) with the risk of increased infection
- Decrease of the red blood cells with the risk of anaemia, with increased difficulty breathing and weakness
- Decrease in platelets with increased risk of bleeding in the skin and mucous membranes, e.g. nosebleeds
- Change in taste or eating problems
- Damage to mucous membranes and inflammation of the mouth and throat, stomach, intestines and urinary tract
- Diarrhoea, constipation
- Nausea, vomiting, loss of appetite
- Fatigue (tiredness and exhaustion)
- Hair loss
- Damage to the heart, kidneys or lungs
- Infections

- Nerve disorders, such as sensory disturbances, tingling or pain in the outer limbs (peripheral neuropathy, see box)
- Limited fertility
- Reduced libido during the treatment phase

After chemotherapy, patients should drink a lot of fluids in order to promote the excretion of cytostatic drugs and maintain kidney function.

Increased risk of infection

In the case of the following complaints, you should contact your doctor as soon as possible, especially during chemotherapy:

- Fever, i.e. elevated temperature >38°C
- Chills with or without fever
- Diarrhoea longer than 48 hours
- Coughing, respiratory chest pain, shortness of breath
- Burning or pain when urinating, pain in the kidney area
- Changes in skin or mucous membranes: Reddening, whitish deposits or blisters, especially when blisters appear in groups on reddened skin
- Disturbed consciousness, confusion

In case of suspected infection or corresponding complaints, a rapid diagnosis and the initiation of a therapy are critical. You may be treated with an antibiotic more quickly than healthy people. The spread of an infection can be prevented by rapid intervention.

Many of these possible infections can be caused by the body's own pathogens (e.g. bacteria in the body's own intestinal flora or reactivated herpes viruses in shingles). For this reason, you cannot protect yourself completely from pathogens. However, you can reduce the risk by following a few rules of conduct:

- Avoid shaking hands, especially during flu season. Most viral infections are transmitted via the hands.
- Wash your hands regularly to reduce the germ load.
- Avoid large crowds during the flu season.
- Avoid contact with people who have the flu. The same applies to contact with children with chickenpox, measles, rubella or other childhood diseases.
- During a treatment: Carefully wash salad, vegetables, and fruit that cannot be peeled.

Peripheral neuropathy

Chemotherapeutic agents such as vincristine can lead to peripheral neuropathy.

Neuropathies are diseases of the nerve cells. In peripheral neuropathy, nerve fibres of the peripheral nervous system are damaged. Symptoms include legs that burn or tingle, but also stabbing pain in the hands or feet and increased sensitivity to heat or cold. The symptoms often disappear again over the course of months.

Chemotherapy of the older generation in particular causes nausea. This is caused by the effect of cytostatic drugs on the refractive centres in the body. Numerous drugs are available for the prevention and treatment of nausea. Make sure that in case of severe nausea or vomiting you take the recommended medication or contact your doctor.

The cytostatic drugs (but also irradiation of the abdomen) damage healthy intestinal cells, which can lead to digestive disorders, constipation and diarrhoea.

Tips against diarrhoea:

- Eat bananas, applesauce or raw, grated apples, blueberries as a puree or dried berries.
- Drink a lot of fluids, add some salt to mineral water if necessary.
- Potatoes (mashed potatoes), white bread, rice, noodles and bouillon are usually well tolerated.
- No high-fat food or coffee
- Eat low-fat dairy products, such as quark, yoghurt, low-fat cheese, buttermilk.

Tips against constipation:

- Drink a lot of fluids.
- Move a lot.
- After getting up, drink a glass of lukewarm water or fresh fruit juices, possibly caffeinated beverages.
- Soak dried plums in a glass of water in the evening and eat them in the morning. Dried fruit can also help.
- Preference should be given to high-fibre foods, such as fruit and vegetables, pulses, onions, cabbage, wholemeal products, nuts and maize.

Nutrition

During a treatment it is not necessary to pay attention to a special diet. All that tastes good is permitted. However, a diet rich in vitamins and minerals with sufficient fibre is recommended. Alcoholic drinks should rather be avoided on the day of therapy and on the days after. Some drugs are not compatible with alcohol, for example Natulan (procarbazine). Ask your doctor or health care professional.

On the day of chemotherapy or radiotherapy, as well as in case of nausea and vomiting, you should eat light food in many small meals. During this time, eat what you like and what you tolerate well. Look for food that stimulates the appetite.

Lightly seasoned food, starchy foods and cold drinks (cola) have proven to help. If you lose your appetite while cooking, have someone else cook for you. Eat and drink slowly.

4.2 Side effects of radiotherapy

The side effects of radiation therapy vary from person to person and depend on the radiation dose, the size and sensitivity of the irradiated body region. Side effects can be divided into acute symptoms that occur during and in the weeks following the therapy, and late effects that may only become noticeable decades later. The «Radiotherapy» guide of the Swiss Cancer League provides a good overview of acute side effects (see section 17.2).

Some lymphoma patients, especially patients with Hodgkin lymphoma, may be relatively young at the start of therapy, which means that special attention must be paid to the late effects. However, it is not easy to identify late effects, as many patients are not regularly checked after 20 or 30 years. Some things can be forgotten, documents are lost.

Today, side effects can be observed in former patients who were treated in the 70s or 80s, for example. The irradiation technology at that time was less gentle and larger areas were irradiated than today. This can lead to damage to the heart or lungs or to new tumours in the irradiated area. This damage is exacerbated by smoking. It is therefore important to remember that a part of the body was irradiated earlier and to inform the doctor if symptoms occur.

4.3 Side effects of antibody therapy

Antibody therapy is generally well tolerated. Without pre-treatment, fever and chills can occur, especially during the first infusion. To prevent or alleviate such reactions, drugs against allergic reactions are administered before the infusion. Patients are monitored and checked during the entire infusion. At the first signs of a reaction the infusion is stopped. Once the symptoms have subsided, in most cases the infusion can be restarted at a slower rate. With each additional infusion the symptoms usually become less severe or disappear completely.

Circulatory problems and shortness of breath rarely occur and must be treated immediately. This is also the reason for the monitoring during and after the therapy, which usually lasts several hours. In addition, antibody therapy can cause fatigue and lack of appetite.

4.4 Side effects of radioimmunotherapy

As a rule, the side effects of radioimmunotherapy are relatively minor. During the first two weeks, the side effects are similar to those of antibody therapy (see 4.3). The additional radiotherapy increases fatigue and loss of appetite, usually for a few days. The blood values usually only decrease after three to six weeks. Nevertheless, serious infections, blood deficiency or bleeding are rare. Before radioimmunotherapy, you will receive detailed information material that you should read thoroughly.

4.5 Fatigue

Fatigue is often misunderstood and trivialised, although it can severely impair the patient's quality of life. The term fatigue describes an exhaustion that goes beyond normal tiredness. Patients are extremely tired, dull, listless, exhausted. Fatigue is one of the most common accompanying symptoms of chemotherapy and radiation therapy. Unlike normal tiredness, fatigue cannot be overcome by adequate sleep. Fatigue can last long after chemotherapy.

Possible causes

The tumour itself is certainly a primary cause for the occurrence of fatigue. Chemotherapy and radiation therapy as well as surgical interventions can increase fatigue. However, treatment with painkillers, sedatives or sleeping pills, or even anti-convulsants can also cause fatigue. Fatigue can be aggravated by pain, nausea, agitation or shortness of breath.

« Fatigue is one of the most common side effects of chemotherapy and radiation therapy. »

The causes of fatigue should be treated as well as possible. A clear daily structure with activity and rest phases is important. Regular walks or light sport will alleviate fatigue. Avoid long periods of sleep during the day. Discuss the treatment of sleep disorders or any accompanying psycho-oncological care with your doctor. The brochure «Rundum müde» (All around tired) of the Swiss Cancer League provides detailed information on the subject of fatigue (see 17.2).

4.6 Hair loss

Even today, lymphoma patients often have to expect hair loss. Chemotherapy radiotherapy attacks cells that divide frequently. These include cancer cells, but also hair cells. Therefore, many cancer patients suffer from partial or temporary hair loss. Not all drugs cause hair loss in the same way. However, there are drugs that almost always cause hair loss, such as adriamycin, Endoxan or Etopophos, which are included in the R-CHOP and the BEACOPP regimens. Usually, hair begins falling out two to four weeks after the first chemotherapy. It is possible that the hair grows even stronger after the completion of chemotherapy than before the treatment. Permanent hair loss, for example after very high doses of irradiation, is very rare today.

Not suitable for lymphomas

To date, the only really effective measures against cytostatic hair loss are the cooling caps. As lymphoma cells can be found anywhere in the body, cooling caps cannot be used in lymphoma therapy.

Tips:

- If you decide on a hair replacement, such as a wig or toupee, get it early.
- With a doctor's prescription, the health insurance company for OASI recipients or the disability insurance company for non-OASI recipients covers the cost of a wig up to a limited amount. Recognised wig shops have corresponding insurance application forms available.
- If you don't like wigs, you can give free rein to your creativity: Wear scarves, a cap, a hat, a headband or a turban.
- For women with hair loss during chemotherapy and radiotherapy, cantonal cancer leagues offer courses for practical tips on different headgear.

4.7 Inflammation of mucous membranes in the mouth

Chemotherapy can lead to painful inflammation of the mouth and throat, as chemotherapy damages the oral mucosa. There is an increased risk of canker sores and infections. This is called mucositis, an unpleasant side effect of chemotherapy.

Tip:

- Visit the dentist before starting therapy, clean your teeth with a soft toothbrush, rinse your mouth after each meal.

5 Work, care, support and assistance

5.1 Ability to work

Some lymphoma patients are fully able to work and want to continue doing so. However, if you do not feel well or if intensive treatment is imminent, you should have your doctor write you a note of illness. It is better to pause during a treatment than to drag yourself through work and thus put even more strain on the body.

Most employers have sympathy for this situation. Some are also insured against the sickness of their employees. If you fear difficulties with your employer, contact your company's social services office or a regional cancer league (see addresses in section 17.2). The Swiss Cancer League can conduct delicate negotiations for you if you feel that you cannot cope with the situation on your own.

« Most employers have sympathy for the situation. »

5.2 Labour law – duty to inform

The obligation to provide information when applying for a position is precisely regulated in the labour law. The guidelines of the Swiss Cancer League «Chronisch krank – was leisten die Sozialversicherungen?» (Chronically ill – what do the social insurance funds do), Guideline 2015, states:

«An obligation to inform exists if a cancer is in an acute state and a (continued) inability to work is expected in the short term; but not if the last operation was 6 months ago and there is good hope that there will be no relapse.»

«If someone conceals an illness in spite of an existing obligation to provide information, a termination or even a unilateral immedia-

te termination of the contract due to error or deception must be expected.»

«On their own initiative, during an interview, applicants must only mention serious complications which are likely to affect the performance of the employment contract in a substantial way.»

«If an employer specifically asks the question about existing or past health impairments, this must in principle be answered truthfully. However, there is no need to provide information on past illnesses where there is no serious risk of relapse.»

«Anyone who conceals an illness despite being asked the appropriate question is committing fraud. He or she must expect, if the matter comes to a head later, that the employer will terminate the employment relationship or (in blatant cases) dissolve the contract immediately.»

Further information can be found in the above-mentioned guide on the homepage of the Swiss Cancer League.

5.3 Care and nursing

Some lymphoma patients are not necessarily dependent on physical support. Much more important is emotional support: the knowledge that you are not alone. If possible, relatives and acquaintances should offer the patient a setting in which he or she feels comfortable. It is not about taking all the work off the patient's hands and treating him or her with kid gloves.

It is much more important to take on those tasks in everyday life that obviously cause the patient a lot of trouble and/or fatigue.

Should it nevertheless be necessary, during the treatment and the course of the illness, for the patient to be cared for at home, relatives and acquaintances can call for help. Spitex services come to the home regularly, perform nursing tasks such as washing the patient, but also everyday tasks such as shopping, cooking, and cleaning.

« The regional cancer leagues can answer your questions and help you deal with institutions. »

Some cantons also offer a specialised Spitex for tumour patients, known as «Onkospitex» or «Spitalexterne Onkologiepflege» (SEOP). This service takes over treatment according to the doctor's prescription, supervises pain therapies, makes injections, infusions, and organises the rental of nursing beds if necessary.

Spitex services are covered by the health insurance if they are prescribed by a doctor. However, the deductible remains to be paid. The Swiss Cancer League offers further advice and support to help cancer patients (see addresses in section 17.2).

Many patients need information on whether and when claims can be made against an insurance company (e.g. health insurance, disability or old-age and survivor's insurance) and whether there is a right to supplementary benefits in addition to a pension. The regional cancer leagues can answer your questions and help you deal with institutions.

Further information can be found in the brochure «Chronisch krank – was leisten die Sozialversicherungen» (Chronically ill – what do the social insurance schemes provide), available from the Swiss Cancer League.

5.4 Psychological support (psycho-oncology)

Psycho-oncology provides support to those affected and their families in a phase of life burdened by illness and therapies. It deals with the psychological and psychosocial consequences of cancer. It focuses on the well-being of the patient with cancer in his or her particular life situation. Almost always, it provides counselling on the following topics: The fear of a relapse, search for meaning, dealing with therapy side effects and pain, family, partnership and strategies for coping with the disease.

Increasingly, oncology departments are offering psycho-oncological consultations, which are led by psychologists or psychiatrists.

5.5 Mental health

A cancer diagnosis must be processed individually by every person affected. Some patients can find a deeper meaning in the disease, others not at all. Often patients stop after being diagnosed with cancer. Some think: «If I continue in the same way as before, nothing will change, not even the disease». Many believe that the psyche has an important impact in being ill. However, science does not provide a clear answer as to how strongly the psyche can influence the further course of the disease. Certainly there is no «cancer personality» that would increase the risk of cancer in certain individuals or due to personal attitudes. But that body and mind belong together is an old bit of wisdom. For some people affected, it can be important to bring about change, to set goals, to stop feeling like a victim of a frightening disease.

There are numerous ways to improve mental attitude:

- Lifestyle changes
- Energetic therapy, such as kinesiology, polarity
- Psychotherapy (individual and group therapy)
- Art or painting therapy, eurythmy
- Simonton method of visualisation
- Meditation, spirituality
- Mental training

(see also section 3.10)

5.6 Patient organisations / patient support groups

There are various patient organisations in Switzerland that can give information and support. For lymphoma patients, «lymphome.ch • patientennetz schweiz» offers patient support groups in various Swiss regions.

In these patient support groups people talk about personal problems, but also information and personal experiences with therapies are shared. The group meetings are kept small in order to maintain personal contact. The group meetings are open to those directly affected and their families. This creates a balance between giving and taking among the participants.

In order that problems can be discussed freely and openly, the members commit themselves to discretion towards the outside world. The participants feel understood and accepted in the group. This not only strengthens self-esteem, but also helps to develop strategies for successful coping behaviour.

Participation in a patient support group is one way to improve one's personal situation, individually or with others, to find a way through a difficult phase of life. Meeting people with the same condition offers those with lymphoma the opportunity to actively and constructively deal with the disease.

5.7 For affected parents with children

The diagnosis of lymphoma is not only a shock for those affected – it impacts the entire family. Patient, partner and children are full of fear and doubt. For mothers and fathers, many questions arise as a result:

- Who's going to tell the child?
- Should I even tell my child I have cancer?

Who's going to tell the child?

The answer depends on the individual family situation. Ideally, both parents should talk to the child. In this way, the child senses from the beginning that everyone is involved and is being honest. If this is not possible, the following questions may help:

- Who is the child most likely to talk to about their feelings?
- Who in the family does the child turn to when feeling sorrow? Is there a trusted person?
- Who in the family feels able to to talk about one parent's cancer?

Not only the information is important, the child must feel at the same time that he or she can continue to count on the love and support of the parents – following the motto: «We'll get through this together.»

Get prepared for the conversation with your child. Psycho-oncologically trained specialists or even the paediatrician can give you suggestions and thus a feeling of security.

Should I even tell my child I have cancer?

Yes, absolutely. It is not possible in a family to make the disease a secret among adults. A child will quickly sense that something is wrong. Even a glance between parents, a quickly ended telephone conversation or teary eyes give even small children the hint: «Something's happening here that's upsetting the parents!» Children who sense that something threatening is in the air, but do not know what, may develop their own fantasies. These fantasies can be much more ominous than cancer.

Therefore: Talk to your child about your cancer. It is important that your child can rely on being informed about important changes in the family, otherwise he or she will feel excluded and lonely. The word «cancer» should be said out loud to avoid ambiguity.

5.8 If a close person suffers from lymphoma

How you can help

You have learned that a person close to you has been diagnosed with cancer. You are very concerned and are considering how you can help. Every person has different needs: People who have to come to terms with a cancer diagnosis seek and find their own personal way of dealing with illness and treatment.

If you would like to help, here are some tips. Many people feel quite helpless in the first moment when they learn that a close person is ill and therefore cannot react spontaneously. They are even afraid that the people affected will feel harassed if they call or email, so out of insecurity they don't call or email. For the person concerned it is often good to know that family and friends are enquiring and taking an interest.

Assistance is possible in various ways:

- Tell the person concerned that you are there for him/her.
- If necessary, offer to take the person to his or her doctor's appointment.
- Offer to take care of the children from time to time or regularly.
- Offer to do housework: Cleaning, laundry, cooking, gardening, etc.
- Do what you think will make the patient happy.

Take care of yourself too!

A lymphoma diagnosis triggers fear and uncertainty in the affected person and their loved ones. Now the patient and the illness are at the centre and it is easy for family members to put aside their own needs or avoid talking about their own problems, as these seem insignificant at the moment.

However, it is important that family members do not forget their own interests. Despite good intentions, it is possible that energy reserves are not always sufficient to cope with everyday life with all its obligations. It is therefore important that family members do not overtax themselves and respect their own limits. Family members should create short free spaces during the day, small islands of time to put their feet up and relax, to read the newspaper or listen to music. If family members become overwhelmed, they should not be afraid to seek support.

6 Frequently asked questions

Can and may I still participate in sport?

From a medical point of view, there is nothing wrong with practicing sport. However, avoid physical overexertion and make sure to maintain balance. Adapt the sporting activity to your state of health. Regular exercise has positive effects on your general condition and mood. High-performance sport should be avoided during therapy phases.

How do those around me react to my illness?

The topic of cancer is still often taboo in our society and a conscious awareness often exists among people who know someone affected. Since this topic also causes great helplessness in non-affected people, there are different reactions. Some people retreat, perhaps because they are not good at dealing with cancer or because they know too little about cancer.

Family members often experience feelings of helplessness and powerlessness, not being able to do anything, just having to watch. But their presence and attention are an invaluable help and support.

How do I find the right words?

It is a great challenge to say: «I have cancer.» Saying these words out loud can trigger emotions that you have previously suppressed. Talking to someone about it makes the disease even more concrete. Although it may be difficult to find the right words, this has a therapeutic effect because you admit to yourself that you are ill. This can be an important step in dealing and living with cancer.

It is up to you to inform those around you about the extent of the illness. The better those around you are informed, the better they can support you.

How do I tell my partner?

Your partner will probably be the first person you inform about your cancer diagnosis. He or she will care for you during treatments and can best support you. It is therefore important that you speak openly and honestly about your cancer and the prognosis. If you allow your partner to accompany you to the doctor's appointments, you may feel less isolated. If you have a partner who gives you support at many levels, the fight against cancer can develop into teamwork.

6.1 Questions for the doctor

Do not be afraid to ask your doctor questions. Prepare yourself for discussions with the doctor.

Questions about the diagnosis:

- What is lymphoma?
- What type of lymphoma do I have?
- Is it an indolent or aggressive lymphoma?
- At what stage is the disease?
- What does this diagnosis mean for my life in the future?
- What treatment options are available?
- How long do the therapies last?
- What are the chances of success of the treatment?
- What are the chances of being cured?
- What are the possible late effects?
- Where are the therapies performed?
- What influence will the treatment have on my everyday life?
- Will I be able to work during therapy?
- What changes will I have to adapt to?
- Will special arrangements have to be made with regard to childcare, care for elderly relatives, etc.?

Questions about treatment:

- Which therapy is planned for me?
- How is the treatment performed? How often and for how long?
- Is this treatment carried out on an inpatient or outpatient basis?
- How long does a treatment take?
- Can this treatment cure my illness?
- Can I do anything for myself during the treatment?
- What do I have to pay particular attention to?
- What happens if I miss therapy?
- When is it necessary to notify the doctor?

Questions about side effects:

- What side effects and risks must I expect?
- Why are regular blood tests necessary?
- What should I do if I get a fever or if an emergency occurs?
- Are there any foods that I should or should not eat?
- Can I have alcoholic beverages?
- Who and when should I best call if I have questions?

Questions after completion of the treatment:

- How do I know that the therapy was successful?
- What check-ups are necessary and at what intervals?
- Who can I contact after the treatments if I have problems?
- What is the probability that the disease will occur again and what happens then?
- What are the signs of another occurrence?

You can also read tips on this topic in the ho/noho brochure «Fragen rund um mein Lymphom» (Questions about my lymphoma).

7 Patient rights and insurance

7.1 Health insurance and other insurance

Every person resident in Switzerland is covered by compulsory social health insurance in accordance with the Health Insurance Act (KVG/LAMal), which guarantees basic medical care. In this basic insurance, health insurers must accept all applicants without restriction, regardless of age and state of health. People living in financially modest circumstances are entitled to reduced health insurance premiums, which are regulated differently from canton to canton. The benefits that must be covered by a health insurance fund are precisely defined. When a treatment is recommended to you, it must first be verified that your health insurance company will cover the costs. Requests for reimbursement of costs for a specific medication are usually handled by the doctor treating the patient. He or she is obliged to point out possible gaps in the coverage of costs by the health insurance. If you have questions or problems concerning social security law (employment law, unemployment insurance, disability insurance, etc.), you can contact a legal service, for example «Inclusion Handicap», see Internet links for further information.

« People living in financially modest circumstances are entitled to reduced health insurance premiums, which are regulated differently from canton to canton. »

Completely different rules apply to supplementary insurance policies that are newly concluded. Before providing supplementary insurance, insurers are allowed to carry out risk assessments. People with a lymphoma diagnosis are considered by all insurers to be too great a risk, regardless of the course of treatment to date, and are therefore only accepted with reservations. The same problem could arise with a life insurance policy above a certain liability amount (200,000 Swiss francs). The insurers may also carry out a risk assessment in this case

and will only offer you insurance with reservations. If you were to die prematurely of lymphoma, the premium would not be paid. This can also affect a loan application at the bank or a mortgage application, because often a life insurance policy must be deposited for this.

Costs arising in the course of a clinical trial are usually allocated as follows:

- Costs that are directly related to a clinical trial are usually covered by the trial centre.
- Costs that are incurred as part of a clinical trial, but which would also be incurred in a standard treatment, are paid by the health insurance companies.

In order to avoid unexpected cost consequences, we recommend prior clarification with the health insurance in any case.

7.2 Compulsory health insurance benefits

- Costs for diagnosis and treatment of diseases and their consequences are covered by the basic insurance. However, all services must be effective, appropriate and economical. Patients must first pay the excess that they have set, and in addition, they must pay ten percent of the treatment costs up to an annual cost sharing of 700 francs.

- The health insurance providers only reimburse the cost of a medicinal product as part of the statutory health insurance mandated by the Health Insurance Act (HIA) if it has been prescribed by a doctor and is on the List of pharmaceutical specialities (LS) managed by the Federal Office of Public Health (FOPH).

- Hospitalisation: The regulations as described in the first point above apply to the assumption of costs for diagnosis and treatment in a hospital, provided that the diagnosis and treatment are carried out in a hospital that is included in the hospital list of the canton of residence. In addition, ten francs per day is charged for hospitalisation, but only for single persons.

- The costs of outpatient nursing care (recognised Spitex services or outpatient oncology care SEOP) are covered if they have been prescribed by the doctor. The medical prescription is valid for a maximum of three months, or six months for long-term patients. Regular costs for household assistance are only covered by supplementary insurance.

- Nursing costs in a nursing home or in the nursing facility of a hospital are also only covered if prescribed by a doctor. However, the actual care costs are not covered by the basic insurance. You will also need additional insurance for this. This means that a stay in a nursing home or in the nursing facility of a hospital can only be financed to a small extent by the mandatory basic insurance.

7.3 At the workplace

If you have been diagnosed with lymphoma, but you feel fully able to work, you are not obliged to inform your employer. Even if the lymphoma and the treatment have an effect on the ability to work, the employer does not in principle need to be informed about the nature of the disease. However, in this case you must state that you are not fully able to work due to illness. To promote an open employment relationship, however, it is advisable to report honestly about cancer. In most cases, a doctor's certificate is

« If you have been diagnosed with lymphoma, but you feel fully able to work, you are not obliged to inform your employer. »

required from the fourth day of absence due to illness. This records the level of incapacity to work and the duration of the absence.

Anyone who is unable to work because of lymphoma is protected against dismissal for a certain period: 30 days in the first year of service, 90 days from the second to the fifth year of service, and 180 days from the sixth year of service. Any notice of termination given during this blocking period is not valid.

Anyone who can no longer work due to illness is still entitled to a wage for a certain period of time. The entitlement is calculated within the year of service. Several absences in the same year of service are added together. The continued payment of wages depends on the number of years of service and the canton in which you work.

Your employer may also have taken out voluntary daily sickness benefit insurance for longer absences, which usually covers 80 percent of your salary for a longer period (often 720 days). You will find the exact details in your employment contract. After 720 days, the benefit of the daily allowance insurance expires forever, even if you are only partially unable to work. If you are unable to work for a longer period of time, you must remember to register with the IV (disability insurance) in good time. Whenever possible, an IV application should be submitted at least six months before the expiry of a daily allowance insurance policy. To do this, you must apply to the cantonal IV office for an appropriate form.

Since 1 January 2008, there are also new facilities regarding for early recognition and early intervention. This is a preventive instrument of the IV, which enables people with the first signs of possible invalidity to be quickly identified and to avert the threat of invalidity by using appropriate measures. The notification for early recognition is not considered to be an application for IV benefits.

Find out early on about the conditions your employer offers you. The cantonal employment office can also provide further information. In general, you can contact social services at the hospital or in your community with financial questions. The cantonal cancer leagues provide additional assistance.

7.4 Patient rights

A number of very specific rights can be derived from the general rights of Swiss citizens. The starting point for patients' rights is the fundamental right to personal freedom, which is guaranteed by the Federal Constitution. Among other things, it includes the rights to physical and mental integrity (inviolability) and to self-determination. However, through the Civil Code (ZGB), these rights also apply in private law, i.e. in relations between private individuals. They are important in dealing with hospitals, health authorities and doctors. The following compilation also includes the main principles of the European Charter of Patients' Rights and the «Rights and Responsibilities of Patients» in the Swiss Platform for Patients' Organisations.

- Right of access to treatment: Everyone has the right of access to the health services that his or her state of health requires. Public hospitals must grant equal access to all persons without distinction as to financial means, place of residence, type of illness or time of use of services.

- Freedom of choice of the service provider: In the basic insurance, patients have the right to consult the service provider of their choice. However, persons without supplementary insurance can only be treated in a hospital in their canton of residence.

- Freedom of choice in therapy: Patients have the right to refuse a therapy recommended to them or to choose another therapy. The

health insurance company is required to make a contribution to another equivalent therapy that is at least equal to the costs of the recommended therapy.

- Right to innovation: Everyone has the right to access innovative procedures – also in diagnostics – in accordance with international standards and independent of economic or financial considerations.

- Right to a second opinion: Patients have the right to a second opinion. This means that if a recommendation for a surgical intervention or therapy that is associated with high risks and probable serious side effects is made, a second opinion can be obtained from another healthcare professional. The insurance companies are obliged to cover the resulting costs within the framework of basic insurance.

- Right to individual treatment: Everyone is entitled to diagnostic or therapeutic programmes that are tailored as closely as possible to their own needs.

- Due medical diligence: The success of medical treatment can never be guaranteed, but every patient has the right to a careful and professional treatment.

- Right to data protection and privacy: Everyone has the right to confidentiality of personal data and information during diagnostic examinations, during visits to specialists and generally during medical and surgical treatment. This includes information about the person's state of health and potential diagnostic or therapeutic measures as well as the protection of privacy.

Everyone has the right
to have access
to such health care
as his or her health status
requires.

- Exceptions to the obligation of medical secrecy are only permissible if a law provides for this, if the person concerned gives his/her consent, or if an authority releases the physician from medical secrecy. There must be important reasons for this.

- Right of access to medical records: Patients have the right to full access to their medical history upon request.

- No compulsory examination and treatment: An examination or treatment against the patient's will constitutes a serious encroachment on personal freedom.

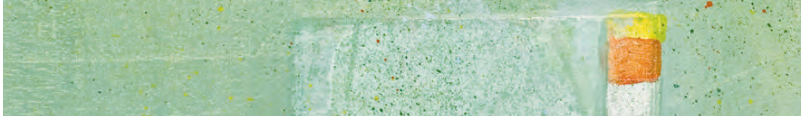
- Right to information: Doctors are obliged to provide appropriate information to enable patients to make a free decision on the proposed treatment. Before prescribing a therapy for the treatment of lymphoma, detailed information should therefore be obtained about the effect, any side effects and possible long-term consequences.

The doctor should also point out alternatives and make clear what can happen if the patient does not want to be treated. According to the Federal Supreme Court, the duty to inform also includes the duty of the physician to inform the patient of any gaps in the coverage of costs by health insurance. Only those who know all the prospects, problems, risks and alternatives can give their binding consent to medical treatment.

« Doctors are obliged to provide appropriate information to enable patients to make a free decision on the proposed treatment. »

II Information on lymphoma subtypes

II The most common lymphomas



8 Diffuse, large B-cell lymphoma

8.1 Introduction

Diffuse large B-cell lymphoma (DLBCL) is the most common lymphoma. About one third of all lymphomas belong to this group, which is subdivided into further subgroups according to their characteristics. The incidence of this disease has increased steadily in many European countries over the last decades – especially among older patients, without the causes of this development being clearly identified. DLBCL can occur at any age, but about half of those affected are over 60 years old. The factors that lead to the development of a DLBCL are not known. The only thing that is clear is that patients with a weak immune system, for example, HIV patients or patients with a transplanted organ, have a significantly increased risk of contracting DLBCL.

If not treated, a DLBCL can grow aggressively and rapidly. Lymph node swelling can occur within a few weeks and quickly lead to symptoms. Therefore, DLBCL is also considered to be an aggressive lymphoma. What sounds dramatic, however, also has positive aspects: Although these lymphomas can grow rapidly, they usually respond very well to therapy (radiotherapy and chemotherapy). The good news: The majority of DLBCLs are curable with today's standard therapies.

8.2 Symptoms

Typical DLBCL symptoms are: heavy night sweats, fever of unknown origin, and unwanted weight loss (B symptoms). These are symptoms that also occur with other lymphomas. However, not all lymphoma patients suffer from such symptoms.

In addition to these general symptoms, most patients experience a rapid enlargement of the lymph nodes, with the lymph nodes in the neck, armpits or groin particularly affected. Aggressive lymphomas also frequently occur in regions outside the lymph nodes. All organs of the body can be affected (see section 16.4).

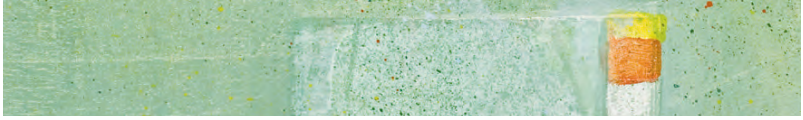
8.3 Diagnosis

At the beginning of the diagnosis there is a detailed conversation and a physical examination. If the suspicion of a lymphoma disease is confirmed, further examinations are ordered (see section 2.7). Depending on the individual situation, further examinations are necessary in order to be able to offer the best possible therapy. A PET-CT examination is practically always included. A bone marrow examination is not necessary in every case.

8.4 Treatment

Due to the often rapid and aggressive course of the disease, immediate and intensive treatment is necessary. Great medical progress has been made here in recent years. The main pillar of treatment is usually classic chemotherapy consisting of several drugs. In many cases, chemotherapy alone brings a cure.

In recent years, this therapy has been continuously improved, for example, due to shorter intervals between individual treatments and in particular though the introduction of the antibody rituximab. Rituximab recognises cancer cells and can help destroy them. By combining the antibody with classical chemotherapy, a further improvement in therapy results has been achieved and cure rates increased significantly. Therefore, combination therapy is the standard treat-



ment for a DLBCL today. It is important to note that the additional antibody administration only has a minor impact on the side effects of the therapy. In most cases the treatment combination (chemotherapy and antibody) is tolerated quite well.

With the help of blood growth factors, chemotherapy-related side effects on the haematopoietic system can be alleviated. The administration of such factors shortens the recovery time of white blood cells. The therapy becomes safer. The risk of dangerous infections during chemotherapy is significantly reduced. This is particularly important for patients with comorbidity.

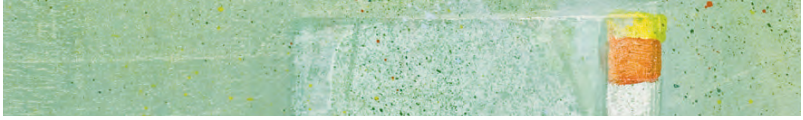
Depending on the spread, location and size of the tumour, radiation therapy can also be carried out. With the newer therapies, irradiation is necessary less frequently. Increasingly, the results of a PET examination are used to decide whether radiation is still necessary after chemotherapy.

If a relapse should occur after treatment of DLBCL, healing is still possible with the help of intensive second line treatment. As a rule, high-dose chemotherapy with subsequent stem cell transplantation is performed, which is only offered in special centres. If this is not possible or reasonable, various other measures, especially chemotherapeutic measures and numerous new drugs, are available. Many are also tested in clinical trials. Although the disease cannot always be overcome, these therapies can usually repress the disease and relieve many symptoms.

The above-mentioned therapy concepts apply to a DLBCL, which usually affects several lymph node stations. In special situations the treatments have to be adapted. This applies especially for some subtypes of DLBCL, for example when the brain or testicles are affected.

8.5 Aftercare

After the therapy is completed and successful, your doctor will discuss aftercare with you. Since most relapses with DLBCL occur within two years and since effective therapies are available even in the event of a relapse, monitoring is more frequent during this period. As a general rule, checks are carried out every three months during the first two years. Thereafter, checks are carried out every four, six, or twelve months. Follow-up examinations include a clinical examination, a laboratory analysis, and often also X-ray or ultrasound examinations.



9 The mantle cell lymphoma

9.1 Introduction

Mantle cell lymphoma (MCL) is a separate lymphoma disease from the group of B-cell lymphomas. About five percent of all lymphomas belong to this category. The disease occurs on average between the ages of 60 and 65 years. Men are affected significantly more often than women. The course of the disease can progress rapidly without treatment.

The disease develops in lymph cells in the mantle zone of the lymph node. The exact causes for the development of MCL are still unknown.

9.2 Symptoms

Typical symptoms of MCL are swelling of the lymph nodes, which often occur in several parts of the body. They are usually not painful, but increase in size as the disease progresses. In some patients, the disease leads to a drop in performance, unexplained weight loss, and severe night sweats. If the bone marrow is affected, this can lead to a reduction in blood cells. This in turn increases fatigue and leads to respiratory distress when under exertion.

With MCL, the stomach or intestines are more frequently affected than in other lymphomas. Such an involvement can lead to abdominal discomfort or stool irregularities. There may also be blood in the stool, which can manifest itself in the form of conspicuously dark stools or fresh blood loss. In some patients, the spleen enlarges, which can cause a feeling of pressure or a prick in the left upper abdomen. In some cases

there are no symptoms and the disease is discovered by chance during a medical examination. In some patients, the diseased lymphoma cells migrate into the blood. This is called the «leukemic» phase (flushing out of white blood cells).

9.3 Diagnosis

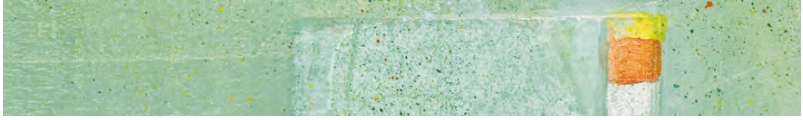
The extraction of a tissue sample (biopsy) from an affected lymph node or organ is critical for the diagnosis. After the diagnosis has been made, a determination of cancer spread is carried out to determine the stage of the disease and to identify any problems that may be caused by the disease. Usually a PET-CT examination is performed. Further examinations may become necessary in special situations, for example a gastroscopy or colonoscopy.

9.4 Treatment

The lymphoma is localised in a small proportion of patients only. If only a single lymph node region is affected, radiation treatment can lead to healing. In most cases, however, the disease is at an advanced stage. Then a «systemic» treatment is used (i.e. treatments that work throughout the body).

As a rule, treatment is started after the diagnosis is complete. In exceptional cases, an initial observation phase under close medical supervision may also be carried out.

The treatment concepts for mantle cell lymphoma are less well investigated in trials than for the more common lymphoma diseases due to their low frequency. Nevertheless, valuable progress has been made recently, leading to the approval of new effective drugs.



Patients who are younger than 60 to 65 years of age and who do not suffer from significant concomitant diseases are usually treated with intensive therapy procedures. These initially consist of repeated chemotherapy treatments. This is usually followed by high-dose chemotherapy with subsequent blood stem cell transplantation.

Since many patients are 65 years and older, it is often not possible to carry out such intensive treatment procedures because of the expected side effects. Milder therapies are used for these patients.

Whenever possible, patients should be treated in clinical trials. The results of such studies have led to the approval of ibrutinib, the tyrosine kinase inhibitor (see glossary). This medicine can be taken as a tablet. It is effective against mantle cell lymphoma and causes few side effects.

9.5 Aftercare

In general, after completion of treatment, regular follow-up checks are carried out to identify early on when further treatment is necessary. The intervals between the checks as well as the necessary examinations are individually adapted and determined in consultation with the treating specialist (haematologist, oncologist). Aftercare includes clinical examinations, blood tests and, if necessary, imaging procedures.

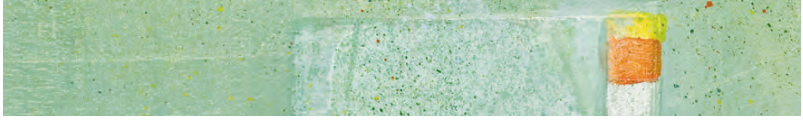
10 Hodgkin lymphoma

10.1 Introduction

Hodgkin lymphoma takes its name from Thomas Hodgkin, an English physician who first described the disease in 1832 (also known as «Morbus Hodgkin», morbus is Latin for «the disease»). Hodgkin's is one of the most common lymphomas of early adulthood. Typically, those affected are around 30 years old. Men are slightly more often affected than women. Every year, about 200 people fall ill in Switzerland. Not infrequently, they have suffered from mononucleosis before. «Mono» is caused by the Epstein-Barr-Virus (EBV). The exact relationship between the virus and the occurrence of Hodgkin remains unclear. Almost all people go through an EBV infection in the course of their lives. Many people don't notice it. In the vast majority of cases, no lymphoma develops afterwards. The following message is important: Hodgkin lymphoma is not a contagious disease.

10.2 Symptoms

In Hodgkin's patients, lymph node swelling occurs first, usually in the neck. Many affected people notice this by chance when they are doing personal hygiene or are made aware of it by other people. The swelling doesn't hurt. Not infrequently, however, the swelling is significant in the thorax, so much so that the nodes press on the windpipe and lead to breathing difficulties. Occasionally a disturbing, sometimes severe itching occurs. Almost half of all patients also suffer from heavy night sweats, weight loss and a fever of unknown origin above 38 degrees (B symptoms). The fever can last for weeks and does not respond to antibiotics.



10.3 Diagnosis

A whole series of examinations is necessary for the diagnosis and the determination of the therapy. In a first step, a tissue sample is taken (biopsy). This is usually a minor surgical procedure that is performed in a place that is easily accessible and, if possible, does not leave a cosmetically disturbing scar.

In addition, various blood tests are carried out. The PET-CT examination (see glossary) is now standard. Bone marrow examination is now only rarely necessary.

After completion of the examinations, the patients are divided into one of three groups: low, medium and high risk. Patients in these three groups are treated differently.

For patients and partners who are not finished having children, the issue should also be addressed at an early stage. This is very important because the treatment of Hodgkin lymphoma can lead to infertility.

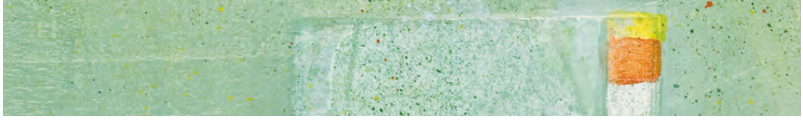
Men have the option of having sperm frozen before starting treatment. This can be used for procreation at a later date. Today, the preservation of oocytes is also possible for women. Early information is important, as the creation of a «procreation reserve» requires time (see section 3.9).

10.4 Treatment

Low risk

Low risk means that at most two lymph node regions on the same side of the diaphragm are affected (e.g. neck and armpit). The nodes also must not be too large. The standard treatment for this group consists of two cycles of chemotherapy and radiation therapy. The ABVD regimen is often chosen as chemotherapy (ABVD is the abbreviation for the four cancer drugs adriamycin, bleomycin, vinblastine and dacarbazine). Four infusions in total are necessary at intervals of two weeks each. The entire course of chemotherapy therefore takes about two months. Despite this relatively short duration of therapy, hair loss and other typical side effects of chemotherapy must be expected (see chapter 4). Radiotherapy begins about three weeks after the end of chemotherapy and lasts about three weeks. The size of the body region to be irradiated depends on the spread of the lymphoma. The «radiation field» is kept as small as possible. The radiation dose is also relatively low. After chemotherapy has been completed, a PET examination is usually performed. In about 80% of patients a «negative PET» is seen after only two to three cycles of ABVD, which means that Hodgkin's has completely disappeared after this short time.

Despite the negative PET, the previously affected area is irradiated according to standard therapy. If this irradiation is carried out, the relapse rate within five years is about 5%, which means that one out of every 20 people affected has to undergo secondary treatment. This treatment is usually more intensive than the initial treatment. It may even require high-dose therapy with bone marrow transplantation. However, most patients are cured with this secondary treatment.



According to several studies, irradiation can also be omitted when the PET is negative. This increases the relapse rate from 5% to 10%, which means that one in ten patients has to undergo secondary treatment. Again, most patients are cured with this secondary treatment.

This procedure has the advantage that less radiation is used. This is because even small doses of radiation can possibly lead to side effects in the long term. If the heart is irradiated, heart attacks can occur later, for example, due to increased arteriosclerosis. With the current standard therapy, relapses are less frequent, but all patients are irradiated. With the new options, the relapse rate is somewhat higher, but nine out of ten patients with a negative PET do not need to be irradiated and will therefore not suffer from any late effects of radiotherapy.

These options must be carefully discussed with the doctor treating you.

Medium risk

There is a medium risk if individual lymph nodes have become very large, if there are additional B symptoms, or if the erythrocyte sedimentation rate is greatly increased. A chemotherapy regimen is now also used that has proven to be effective mainly in cases of advanced Hodgkin's disease: the BEACOPP regimen (bleomycin, etoposide, adriamycin, cyclophosphamide, oncovin, prednisone, procarbazine), which is given twice every three weeks on an outpatient basis. Experts speak of an «escalated« therapy because the drug doses are significantly higher than in the standard scheme. In addition, two cycles of the ABVD scheme are used. The entire chemotherapy period lasts at least four months, followed by radiotherapy. If the entire treatment proceeds according to plan, relapses occur only slightly more frequently than in low-risk patients.

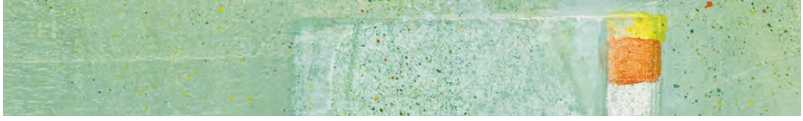
Similar to low-risk patients, experts are currently discussing whether radiotherapy can be omitted if PET shows a complete disappearance of Hodgkin's after chemotherapy. This question is being investigated in clinical trials. Ask your doctor whether you can participate in a trial.

High risk

In advanced Hodgkin lymphoma, lymph nodes throughout the body are affected. In addition, organs such as the liver, lungs or bone marrow can be riddled with cancer cells. At this stage, six cycles of the BEACOPP regimen described above are usually performed (at three-week intervals whenever possible), often without subsequent irradiation. Such a therapy scheme can be very wearing. The entire duration of therapy can last up to nine months, including recovery time. The number of relapses is slightly more frequent than in a low-risk Hodgkin's. However, the forecast has improved considerably over the past ten years.

In case of a relapse, intensive therapies are necessary. These are usually carried out during an inpatient stay. In most cases, high-dose chemotherapy with autologous stem cell transplantation is performed. The cure rate is high even after this second therapy.

In Switzerland, Hodgkin's disease is usually diagnosed and treated during therapy trials. In these trials, patients are offered the most modern active ingredients and therapies. Many centres participate in the therapy optimisation studies of the German Hodgkin Study Group (see www.lymphome.de). These studies are coordinated in Switzerland by the SAKK, the Swiss Group for Clinical Cancer Research (www.sakk.ch). If a patient does not want to or cannot participate in a trial, standard treatment is available outside the trial.



10.5 Aftercare

Aftercare is carried out every three to four months in the first few years, then every six months, and approximately once a year from the fifth year onwards. Relapses usually occur in the first few years, after five years a relapse is very rare. The focus is then rather on the question of possible late effects. Lungs, heart and thyroid gland must be checked regularly. In women, regular examinations of the breast (mammography, MRI, etc.) must also be carried out after radiation.

11 Follicular lymphoma

11.1 Introduction

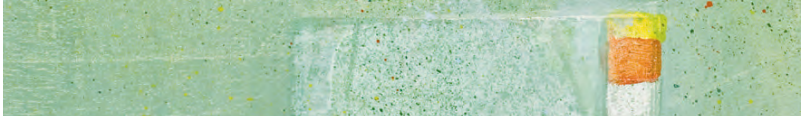
Follicular lymphoma (FL) is the most common indolent, i.e. slowly growing lymphoma. Follicular lymphomas represent about 20 percent of all malignant lymphomas. In recent decades its frequency has increased significantly. Every year, five to seven people fall ill for every 100,000 inhabitants in Switzerland. The patients are usually around 60 years old at the time of diagnosis. FL occurs slightly more frequently in women than in men.

Why FL develops is not known in detail. Very often, a change in the genetic material is discovered in the tumour cells of FL patients, a translocation: an exchange of parts of chromosome 14 with chromosome 18. This change slows down the breakdown of the mutated cells and these accumulate in the lymph nodes. But FL is not a hereditary disease.

11.2 Symptoms

The first and most common symptom is enlarged lymph nodes. Other symptoms are fever, night sweats and weight loss. Often, however, those affected have hardly any troubles, even if the disease is already well advanced. Therefore, the disease is usually diagnosed late in many patients.

In addition to the lymph nodes, the spleen, bone marrow and lymphatic tissue in the throat can also be affected, in rare cases the gastrointestinal tract or skin. If the bone marrow is severely affected, blood formation may be impaired. Frequently, symptoms such as fatigue or reduced performance also occur.



11.3 Diagnosis

For the diagnosis, the doctor usually requires a tissue sample (biopsy) of an affected lymph node. The FL is divided into three grades: Grades 1, 2, 3A and 3B. Among other things, this has an impact on subsequent treatment. An FL with grade 3B is treated like an aggressive lymphoma (see chapter 8).

Once the diagnosis has been made, «staging» examinations are carried out to determine the extent of the disease. As a rule, PET-CT, blood and bone marrow examinations are carried out.

Once the results are available, a stage classification is made (stages I to IV). The stage determines the type and intensity of treatment.

With the «International Prognostic Index for Follicular Lymphoma» (FLIPI), patients with FL can be classified into prognostic groups.

11.4 Treatment

If FL is discovered early and is still limited to one or two lymph node regions (stage I and II), radiation (radiotherapy) is the preferred treatment and there is a good chance of recovery.

Patients in advanced stages (stage III and IV) who have no symptoms often are told to wait until either symptoms appear or the extent of the disease clearly increases. This procedure is often difficult for the patient to understand. In FL patients, large studies have shown that long-term treatment results cannot be improved with an early start of treatment. The patients are of course under regular oncological monitoring.

If therapy is necessary, it can be carried out with the active substance rituximab alone or with a combination of cytostatic drugs.

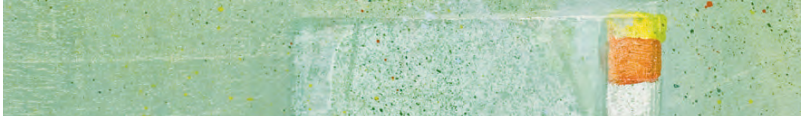
Treatment with rituximab alone is particularly suitable for patients who cannot tolerate or do not wish to undergo more intensive therapy or who have very favourable prognostic factors.

Chemotherapies used to use the R-CHOP (cyclophosphamide, doxorubicin, vincristine and prednisone) regimen or combinations such as CVP (cyclophosphamide, vincristine, prednisone) or FC (fludarabine, cyclophosphamide) (see glossary). Today, the drug bendamustin along with a B cell antibody is commonly used as initial therapy.

After a combined immuno-chemotherapy, a antibody maintenance therapy with rituximab can be used to prolong the time period until a relapse occurs. The antibody is administered every two to three months during two years.

Also conceivable is radio-immunotherapy (see section 3.5), a combined immuno-chemotherapy and radiation treatment that attacks the cancer cells from several sides at once. If radio-immunotherapy is used after chemotherapy or combined immuno-chemotherapy, the treatment results can be improved.

In younger patients with a relapse, high-dose chemotherapy with transplantation of the patient's own stem cells (autologous stem cell transplantation) is a treatment option (see section 3.7). In high-dose chemotherapy, cytostatic drugs are used in very high dosages – with the aim of killing as many lymphoma cells as possible. This treatment also destroys the healthy blood stem cells (hematopoietic stem cells) in the bone marrow. Therefore, before high-dose chemotherapy, the patient's own blood stem cells must be collected and frozen until they



are used. After the high-dose chemotherapy, the patient's own stem cells are returned to him/her intravenously. The stem cells reach the bone marrow, multiply there and thus restore normal blood formation. It takes 10 to 14 days for blood formation to recover after high-dose chemotherapy. During this time the patient's immune system is very weakened and the risk of serious infections is correspondingly high. Patients often need broad-spectrum antibiotics and medication against fungal and viral infections during this treatment phase. Transfusions of red blood cells (erythrocytes) and blood platelets (thrombocytes) are also often necessary. In Switzerland, such stem cell transplants are only carried out in specialised centres.

Overall, the treatment options for patients with follicular lymphoma have increased in recent years and the treatment results have improved. The tyrosine kinase inhibitor idelalisib is effective in relapses.

11.5 Aftercare

Aftercare for an FL includes a physical examination as well as an enquiry about any difficulties. In symptom-free patients where the decision was made to wait and watch for therapy, examinations are usually carried out every three to four months. Those affected must also observe themselves and report immediately if they discover new symptoms or new lumps. Psychologically, such a waiting phase is usually a challenge for patients.

Follow-up care for patients who have already been treated is usually every three months for the first two years after treatment, later every four to six months. Routine computed tomography is increasingly being abandoned for patients without symptoms in order to reduce radiation exposure. Instead, other imaging procedures such as ultrasound examinations can be performed.

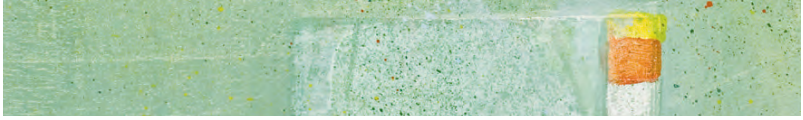
12 Chronic lymphatic leukaemia

12.1 Introduction

The abnormal cells of chronic lymphocytic leukaemia (CLL) are B-lymphocytes. CLL tumour cells are mainly found in the blood and bone marrow. If a blood sample with many white blood cells is left standing for a longer period of time, the malignant cells in the glass tube become visible as a white stripe. This observation also led to the name leukaemia (Greek: leukos [white], haima [blood]).

CLL is one of the most common blood diseases. The risk of developing CLL increases with age. The reason for the development of CLL is still unknown. The good news is that in many cases, CLL progresses very slowly (over years or decades) and often causes few symptoms.

Lymphocytic B-cell lymphoma
Lymphocytic B-cell lymphoma, abbreviated SLL (stands for «small lymphocytic lymphoma») is a subtype of CLL with no or only few tumour cells in the blood. Symptoms and treatment are similar to CLL. The lymph nodes are mainly affected and to a lesser extent the blood and bone marrow. SLL patients are also usually older than 60 or 70 years.



12.2 Symptoms

Today, CLL is often discovered by chance, for example when a blood sample has to be taken before an operation. Many patients have no complaints for years. Over the years, the number of tumour cells can increase. In the bone marrow the normal cells are displaced. Anaemia with respiratory distress and weakness may occur. A disturbance of the immune system with frequent infections occurs. The immune system can also overreact and attack the body's own cells. Typically the red blood cells are affected. The decomposition of the red blood cells can lead to severe anaemia and the decomposition products of the blood lead to jaundice, a yellowing of the skin. In advanced stages, the lymph nodes, the liver or the spleen may also swell. This can be noticeable and disturbing for the patient. Fever, night sweats, and weight loss may occur.

12.3 Diagnosis

Today, as mentioned above, CLL is often discovered during a routine blood test, for example during an operation or a «check-up». A striking feature is an increase in lymphocytes (lymphocytosis), a subgroup of white blood cells. Today, the diagnosis of CLL in the blood can be made from a blood sample using modern equipment. However, an examination of the bone marrow or a lymph node biopsy may become necessary.

Staging and prognostic factors

In order to assess the stage of the disease, the condition of the lymph nodes and the size of the liver and spleen are examined by palpation, in addition to the blood count. In Europe, the clinical classification of the disease stage is usually based on the Binet classification.

In CLL, there are numerous prognostic factors that are detected using special methods. If changes in chromosome 17 are detectable, modern drugs such as the tyrosine kinase inhibitor ibrutinib are used today.

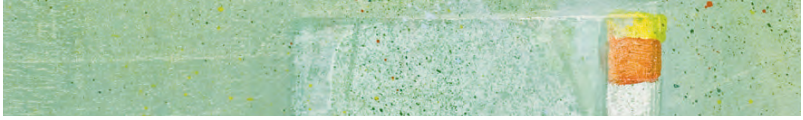
12.4 Treatment

As with other indolent lymphomas, the concept for CLL is to treat patients only when symptoms are present or the number of healthy blood cells is reduced, i.e. when there is an anaemia or a reduction in platelets with bleeding.

Due to the increasingly frequent early diagnosis and often slow progression of the disease, many patients with CLL can live for years without symptoms and without treatment. Patients in the early stages (most Binet A, many B) without disease-related complaints are therefore not treated initially. This procedure is known as «wait and watch». The treatment depends mainly on the general physical health of the patient.

Patients with disease-related complaints or patients in advanced stages of the disease are treated with cytostatic drugs and B-cell antibodies. Radiotherapy and surgery are of little importance in the treatment of CLL.

The goal of the therapy is a significant improvement or disappearance of the symptoms. This can be achieved over many years and even decades. According to current knowledge, curing with cytostatics and antibodies is very rare. However, a cure can be achieved in some patients using allogeneic stem cell transplantation. However, this procedure is limited to younger patients with an unfavourable course of disease. But even in young patients, such transplantation can cause considerable side effects.



Whenever possible, patients should be treated in clinical trials. Patients with more serious concomitant diseases will continue to be successfully treated with the cytostatic drug chlorambucil, which has been tried and tested for decades, in combination with a newly developed B-cell antibody (obinotuzumab). For patients who are «healthy» with the exception of CLL, therapies with the cytostatic drugs fludarabine and cyclophosphamide as well as the antibody rituximab• are recommended or, from the age of 65 years, with the cytostatic drug bendamustin in combination with rituximab•.

Today, targeted drugs such as the tyrosine kinase inhibitors ibrutinib or idelalisib (combined with rituximab•) are the treatment of choice for patients with changes on chromosome 17 (deletion 17p or TP53 mutation), for patients resistant to therapy, or for early relapses.

12.5 Aftercare

Regular check-ups include a supplement to the patient's medical history, an examination of the lymph nodes, liver and spleen by means of palpation, and blood tests every three to six months. These follow-up examinations are usually carried out alternately by the family doctor or by the haematologist and/or oncologist.

• Off-label, see glossary

13 Marginal zone lymphoma

13.1 Introduction

Marginal zone lymphoma (MZL) belongs to the family of indolent, i.e. slowly growing B-cell lymphomas. The marginal zone is an area of lymphatic tissue where the cells of this type of cancer develop. Basically, this disease is divided into three different categories: A first group is called **MALT marginal zone lymphoma** (where MALT stands for «mucosa-associated lymphatic tissue», the lymphatic tissue associated with the mucous membrane). A second group describes the very rare variant of a **marginal zone lymphoma, which predominantly affects the spleen**, and a third group describes the disease when it affects the lymph nodes, **the nodal MZL**.

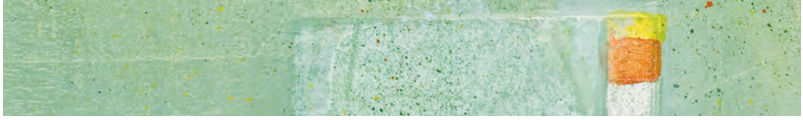
The MZL of the spleen and the nodal MZL are rare, MALT-MZL occurs somewhat more frequently.

The three categories are briefly introduced below.

13.2 MALT marginal zone lymphoma

13.2.1 Introduction

Lymphomas of this type are by far the most common in the mucous membranes of the digestive tract, usually the stomach. The mucous membranes are then often chronically inflamed. It is assumed that this lymphoma is mainly caused by the bacterium Helicobacter pylori or that the bacterium at least influences the course of the disease. This bacterium can lead to the development of chronic gastritis (inflam-



mation of the gastric mucosa). In a second step this can develop into lymphoma. However, other bacteria can also play a role in the development of MALT lymphomas in other organs, such as the skin or the eye; for example, certain Borrelia pathogens that are transmitted by ticks, Chlamydium psittaci that is transmitted by birds, and Campylobacter, a bacterium that can cause diarrhoea. People who have suffered or are suffering from autoimmune diseases are also at increased risk of developing MALT lymphoma.

13.2.2 Symptoms

In general, the symptoms occur at the origin of the disease – usually they are unspecific. In the stomach, this tumour can, for example, cause the same symptoms as an inflammation of the mucous membrane of the stomach or a stomach ulcer. MALT-lymphomas can basically develop in almost all organs and tissues, for example in the salivary glands, in the lacrimal glands, in the eyelid or in the skin.

Sometimes the lymph nodes are affected, in about ten percent of the cases the bone marrow is also affected and sometimes it spreads throughout the body. However, MALT lymphoma can also remain localised over a longer period of time and not spread further in the body. The majority of MALT patients have a favourable prognosis. Many patients only suffer from mild symptoms (indolent form). The disease rarely takes an aggressive course, and only a few patients die of MALT lymphoma.

13.2.3 Diagnosis

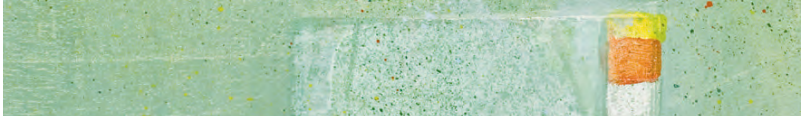
The diagnosis is based on the examination of a tissue sample (biopsy). If the lymphoma is localised in the stomach, the presence of the bacterium Helicobacter pylori can be determined by means of various examinations in the blood, in the air we breathe and in the stool. Gastroscopy can be used to determine how far advanced the disease is, or how severely the stomach wall and surrounding tissue are already affected.

13.2.4 Treatment

For MALT gastric lymphoma, the type of treatment depends on whether or not the H. pylori bacterium has been detected in a patient. If the bacterium is present, the bacterium is quickly treated with appropriate antibiotics. 80 percent of patients treated with antibiotics are cured of gastritis within 10 to 15 days. If the antibiotics of the first phase do not respond, the doctor will try therapy with other antibiotics in a second phase. The destruction of the bacterium causes complete dissolution of the MALT lymphoma in about 50 to 70 percent of cases.

Treated MALT patients may occasionally develop stomach cancer. Therefore, careful follow-up with regular gastroscopies over a longer period of time is necessary even for patients whose MALT lymphoma has been completely cured.

If a patient does not respond to these treatments, the stomach may need to be surgically removed or radiotherapy may follow. If drug therapy is necessary, then it is usually a combined chemo-immunotherapy.



If MALT lymphoma does not occur in the stomach but, for example, in the thyroid or lacrimal gland, the standard therapy must be adapted to the individual patient. In patients with MALT lymphoma around the eyes, irradiation with a low radiation dose can lead to complete disappearance of the lymphoma.

Many patients with MALT lymphoma have an exceptionally good chance of survival.

13.3 Marginal zone lymphoma of the spleen

13.3.1 Introduction

Patients with a marginal zone lymphoma (MZL) of the spleen usually have hardly any ailments over a long period of time. In these cases treatment can wait.

13.3.2 Symptoms

After a certain period of time, the growing spleen can cause problems. There may be pain in the upper abdomen and pressure on the surrounding organs. If the spleen presses on the stomach, this can lead to a feeling of fullness and loss of appetite. When the spleen becomes very large, splenic infarctions can occur, which in turn can suddenly cause very severe pain.

13.3.3 Diagnosis

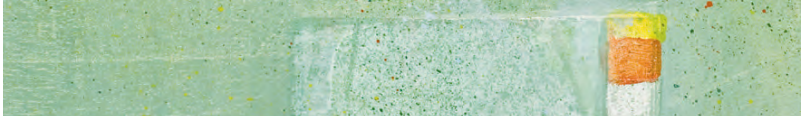
To make a diagnosis, the spleen usually has to be removed, but a bone marrow biopsy can also provide important information. The removal of the spleen is necessary to determine the causes of spleen enlargement. Diagnostic tissue sampling of the spleen is not performed due to the risk of bleeding. The hepatitis C virus appears to be partially involved in the development of this lymphoma. The hepatitis C virus thus behaves in the development of this lymphoma in a similar way to the Helicobacter bacterium in MALT lymphoma of the stomach. A possible hepatitis infection must therefore be looked for at the time of diagnosis.

13.3.4 Treatment

Removal of the spleen (splenectomy) has been the treatment of choice for a long time. Its advantage is the long-term effect. Patients can be cured after this operation. Other patients may require further treatment after years. In recent years, however, the antibody rituximab• directed against the B cells has been used more and more often, at best in combination with chemotherapy, to avoid a splenectomy.

For patients with hepatitis infection, antiviral treatment with liver specialists must be considered. In certain cases, the treatment of hepatitis may also result in a decrease in lymphomas. If chemotherapy is performed, it is usually combined with rituximab• in case of lymphomas that have spread (if bone marrow or lymph nodes are affected) or in case of an aggressive course.

• Off-label, see glossary



13.4 Marginal zone lymphoma of the lymph nodes

13.4.1 Introduction

The MZL of the lymph nodes belongs to the rather rare indolent lymphomas. It generally occurs in people over 60 years of age. Women are affected slightly more often than men. This lymphoma is also associated with hepatitis C infection.

13.4.2 Symptoms

Many patients notice an increase in the size of the lymph nodes. Mostly the lymph nodes on the neck are affected, possibly also lymph nodes on other parts of the body.

13.4.3 Diagnosis

The diagnosis is based on a lymph node biopsy. The initial examinations are the same as those used for the other types of MZL lymphomas. At the time of diagnosis the bone marrow may be affected.

13.4.4 Treatment

The forms of treatment are similar to those for follicular lymphoma. Therapeutic options include chemotherapy, for example with chlorambucil or bendamustin. Mostly, rituximab• is used. In patients with hepatitis C, antiviral treatment can lead to a reduction in lymphoma.

• Off-label, see glossary

14 Waldenström's Macroglobulinemia

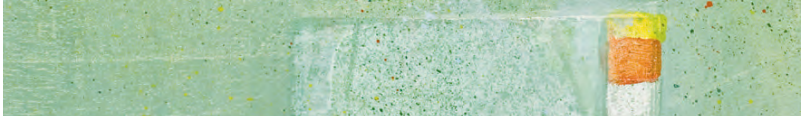
14.1 Introduction

Waldenström's Macroglobulinemia (MW) is a disease of the white blood cells (B lymphocytes). The disease was first described in 1944 by the Swedish doctor Jan Gösta Waldenström. Characteristic of this disease is an overproduction of a certain antibody (immunoglobulin M [IgM]). IgM is a relatively large molecule and can lead to viscosity of the blood plasma (plasma viscosity). Often the bone marrow is also affected with MW.

Waldenström's Macroglobulinemia is a rare disease: In Switzerland, fewer than 50 people fall ill with it each year. The mean age of MW patients at diagnosis is around 65 years. Men are more frequently affected than women. The cause of the disease is largely unclear. In about 20 percent of cases, MW is hereditary.

14.2 Symptoms

In a quarter of the patients, «Waldenström» is determined by chance during a routine examination. The MW often develops insidiously and subsequently manifests itself as general weakness and fatigue, with loss of appetite, weight loss and fever. Occasionally there are also nerve disorders with loss of sensation and strength, or «Raynaud's phenomenon» in which individual fingers suddenly turn white. The protein IgM produced in excess with MW can make the blood viscous. This in turn can lead to dizziness, headaches, blurred vision or even bleeding. The disease also affects various organs and the bone marrow, which can lead to anaemia with symptoms such as fatigue. Blood platelets can also be reduced, which leads to increased bleeding.



14.3 Diagnosis

A strongly elevated IgM level in the blood usually proves Waldenström. In many cases the IgM-producing lymphoma cells can be detected in the bone marrow or in an enlarged lymph node. In addition to the usual examinations for lymphomas (see section 2.7), special tests are carried out to check the coagulation and viscosity of the blood. The mutation MYD88 L265P can be detected in more than 90 percent of patients.

14.4 Treatment

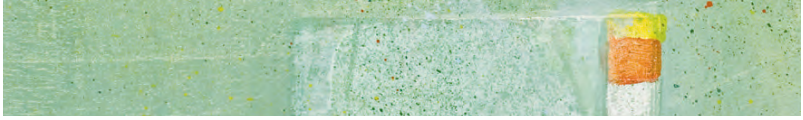
As with other indolent lymphomas, treatment of Waldenström's Macroglobulinemia can be postponed if there are no symptoms. If symptoms occur, the treatment depends on the severity of the symptoms, age, and additional diseases. The range of treatment extends from simple therapies with tablets to high-dose therapy with autologous blood stem cell transplantation. If the IgM protein has increased significantly within a short period of time, «blood filtering» (plasmapheresis) is occasionally necessary: a very complex, but also quickly effective treatment.

The antibody rituximab• directed against the B cells can also be very helpful. Often a combined chemo-immunotherapy is recommended. A new group of drugs, called tyrosine kinase inhibitors (TKI) such as ibrutinib, appear to be very effective.

• Off-label, see glossary

14.5 Aftercare

If there is a treatment response, follow-up examinations take place approximately every three to six months. If the disease breaks out again, a new round of treatment becomes necessary. If the relapse occurs more than twelve months after the initial treatment, the original therapy can be repeated. Patients who experience a relapse in the first twelve months after therapy should be treated with other agents (alone or in combination). In this situation, high-dose chemotherapy with autologous stem cell transplantation may be necessary.



15 T-cell lymphoma

15.1 Introduction

B cells and T cells are part of the immune system and belong to the white blood cells. The majority of lymphomas originate from B cells or T cells and accordingly are also called B-cell or T-cell lymphomas. Only about ten percent of all lymphomas are T-cell lymphomas. T-cell lymphomas are divided into numerous, sometimes very rare subgroups. They can affect the skin, the lymph nodes (nodal) or the internal organs. They can grow slowly (indolent) or take an aggressive course.

How T-cell lymphomas develop is largely unclear. Patients who have suffered or are suffering from chronic inflammation of the bowel (for example, celiac disease, an intolerance to the cereal protein gluten) have an increased risk of T-cell lymphoma. The T-cell leukaemia virus, a pathogen related to the HI virus that occurs in Japan and the Caribbean, leads to a special form of T-cell lymphoma.

15.2 Symptoms

A typical T-cell lymphoma of the skin is mycosis fungoides (MF). In the beginning only the skin may be affected, reddish inflamed eczema-like spots appear, which can expand in the further course of time and lead to plaques and can turn into nodes. In a subsequent phase, lymph nodes or organs may also be affected. The disease is chronic over years and decades.

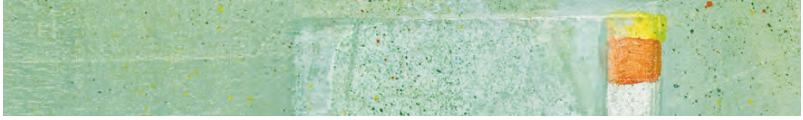
T-cell lymphoma often begins with involvement of the lymph nodes. Due to the symptoms it is usually hardly distinguishable from B-cell lymphoma. It can affect other organs, such as the gastrointestinal tract, bone marrow, liver and often the skin. Often patients suffer from itching, night sweats, fever and weight loss.

A somewhat less common form is called angioimmunoblastic T-cell lymphoma (AITL). Mostly the lymph nodes are affected, often the liver and/or the spleen are enlarged. Skin changes with sometimes severe itching and fever can also occur.

15.3 Diagnosis

The diagnosis of T-cell lymphomas of the skin consists of a combination of clinical examinations as well as the analysis of a skin sample (biopsy) and various blood analyses. In cutaneous T-cell lymphomas, it is important to record the exact extent of the disease (staging) in order to rule out possible involvement outside the skin. In addition to the clinical examination, imaging procedures such as radiography, computed tomography, biopsies of suspicious lymph nodes, and a bone marrow examination can contribute to the diagnosis. The stage of the disease therefore depends on how severely the skin is affected and whether other organs are involved.

In other peripheral T-cell lymphomas, tissue sampling (biopsy) is important for the exact classification of the disease. A marker that can be detected in tumour tissue, the ALK-1 marker, usually indicates T-cell lymphoma with a better prognosis. In general, T-cell lymphomas are more difficult to treat than B-cell lymphomas.



15.4 Treatment

T-cell lymphomas of the skin are usually treated by skin specialists (dermatologists). A variety of locally applied therapies are used. UV light therapies in combination with drugs are very effective. A T-cell lymphoma of the skin is nowadays mostly a chronic skin disease. Chemotherapy is only carried out in exceptional cases.

T-cell lymphoma of the lymph nodes is initially treated with the CHOP or similar chemotherapy regimen. In younger patients, high-dose chemotherapy with autologous stem cell transplantation is usually performed. In case of relapse or non-response to the therapy, allogeneic stem cell transplantation can even be performed if a donor is available. However, this procedure is often not possible due to the age or general condition of the patient.

15.5 Aftercare

The frequency of follow-up examinations depends on the respective lymphoma type, the stage of the disease and the success achieved with the therapy. The checks are often carried out at intervals of three to six months. During the follow-up examinations, the patient's medical history and findings are discussed and, if necessary, further examinations are carried out (e.g. blood samples, radiography, computed tomography, and tissue samples).

16 Rare lymphomas

16.1 HIV-associated lymphoma

16.1.1 Introduction

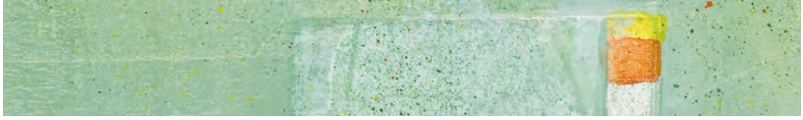
People with a weakened immune system have a higher risk of lymphoma diseases. This may be due to a chronic overload of the immune cells (B cells). Therefore, patients with HIV infection also have an increased risk of developing malignant lymphoma. Frequently, these are aggressive lymphomas, which very quickly lead to ailments and occur in unusual places.

16.1.2 Symptoms

Typical symptoms are general symptoms like weight loss, fever and night sweats. If the central nervous system is affected, headaches, cranial nerve disorders, or epileptic seizures occur. Sometimes the symptoms are difficult to distinguish from the HIV disease. The HIV disease itself can lead to an enlargement of the lymph nodes. This may occasionally delay diagnosis. If enlarged lymph nodes that are already known to occur in HIV disease suddenly increase in volume rapidly, malignant lymphoma could be the cause.

16.1.3 Diagnosis

In addition to the standard tests (biopsy, etc.), the doctor will make an exact assessment of the HIV disease. The viral load and the number of CD4 lymphocytes in the blood must be determined.



16.1.4 Treatment

The treatment of HIV-associated lymphomas is no different from the treatment of other lymphomas with an intact immune system. The increased risk of infection of the patient during treatment as well as drug interactions must be taken into account. In addition, it must be determined whether the patient suffers from hepatitis B or C disease that requires treatment. The drugs used to treat the HI virus are usually well tolerated by the necessary chemotherapeutic agents, but close cooperation between oncologists and HIV specialists is important. Many lymphomas are curable despite HIV disease.

16.1.5 Aftercare

With good control of HIV disease, the prognosis of HIV-associated lymphoma patients is similar to that of other lymphomas. Aftercare is limited to clinical and imaging monitoring. In the event of a relapse, HIV patients can now also be treated with high-dose chemotherapy and autologous stem cell transplantation.

16.2 Primary mediastinal B-cell lymphoma

16.2.1/2 Introduction/Symptoms

Primary mediastinal B-cell lymphoma (PMBCL) mainly affects women between 30 and 40 years of age. PMBCL develops in the chest area, behind the sternum (mediastinum) and, due to the extensive growth between the lungs and oesophagus, leads to breathing difficulties, pain in the shoulder girdle, swelling of the throat and difficulty swallowing.

16.2.3 Diagnosis

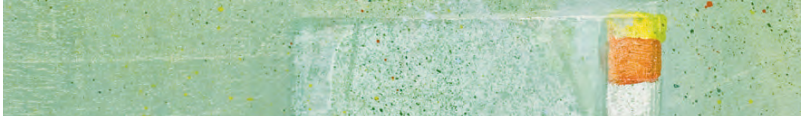
The diagnosis is based on the examination of the affected tissue behind the breastbone. Tissue biopsy is often difficult because the lymphoma grows into the surrounding structures. PMBCL is closely related to Hodgkin's disease and should be clearly distinguished from it.

16.2.4 Treatment

Like all aggressive lymphomas of the B-cell type, PMBCL is treated with a combined immuno-chemotherapy. One of the frequently used therapies is called DA-EPOCH-R (see glossary). This is one of the few treatments that is performed as an inpatient. The cure rates are high. PET-CT examinations (see glossary) before and during treatment are essential. The course of the PET-CT examinations also helps in deciding whether radiotherapy is still necessary after chemotherapy. The irradiation of the chest area is very delicate because vital structures such as the heart or lungs cannot be completely blended out of the radiation fields.

16.2.5 Aftercare

The rare relapses usually occur in the first two years after diagnosis. Late post-radiation care includes regular monitoring of lung function, coronary vessels and heart valves. This aftercare should be lifelong.



16.3 Burkitt's lymphoma

16.3.1 Introduction

Classical Burkitt's lymphoma is a rare disease in children and adults, named after the British doctor Denis Burkitt. It is responsible for about one percent of all lymphoma diseases.

16.3.2 Symptoms

A very high cell division rate is characteristic of the disease: It is one of the fastest growing tumours. This can lead to extensive lymphoma masses. The symptoms therefore often include not only the classic B-symptoms such as night sweats etc., but the rapidly growing tumour masses can press on the trachea, intestine or kidneys, and serious symptoms can quickly develop.

16.3.3 Diagnosis

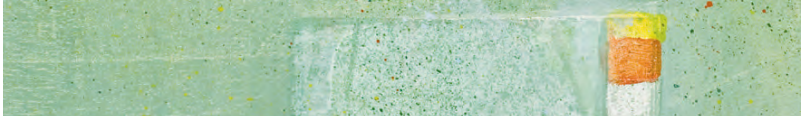
The diagnosis is based on the tissue examination of an affected lymph node or organ. In addition, the tissue specialist looks for typical changes in the genetic material of lymphoma cells: on the one hand, a change in a gene called c-myc, on the other, chromosome translocations (exchanged gene fragments on chromosomes). Diagnostic imaging, a bone marrow examination, and an examination of cerebrospinal fluid are carried out before starting treatment. The prognosis depends on the extent of the disease in the body.

16.3.3 Treatment

The treatment usually involves short but intensive combinations of chemotherapy and immunotherapy. In order to avoid an involvement of the meninges or the brain, a preventive administration of chemotherapeutic agents is necessary, some of which are injected into the cerebral-spinal fluid. The treatment of Burkitt's lymphoma is very demanding, even in young patients. The possibility of high-dose chemotherapy with a blood stem cell transplant is often considered. The treatments are usually carried out in the hospital. Burkitt's lymphoma is curable in many cases today.

16.3.4 Aftercare

Aftercare for Burkitt's lymphoma consists of regular check-ups with blood count and possibly imaging examinations. The frequency of follow-up examinations usually depends on the treatment protocol used.



16.4 Lymphoma with extranodal involvement

16.4.1 Introduction

We speak of an extranodal involvement when it is not primarily the lymph nodes that are affected, but rather internal organs such as the spleen, liver, lungs, or intestines. Extranodal involvement is not a disease in itself, but a manifestation of lymphoma that is more likely to occur in aggressive lymphomas. Extranodal lymphoma foci also have prognostic significance and influence therapy.

Lymphomas in brain tissue and the testicles are special extranodal forms and require special treatment.

16.4.2 Treatment

The treatment is usually in the form of a combined immuno-chemotherapy. In special cases radiotherapy is also added.

16.4.3 Aftercare

Follow-up care is the same as for the underlying lymphoma (see chapters 8 and 11).

III Annex

17 Service

17.1 Glossary

Aggressive Rapid progress, if not treated (within weeks or a few months)

Anaemia Reduction of red blood cells

Antibodies Defence molecules of the immune system

B-cell (Also B-lymphocyte) part of the immune system, produces antibodies to fight pathogens

Benign Of a mild type that does not threaten life

Biopsy Removal of a tissue sample

Blood stem cell Stem cell in the bone marrow, from which all cells of the blood can develop

Bone marrow puncture Removal of bone marrow tissue to examine the cells of blood formation, mostly from the pelvic bone and rarely from the sternum

B-symptoms Fever, night sweats, weight loss

Carcinogenic Promotes or causes cancer

Chemotherapy Treatment with drugs that inhibit cell growth, reduce cell proliferation, or block the functional reserves of the cells

CHOP Chemotherapy consisting of a combination of the active substances cyclophosphamide, doxorubicin, vincristine and prednisone

CLL Chronic lymphatic leukaemia: most common form of cancer of the white blood cells (leukocytes) in adults

CT Computed tomography: computer-assisted acquisition and analysis of serial images with X-rays

CVP Chemotherapy consisting of a combination of the drugs cyclophosphamide, vincristine and prednisolone

Cytokines Proteins that are released by cells of the immune system. They serve as information signals between different cell systems of the body. Interferons are cytokines which, in high concentrations, can act like chemotherapy.

Cytostatics Collective term for the older generation of broadly effective drugs against cancer

DA-EPOCH-R Dose-adapted therapy with etoposide, doxorubicin, cyclophosphamide, vincristine, prednisone and rituximab (chemotherapy treatment)

Diagnostics Collective term for all examinations that lead to the determination of a disease

Dosage Determination of the active ingredient quantity per time unit (day, week, and so on)

Growth factor Substance that stimulates the production of certain body cells (for example blood cells)

Haematology Science of blood and its diseases

High-dose therapy Strong chemotherapy, which leads to damage to the bone marrow and makes a stem cell transplantation necessary

HTLV-1 (Human T-Lymphocyte Virus-1), a retrovirus that can rarely cause cancer in humans. It is more common in some areas of Japan and Africa.

Immune defence Body defence against disease

Immune system Regulation system for body defence functions

Indolent Slow-growing

Leukaemia (Blood cancer) collective term for malignant diseases of the blood cells. Leukaemia develops in the bone marrow.

Lymph Lymph fluid that moves through the lymphatic system and transports the white blood cells outside the blood

Lymphatics Lymphatic vessels

Lymphocytes Cells that are involved in immune defence (subgroup of white blood cells)

Lymphoma The term actually stands for an enlarged lymph node. The term is usually used as a collective term for all malignant diseases of the lymphatic system.

Malignant Tending to infiltrate, metastasize, and terminate fatally

MALT Mucosa-associated lymphatic tissue. Such tissue is found in the stomach, lungs, thyroid gland and around the eye.

Medical history Case history, description of symptoms

Monoclonal antibodies Antibodies directed only against a specific structure and produced in the laboratory

MRI Magnetic resonance imaging; also magnetic resonance tomography (MRT), imaging examination method that works with strong magnets but without X-rays

Myeloma B-cell lymphoma, which usually originates from the bone marrow and attacks blood and bones (see www.multiples-myelom.ch)

Nodus Node

Non-Hodgkin lymphoma (NHL) Any lymphoma that is not Hodgkin lymphoma. Hodgkin lymphomas contain abnormal cells called 'Reed–Sternberg cells'. NHL is any lymphoma that does not contain this type of cell

Off-label Off-label (or off-label use) means the use of medicinal products outside the area of application for which the marketing authorisation was granted. Example: When a drug approved for one type of lymphoma is prescribed to treat another type of lymphoma. Information on the current status of approvals is provided by the Arzneimittel-Kompendium (www.kompendium.ch). Off-label determinations can be a problem for patients with rare lymphomas, as many drugs are effective but not approved for rare lymphomas. In this case, the assumption of costs must be clarified with the health insurance company before the start of therapy.

Oncologist Physician who specialises in cancer treatment

Pathology Teaching of diseases. In an institute for pathology, tissue samples are examined and tissue diagnoses are made.

PET Positron emission tomography, imaging examination method in which weakly radioactively labelled sugar molecules are injected. A lot of sugar is converted in tumour cells. The tumour tissue can then be displayed as an image. Half a day before a PET examination no sugar (only water) should be taken.

PET-CT Combination of positron emission tomography (PET) and computed tomography (CT). Imaging method, e.g. for the detection of tumours

Port-a-Cath Permanent access to the blood system (port catheter)

Prognosis Prediction of the course of a disease

Radiology X-ray department. Today all imaging examinations are carried out here (MRI, ultrasound, radiography, PET, etc.)

Recurrence	Relapse, recurrence of the disease
Staging	Classification into individual stages, which indicate the state of development of a lymphoma
Symptom	Indications of disease
T-cells	(Also T lymphocytes), defence cells of the immune system, especially for defence against viral and fungal infections
Tumour	An abnormal benign or malignant new growth of tissue
Tyrosine kinase inhibitors	Drugs that target cancer cells while leaving healthy cells largely undamaged

17.2 Contact addresses

17.2.1 Cancer phone and cancer leagues

Cancer phone of the Swiss Cancer League

Tel. 0800 11 88 11, free call, Mon – Fri, 9 am – 7 pm
www.krebsforum.ch, helpline@krebsliga.ch
Chat - www.krebsliga.ch/cancerline
Skype - cancer phone.ch, Mon – Fri, 11 am – 4 pm

Swiss Cancer League

Effingerstrasse 40, Postfach 8219, 3001 Bern
Tel. 031 389 91 00
www.krebsliga.ch, info@krebsliga.ch

Aargau Cancer League

Kasernenstrasse 25, Postfach 3225, 5000 Aarau
Tel. 062 834 75 75
www.krebsliga-aargau.ch,
admin@krebsliga-aargau.ch

Basel Cancer League

Petersplatz 12, 4051 Basel
Tel. 061 319 99 88
www.klbb.ch, info@klbb.ch

Bern Cancer League

Schwanengasse 5/7, 3011 Bern
Tel. 031 313 24 24
www.bernischekrebsliga.ch,
info@bernischekrebsliga.ch

Ligue fribourgeoise contre le cancer, Fribourg Cancer League
Route St-Nicolas-de-Flüe 2, Case postale 96,
1705 Fribourg
Tel. 026 426 02 90
www.liguecancer-fr.ch, info@liguecancer-fr.ch

Ligue genevoise contre le cancer, Geneva Cancer League
11, Rue Leschot, 1205 Genève
Tel. 022 322 13 33
www.lgc.ch, ligue.cancer@mediane.ch

Grison Cancer League
Ottoplatz 1, Postfach 368, 7001 Chur
Tel. 081 252 50 90
www.krebsliga-gr.ch, info@krebsliga-gr.ch

Ligue jurassienne contre le cancer, Jura Cancer League
Rue des Moulins 12, 2800 Delémont
Tel. 032 422 20 30
www.liguecancer-ju.ch, ligue.ju.cancer@bluewin.ch

Ligue neuchâteloise contre le cancer, Neuchâtel Cancer League
Faubourg du Lac 17, 2000 Neuchâtel
Tel. 032 721 23 25
www.liguecancer-ne.ch, LNCC@ne.ch

Eastern Switzerland Cancer League: SG, AR, AI, GL
Flurhofstrasse 7, 9000 St. Gallen
Tel. 071 242 70 00
www.krebsliga-ostschweiz.ch,
info@krebsliga-ostschweiz.ch

Schaffhausen Cancer League

Rheinstrasse 17, 8200 Schaffhausen
Tel. 052 741 45 45
www.krebsliga-sh.ch, info@krebsliga-sh.ch

Solothurn Cancer League

Hauptbahnhofstrasse 12, 4500 Solothurn
Tel. 032 628 68 10
www.krebsliga-so.ch, info@krebsliga-so.ch

Thurgau Cancer League

Bahnhofstrasse 5, 8570 Weinfelden
Tel. 071 626 70 00
www.tgkl.ch, info@tgkl.ch

Lega ticinese contro il cancro, Ticino Cancer League

Piazza Nosetto 3, 6500 Bellinzona
Tel. 091 820 64 20
www.legacancro-ti.ch, info@legacancro-ti.ch

Ligue valaisanne contre le cancer, Valais Cancer League

Siège central: Rue de la Dixence 19, 1950 Sion
Tel. 027 322 99 74
www.lvcc.ch, info@lvcc.ch

Consulting office:
Spitalzentrum Oberwallis
Überlandstrasse 14, 3900 Brig
Tel. 027 604 35 41, Mobile 079 644 80 18
www.krebsliga-wallis.ch, info@krebsliga-wallis.ch

Ligue vaudoise contre le cancer, Vaud Cancer League

Place Pépinet 1, 1003 Lausanne
Tel. 021 623 11 11
www.lvc.ch, info@lvc.ch

Central Switzerland Cancer League: LU, OW, NW, SZ, UR

Löwenstrasse 3, 6004 Luzern
Tel. 041 210 25 50
www.krebsliga.info, info@krebsliga.info

Central Switzerland Cancer League, Information Center Zug

Alpenstrasse 14, 6300 Zug
Tel. 041 720 20 45
www.krebsliga.info, info@krebsliga.info

Zurich Cancer League

Freiestrasse 71, 8032 Zürich
Tel. 044 388 55 00
www.krebsligazuerich.ch,
info@krebsligazuerich.ch

Liechtenstein Cancer League

Im Malarsch 4, FL-9494 Schaan
Tel. 00423 233 18 45
www.krebshilfe.li, admin@krebshilfe.li

17.2.2 Patient organisations

lymphome.ch - patientennetz schweiz

Rosmarie Pfau, Weidenweg 39, 4147 Aesch
Tel. 061 421 09 27
www.lymphome.ch, info@lymphome.ch

MPS Myelom Patienten Schweiz

www.multiples-myelom.ch

Swiss network of blood stem cell transplant recipients SNBST

www.blutspende-srk.ch/de/partner/snbst

17.2.3 Spitex Schweiz

Umbrella organisation
of the SPITEX cantonal associations
Effingerstrasse 33, 3008 Bern
Tel. 031 381 22 81
www.spitex.ch *)
E-Mail: info@spitex.ch

*) On this website you will find
all current Spitex cantonal associations.

17.3 Internet links

Cancer in general

www.krebsliga.ch
Services offered by the Swiss Cancer League with link to all cantonal cancer leagues

www.krebsliga.ch/wegweiser
Online directory of psychosocial services, compiled by the Cancer League

www.krebsforum.ch
Internet forum of the Cancer League

www.lymphomacoalition.org
Worldwide Network of Lymphoma Patient Groups

www.cancer.gov
National Cancer Institute USA

www.cancerresearchuk.org/about-cancer
Coping with cancer

Palliative Care

www.palliative ch
Schweiz. Gesellschaft für Palliative Medizin,
Care and support
Office
Bubenbergplatz 11
3011 Bern
Tel. 044 240 16 21
info@palliative.ch
www.palliative.ch *)

*) On this website you will find the latest addresses and any new cantonal sections and networks.

www.bag.admin.ch/palliativecare
Website of the Federal Office of Public Health

www.hospiz.org
Hospices and hospice associations in Switzerland

Living wills

www.samw.ch/en/ethics
Swiss Academy of Medical Sciences

Social insurance/legal advice

www.krebsliga.ch/versicherungsfragen
Chronisch krank – was leisten Sozialversicherungen? (Chronically ill – what do social insurance schemes do?)

www.inclusion-handicap.ch
Umbrella group of disability organisations
Legal advice on social insurance law

Clinical Trials

www.kofam.ch
Federal Office of Public Health's (FOPH) portal for human research in Switzerland

www.sakk.ch
Swiss Group for Clinical Cancer Research

www.isrec.ch
The ISREC Foundation is actively supporting experimental Cancer Research in Switzerland

www.ielsg.org
International Extranodal Lymphoma Study Group (IELSG)

www.lysa-lymphoma.org
The Lymphoma Study Association - a Cooperative group committed to lymphoma research

www.ghsg.org
German Hodgkin Study Group

www.clinicaltrials.gov
Database of privately and publicly funded clinical studies conducted around the world

www.swissmedic.ch
Swiss Agency for Therapeutic Products

www.ema.europa.eu
European Medicines Agency

Young adults

www.youthcancertrust.org
Youth Cancer Trust

www.teenagecancertrust.org
Services for young people in the UK, providing life-changing care and support

www.cancer.gov/types/aya
Adolescents and young adults with cancer

www.criticalmass.org
Young adult Cancer Awareness Alliance

Please support us – your donation helps!

We make our brochures and information material available free of charge to lymphoma patients, their family members and friends. However, we would be very grateful if you could make a contribution in the form of a donation to cover printing and postage costs.

Sincere thanks,
lymphome.ch

Raiffeisenbank Aesch-Pfeffingen, CH 4147 Aesch BL
PC 40 – 1440 - 6
lymphome.ch, CH 4147 Aesch BL
Account no.: 48643.18
Bank code: 80779
Swift / BIC: RAIFCH22779
IBAN: CH13 8077 9000 0048 6431 8

Registration Membership

I would like to become a member.

Last name, first name .....

Address .....

Phone .....

Email ..... Date of birth .....

Date / Signature .....

lymphome ch
patientennetz
schweiz

lymphome.ch
Weidenweg 39
CH-4147 Aesch
www.lymphome.ch

LYMPHOMA
COALITION
Worldwide Network of
Lymphoma Patient Groups