

Living with multiple myeloma

Information for those affected and
their family members

Janssen-Cilag GmbH
www.janssen.com/germany

janssen  Oncology

PHARMACEUTICAL COMPANIES OF *Johnson & Johnson*

With patients, for patients

Our work focuses on the health and quality of life of patients and their families. Doing our best every day to achieve this is a central part of our corporate philosophy. That is why our commitment goes far beyond researching innovative medications. We develop information, training and assistance programs and services, because we want patients and their families to be able to experience special and everyday moments in the same way they took for granted before the diagnosis.

This brochure has been developed in collaboration with practicing physicians and affected patients.

For better patient care

THE POWER OF **PURPOSE**[®]

Dear patient,

In this brochure, we want to tell you and those close to you about all the important aspects of multiple myeloma and answer your questions about the disease. Among other things, you will find out which symptoms someone with multiple myeloma might experience, what the available options are for treating the disease, and where you can seek support.

We have also given you room in the brochure to record your questions and comments, and to take notes.

We also hope this brochure will be a source of encouragement for you! Scientific research has achieved a great deal, especially in recent years, and there are other promising concepts in the pipeline.

All good reasons, in other words, to start the treatment confidently and decisively. We wish you every success with it!

Your Janssen Oncology Team

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Technical terms

are explained on the page where the text appears, unless their meaning is included in the text. All terms in bold are also listed in the glossary, which starts on page 64.

Additional information in the form of a quick reference guide may be found at the end of the brochure.

You can keep a record of your personal notes for your medical appointments from page 55 onwards.

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You can find more **information** from Janssen-Cilag GmbH on **multiple myeloma** at:

www.janssen.com/germany/therapiegebiete/multiples-myeloma
www.krebsratgeber.de/MM



01

Understanding the disease

Cancer development is a complex process.

01

Understanding the disease

Facts and figures on multiple myeloma

Multiple myeloma ...

... is also often referred to as **plasmacytoma**.



... is derived from multiple = many, and myeloma = tumors in the bone marrow.

The causes ...



... are **not fully understood**.
Among other things discussed are

It is ...

... a so-called **B-cell lymphoma**.¹
... characterized by:



The reproduction of abnormal **monoclonal** plasma cells in the bone marrow. Plasma cells are immune system cells. They produce antibodies that protect the body against pathogens, among other things.



Excessive production of complete or incomplete monoclonal antibodies.¹

Ionizing radiation



Pesticides



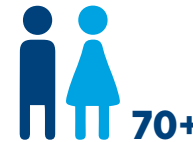
Genetic predisposition



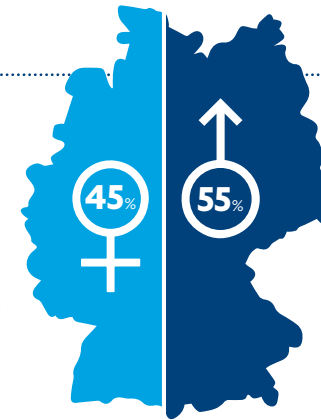
In Germany ...

... every year

approx. 3,600 men¹ (55%) and **approx. 2,900 women**¹ (45%) are diagnosed with **multiple myeloma**.¹



The disease is **most common** in the age group 70 to 79 years.¹



Multiple myeloma is only observed **very rarely** before the age of 40 to 45 years.^{1,2}

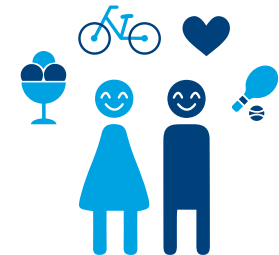
The prognosis ...



... has **steadily improved** in recent years thanks to scientific research.



The disease is not considered curable ...



... however, treatment can bring about **symptom-free phases** and **slow the progression of the disease**.

Bone marrow

The bone marrow contains the precursor cells for blood formation, the so-called blood stem cells. It should not be confused with the spinal cord, a part of the central nervous system in the spinal column.

B-lymphocyte

Also known as a B-cell. B-lymphocytes belong to the white blood cells, which play an important role in the immune system.

Plasma cell

Fully-formed B-lymphocyte, which releases antibodies.

Monoclonal

Clonality refers to the origin of cells or products; monoclonal cells all originate from a single (= mono) precursor cell.

What does multiple myeloma mean?

In simple terms, multiple myeloma is a form of cancer in the **bone marrow**. Bone marrow is sponge-like tissue, well-supplied with blood, that fills the cavities inside many bones. It contains the precursor cells, the so-called stem cells, for blood formation. These are also known as blood stem cells (→*Blood formation, p. 52*).

Good to know:

Although the term "**plasmacytoma**" is often used synonymously for multiple myeloma, strictly speaking, they are not one and the same: In **(solitary) plasmacytoma**, **the tumor cells** are restricted to a single location. In multiple myeloma, on the other hand, the tumor cells are found in several locations.

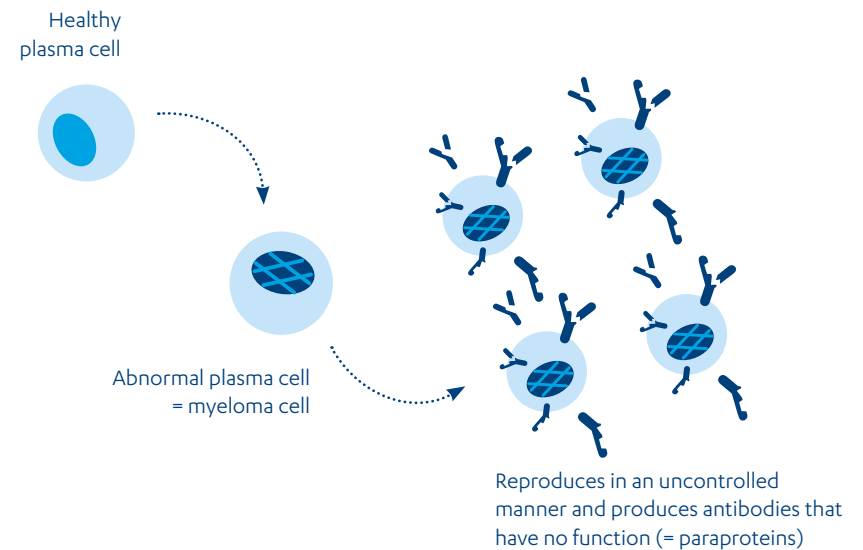
The blood platelets as well as the red and white blood cells are formed from the blood stem cells. The white blood cells include the natural killer cells, T-lymphocytes and **B-lymphocytes**.

Multiple myeloma is caused by a malignant change in certain B-lymphocytes in the bone marrow, the so-called **plasma cells**. They are important cells that form part of the human immune system.

If pathogens enter the body, the plasma cells that have been formed produce **antibodies** that attack and destroy the pathogens. Each plasma cell, therefore, is responsible for a special "attacker" and produces antibodies tailored to this attacker (→*Immune system, p. 53*).

In multiple myeloma, one of these plasma cells degenerates, which in turn produces only one type of antibody. The consequence of this degeneration is that these cells multiply uncontrollably and, even when no infection is present, produce an excessive number of antibodies or fragments of these antibodies (**paraproteins**) (→*Antibodies, p. 54*).

Since only one plasma cell and, therefore, only one type of antibody is affected, physicians talk about **monoclonal** plasma cells or antibodies.



What effect does the disease have on the body?

Erythrocyte

[from the Greek erythrós = red]. Also called red blood cell. Erythrocytes give the blood its red color and help to transport oxygen.

Leukocyte

[from the Greek leukós = white]. Also called white blood cell. Leukocytes are an important component of the immune system. Lymphocytes are a subgroup of leukocytes.

Thrombocyte

[from the Greek thrómbos = clot]. Also known as platelets. Platelets play an important role in blood clotting.

Calcium

Mineral that is important for bone formation, but also many other functions of the body.

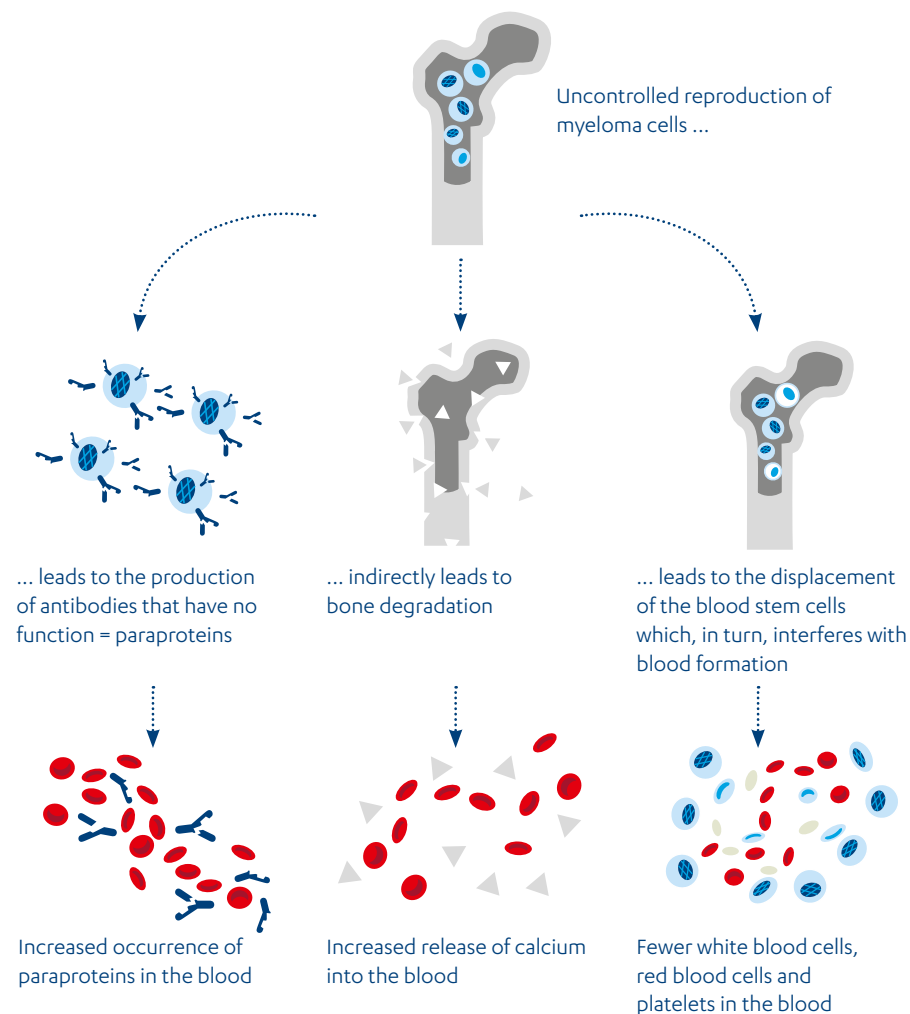
Due to the uncontrolled reproduction of the abnormal plasma cells (**myeloma cells**) and the production of paraproteins, many processes in the body are thrown off balance. The symptoms that result from these changes are described in more detail in section 02.

(→ *Which symptoms might I experience?*, p. 16)

One consequence of the uncontrolled reproduction is that normal blood formation is impaired and other blood cells are displaced. The result of this is that fewer red blood cells (**erythrocytes**), white blood cells (**leukocytes**) and platelets (**thrombocytes**) are produced in the bone marrow. These blood cells play a decisive role in the transport of oxygen around the body, the defense against pathogens, and wound closure.

Myeloma cells are found in the bone marrow, where they indirectly promote bone degradation (**osteolysis**). The bones then become porous and release the **calcium** contained in the bone into the blood. Physicians refer to this as **hypercalcemia**. This increase in the calcium level in the blood can, in turn, have a negative effect on other functions of the body. Hypercalcemia can lead to an irregular heartbeat, among other things.

Occasionally, the myeloma cells only produce antibody fragments, known as **light chains** (→ *Antibodies*, p. 54). These light chains can be deposited as “crystals” (**amyloid**) in the organs, which restricts the function of the affected organs. The light chains are excreted in the urine. If they are present in high enough concentrations, they can build up in the kidneys and may lead to impaired kidney function.





02

Symptoms and diagnosis

Even if the diagnosis of multiple myeloma is a shock at first, do not allow yourself to be discouraged – a positive attitude will help you to deal with the disease.

02

Symptoms and diagnosis









Which symptoms might I experience?

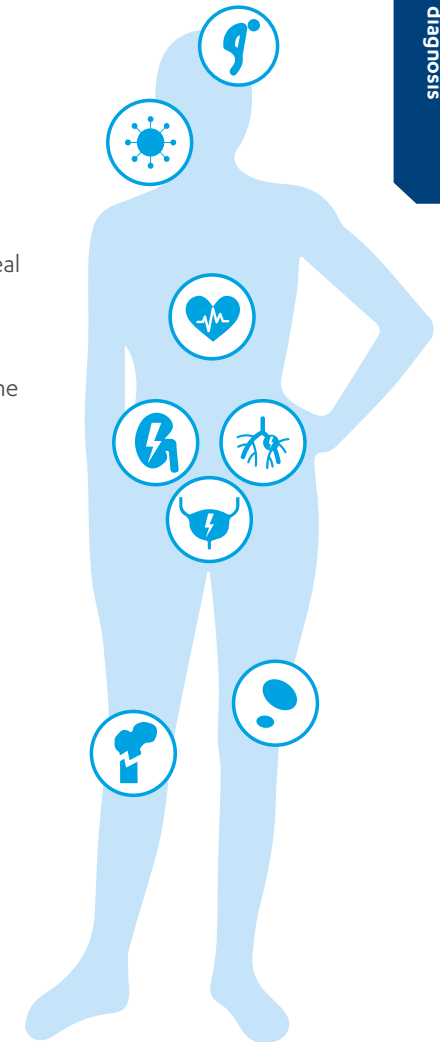
The symptoms of multiple myeloma are often non-specific and can vary from patient to patient. Back pain, exhaustion, weight loss or repeated infections are among those frequently reported.

However, these symptoms are also found in many other illnesses, in other words, they may be caused by something else entirely.

Consequently, myeloma can be present for months before it is diagnosed. Approximately 25% of all patients are still completely symptom-free at the time they are diagnosed.¹ It is not that unusual for myeloma to be detected following a routine blood test.

A person with the disease may experience the following symptoms, among others:

-  • Lethargy, fatigue and shortness of breath due to reduced oxygen transport in the blood (too few erythrocytes; anemia)
-  • Higher susceptibility to infection as a result of an impaired immune system (too few leukocytes)
-  • Increased tendency to bleed or prolonged bleeding due to the failure of wounds to heal (too few platelets)
-  • Impaired circulation in the organs due to the excess production of paraproteins
-  • Kidney damage due to the excretion of light chains
-  • Foam in the urine due to the excretion of proteins
-  • Bone pain and bone fractures due to bone degradation
-  • Drowsiness, confusion or irregular heartbeat due to the release of calcium



Medical history

A set of systematic questions asked by the physician to establish the state of the patient's health.

Cytogenetics

Analysis of the genetic information of the cell.

M-gradient

The M-gradient is a peak that appears in the result of the serum protein electrophoresis test due to elevated paraprotein levels.

Serum protein electrophoresis

Also known as SPE. It is a diagnostic procedure conducted in a laboratory to analyze the proteins in the blood serum.

Antibody class

Antibodies are divided into different classes (IgG, IgA, IgM, IgD and IgE), each of which has a specific function.

Which tests or procedures will be performed?

A wide range of tests and procedures are available if your physician suspects multiple myeloma. Various specialists, who have the ability to conduct various tests and procedures, will help your treating physician with the diagnosis.

As accurate a diagnosis as possible is important for:

- determining what stage the disease is at
- allowing a more precise prognosis to be given
- deciding on a course of treatment
- monitoring the success of the treatment

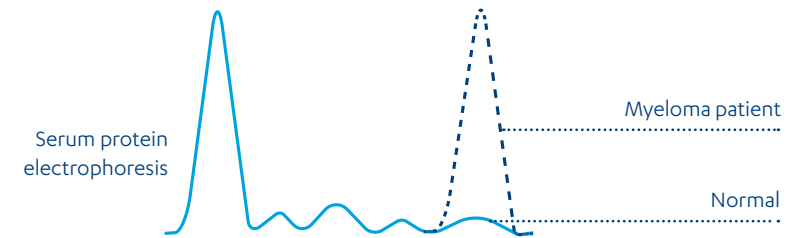
The diagnosis is based, in particular, on the following pillars:

- **Medical history** and physical examination
- Blood count and laboratory diagnostics
- Imaging procedures
- Bone marrow aspiration

Before conducting a physical examination on you, the physician will ask you specific questions about your symptoms, for example, whether you are experiencing bone pain or are feeling lethargic, or whether you regularly have infections.

Laboratory diagnostic testing specifically includes blood and urine tests. The physician can then use the blood count to see, for example, which cells are present in increased numbers and which cells are present in fewer numbers. S/he can also see under the microscope whether the cells have mutated. It is particularly important to establish the **M-gradient** by conducting a **serum protein electrophoresis** test.

The M-gradient indicates that there may be an increased amount of paraproteins in the blood. By testing your urine, your physician can determine, among other things, whether you are excreting more paraproteins than usual.



The imaging procedures are extremely useful for detecting and recording any changes in your bones. They show, for example, the extent to which your bones have been negatively affected, perhaps due to osteolysis.

During bone marrow aspiration, cells are taken from your bone marrow. A microscope is then used to examine whether the plasma cells are present in unusually large quantities. These cells can also shed more light on the genetic information of myeloma cells (**cytogenetics**).

What do my results mean?

Some diseases cause symptoms that are very similar to those experienced with multiple myeloma. Consequently, in order to diagnose multiple myeloma, your physician must first conduct an in-depth analysis on the results of the tests and procedures you have undergone.

The M-gradient is a decisive factor in diagnosing multiple myeloma. This shows your physician whether paraproteins are present in your blood. The classification of the disease depends on which paraproteins are present in increased numbers. If, for example, there is evidence of significant numbers of IgG **antibody class** paraproteins, this is known as IgG myeloma. IgG myeloma and IgA myeloma are particularly common. These types are diagnosed in about 80% of cases.¹

R-ISS

R-ISS stands for “Revised International Staging System.” The International Staging System (ISS) was renamed R-ISS following a review undertaken by the International Myeloma Working Group (IMWG) in 2016.

In order to ascertain the stage of the disease, levels of the following are measured in the blood:³

- **Beta-2 microglobulin**, a protein found on the surface of many cells in the human body. Healthy people have very constant levels of this. Levels increase if cells are multiplying uncontrollably.
- **Lactate dehydrogenase (LDH)**, an enzyme that is released, for example, when cells are damaged and die. High LDH levels indicate that the disease is growing rapidly and is highly aggressive.
- **Albumin**, a protein that is present in the human body, primarily in the blood. Cancer is one of the diseases where low levels of this are evident.

In addition, the *cytogenetics* of myeloma cells play an important role in determining what stage the disease is at: If myeloma cells exhibit certain mutations, the prognosis is less favorable than if these are not present. Mutations such as these are also known as “high-risk mutations”.

R-ISS stage classification in multiple myeloma³

Stage I Serum beta-2 microglobulin <3.5 mg/L
and
normal serum albumin ≥3.5 g/dL
and
no high-risk cytogenetics

Stage II Stage II is not related to stage I or stage III

Stage III Serum beta-2 microglobulin ≥5.5 mg/L
and
high-risk mutation
or
elevated LDH levels

What is my prognosis like?

In principle, the way in which the disease progresses varies greatly and is difficult to predict. In some myeloma patients, the disease remains relatively inactive for many years, while in others it progresses more aggressively and advances rapidly.

The prognosis for multiple myeloma varies from patient to patient and depends on many factors, such as:

- the patient’s biological age
- the stage of the disease and
- any other medical conditions the patient may have

Prognostic data is available based on the R-ISS stage classification. According to this, the five-year survival rate is approximately 80% in stage I, 60% in stage II and 40% in stage III.^{1,3}

Very important: These figures are estimated average values that cannot be applied to each individual case. A prognosis may also improve during treatment.



03

Treatment and follow-up monitoring

Treatment options are continuously improving and expanding.

03

Treatment and follow-up monitoring

Relapse

Relapse is a form of regression, in other words, the disease comes back.

Unfortunately, multiple myeloma is still not curable, but various treatment options are available that can slow down the progression of the disease and improve patients' quality of life. Medical professionals also refer to the state where a patient is free of symptoms or where symptoms have been repressed as **remission**.

Various factors will determine which treatment is most suitable for you and when it should be started. Your physician will talk to you about the approach s/he recommends in your case. For treatment to succeed, it is important that you confide in your physician if you have questions.

If you have concerns, or your medication does not suit you, talk to your physician about possible alternatives. However, it is essential that you consult your physician rather than deciding to stop taking the medication on your own. Adherence to the treatment or "compliance" is essential to make sure the treatment is as effective as possible. One of the most important aspects of this is that you take your medication exactly as your physician has prescribed.

Good to know:

Even after successful treatment, it is not unusual for the disease to return. Physicians then refer to this as a **relapse**. Fortunately, relapses can also often be treated successfully.

When is treatment beneficial?

A diagnosis of multiple myeloma does not automatically mean that treatment is required immediately.

The decisive factor is the extent to which multiple myeloma is already affecting your body. This can be determined on the basis of various laboratory test results and other criteria. The so-called CRAB criteria assist the physician in this regard.

CRAB criteria for starting a course of treatment¹

Hypercalcemia (Calcium elevation = C)	Increased calcium levels
.....	
Renal insufficiency (Renal insufficiency = R)	Kidney damage
.....	
Anemia (A)	Anemia
.....	
Bone involvement (Bone abnormalities = B)	Bone changes

The International Myeloma Working Group updated and expanded the CRAB criteria in 2014. The SLiM criteria were also added at that time.

Magnetic resonance imaging
(= MRI).
Is an imaging procedure for displaying the bones, for example.

SLiM criteria for starting a course of treatment¹

Bone marrow infiltration (S ixty = S)	Clonal plasma cells in bone marrow (more than 60%)
Free light chains (L ight Chain = Li)	A certain ratio of affected to unaffected free light chains in serum
Focal lesions in the MRI (M RI = M)	Bone damage in the MRI

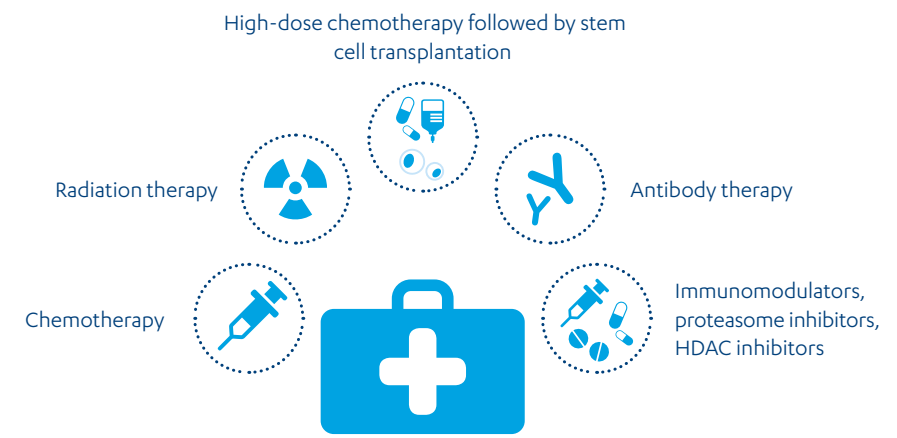
Apart from these criteria, pain caused by myeloma or recurring severe infections may be other indicators for treatment.

The decision to start a course of treatment ultimately depends on many factors or combinations of certain factors, and varies from patient to patient.

Which treatment options are available?

Scientific research means that more advanced treatment options are being developed all the time. This means that multiple myeloma can now also be treated successfully even when the disease returns (relapse). Thanks to this progress, patient survival time has increased continuously in recent years.

The main forms of treatment available are traditional chemotherapy, high-dose chemotherapy accompanied by stem cell transplantation, proteasome inhibitors, immunomodulators, a histone deacetylase (HDAC) inhibitor, antibody therapy and radiation therapy. They differ, for example, in the ways in which they attack the disease and the extent to which they are tolerated.



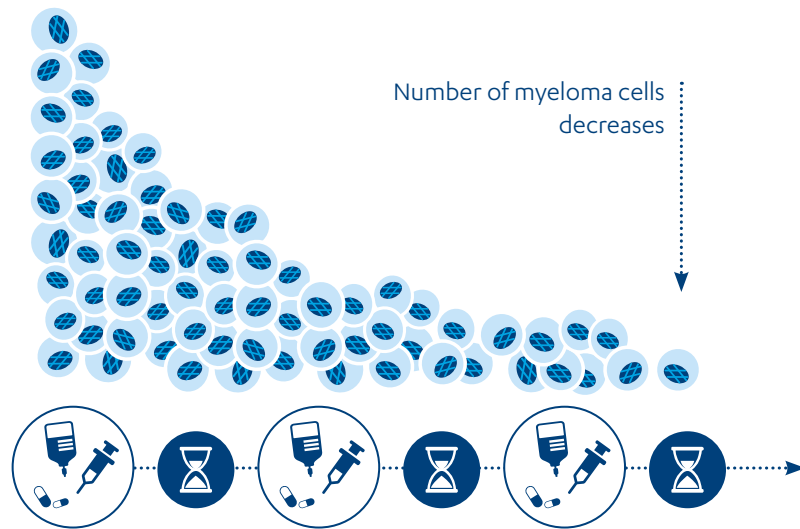
Cytostatic

[from the Greek cytos = cell, and Latin stare = to stand]. A cytostatic is a medication that inhibits cell growth, which helps to stop the cancer growing.

Chemotherapy

In chemotherapy, medication (**cytostatic drugs**) is administered which inhibits cell growth. The goal is to slow down the growth of the cancer, so that, in an ideal scenario, the tumor “dies off.” Various medications are often combined to attack the tumor at different locations. The treatment is also cyclical, in other words, it alternates between treatment phases and recovery phases.

The number of these cycles performed depends, among other things, on the medications used, the condition of the patient, the patient’s response to the treatment and the severity of the disease.



Cytostatics are particularly effective against cells that reproduce very rapidly, like myeloma cells. Unfortunately, cytostatics are unable to differentiate between tumor cells and healthy cells. As a result, they also attack healthy cells if they divide very quickly. These include, for example, the hair root cells and the cells of the hematopoietic (blood-forming) system. This explains why many chemotherapy treatments can result in hair loss, being more susceptible to infections, a tendency to bleed more easily, and **anemia**.

High-dose chemotherapy followed by stem cell transplantation

High-dose chemotherapy is a special form of chemotherapy in which much higher doses of the drugs are given than during normal chemotherapy. The higher doses have a greater effect on the cancer cells. However, this means that patients also experience more severe side effects: It also differs from conventional chemotherapy in that the blood-forming stem cells in the bone marrow are also destroyed in the process. This means that a transplant of healthy stem cells is needed so that the body can replace the blood stem cells that have been destroyed (→*Blood formation, p. 52*).

High-dose chemotherapy followed by stem cell transplantation is currently regarded as a standard method of treatment for multiple myeloma, unless the patient’s general condition and age prevent it.

Graft versus Myeloma

[from the English graft = transplant, versus = against, and myeloma = myeloma]. GvM can also be referred to as transplant versus myeloma.

Types of stem cell transplantation:

Autologous stem cell transplantation = the stem cells come from the patient him- or herself

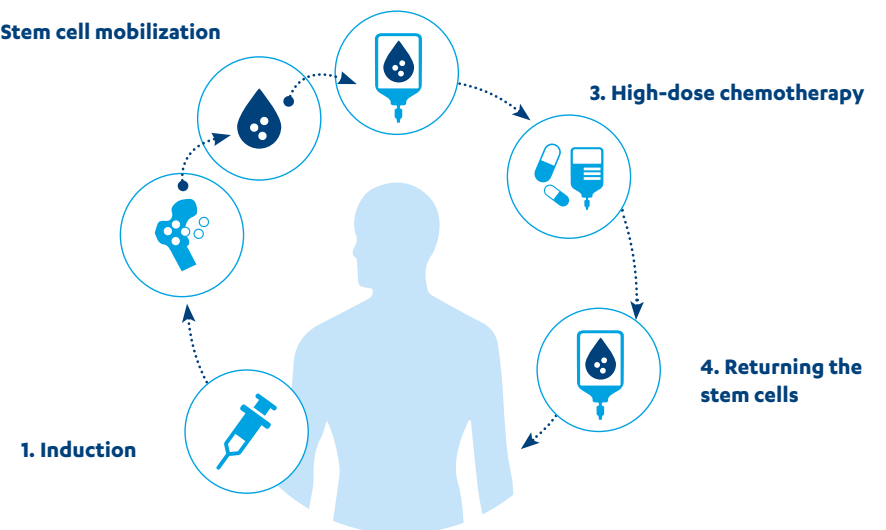
Allogeneic stem cell transplantation = the stem cells originate from a donor. The desired outcome of allogeneic transplantation is a **graft versus myeloma** (GvM) effect, meaning that the donor's immune system destroys the cancer cells. The donor's tissue characteristics must largely match those of the patient to avoid the cells being rejected by the patient's own body. Suitable donors are therefore often close relatives

Peripheral blood stem cell transplantation = the stem cells are taken from the patient's or the donor's blood and then transplanted

Bone marrow transplantation = the stem cells are taken from the patient's or the donor's bone marrow and then transplanted

The following is a description of how autologous stem cell transplantation with stem cells from the blood works:

- 1. Induction:** The aim of induction chemotherapy is to suppress the myeloma cells as much as possible without destroying the stem cells.
- 2. Stem cell mobilization:** Medication is used to stimulate the stem cells so that more of them migrate from the bone marrow into the blood. Blood is then taken from the patient, and the stem cells filtered out of the blood and prepared for transplantation. This means that stem cells are taken from the peripheral blood and not directly from the bone marrow (→ *Types of stem cell transplantation, p. 30*).
- 3. High-dose chemotherapy:** The aim of high-dose chemotherapy is to destroy as many of the patient's myeloma cells as possible.
- 4. Returning the stem cells:** The stem cells taken from the patient are reintroduced into his/her body. They migrate into the bone marrow and start to generate new blood cells again.

2. Stem cell mobilization

Proteasome inhibitors

The proteasome is the cells' "recycling machine." It breaks down proteins that the cells no longer need. These "recycling machines" are obstructed in their work by **proteasome inhibitors**.

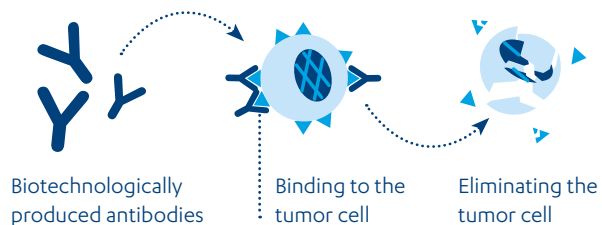
Myeloma cells are veritable "production machines" for antibodies and therefore have a particularly high requirement for protein recycling. Therefore, they are particularly severely affected by proteasome inhibitors. Healthy cells, on the other hand, are less restricted by this inhibition.

Immunomodulators

Immunomodulators aim to influence (modulate) the immune system in such a way that it can fight multiple myeloma. They have an anti-inflammatory effect and can stop the tumor cells from growing. They also prevent the formation of new blood vessels that supply the tumor with nutrients.

Antibody therapy

Antibody therapy involves the use of monoclonal antibodies produced by means of biotechnology. Unlike chemotherapy, these target myeloma cells: They fit the surface of the modified malignant cells, like a key in a lock, and cause the myeloma cell to be destroyed.



Radiation therapy

Radiation is used to ensure that abnormal cells lose their dividing capacity, which prevents further growth of myeloma cells. Healthy cells are less affected by the radiation than abnormal cells, because they are better able to repair the damage.

In radiation therapy, only restricted (localized) areas are treated with radiation. It is used in multiple myeloma or plasmacytoma, especially for the treatment of bone pain. In addition, radiation therapy can prevent fractures in weight-bearing bone segments. Radiation therapy is also used on extramedullary plasma cell tumors, in other words, tumors outside the bone marrow.

To treat multiple myeloma, radiation therapy is administered externally. This means that no radioactive substances are administered.

How are the therapies administered?

Many medicines can simply be taken orally, swallowed, in other words, such as tablets or capsules. Unfortunately, this is not possible with all active substances, because some of them may react sensitively to gastric acid, for example, and become ineffective as soon as they reach the stomach. Taking them orally is useless in this case. This can be one reason why a drug is given as an infusion or as an injection rather than in the form of a tablet.

Intravenous therapy

Therapies are often administered as an infusion into a vein (intravenously; i.v.), as this ensures that the active substance enters the body, or where they cannot or may not in fact be given in another way. The infusion is usually given in the physician's practice or hospital outpatient department and may take several hours. The duration of the infusion depends on the dose and how well you tolerate the therapy.

Tips for the infusion

- Find out exactly what time and where the infusion will take place, and how long it will take
- Bring warm clothing with you
- Remember your patient ID card or your infusion card
- Make sure you have something enjoyable to do to pass the time (music, books, magazines)
- Arrange to be collected after the infusion
- Allow yourself time afterwards to recover



Subcutaneous therapy

Some active substances can now also be given as an injection under the skin (subcutaneously; s.c.), which is often better tolerated. It can be given in a much shorter time, only taking a few seconds/minutes, which can reduce the length of time spent in practices or outpatient clinics.

Tips for subcutaneous injection

- Enter your injection appointments in your calendar
- Remember your patient ID card or your injection card
- Wear loose clothing
- Avoid putting pressure on the injection site



Oral therapy

There are also anti-tumor medications for taking (orally) in tablet/capsule form. Oral therapy can take place at home. The advantage of this is that you spend as little time as possible at the hospital or a medical practice.

Tips for oral intake

- Always take your tablets/capsules exactly as discussed with your physician
- If you find it difficult to remember to take it as part of your daily routine, there are many support options (medication plan, reminder notes, apps, patient support programs). Please contact your physician



Therapies in the context of studies

All new therapies must be extensively tested in clinical studies before they are approved for general use to show that they are effective and can be tolerated. This also applies to cancer therapies. The new drugs and treatment methods are tested for these purposes on a large number of patients at selected medical centers and usually compared with therapies that are already available. Participation in clinical studies is voluntary and linked to certain other criteria.

What are the advantages of participating in clinical studies?

When is therapy in the context of clinical studies beneficial?

Participation in clinical studies can represent another option, particularly for cancer patients, but it can also involve risks. If the drugs that have already been approved do not work or are only partially effective, participating in clinical studies offers another alternative treatment option. As participants in a clinical study, patients are given access to new therapies that are not yet approved and are still undergoing clinical testing. Treatment is administered by selected medical experts and the results are recorded in detail for research purposes. The participants in clinical studies contribute to the development of new drugs and to the improvement of treatment options, even if they do not respond personally to a new treatment method or a new drug.

Each individual should discuss with his/her physician and, if applicable, his/her relatives whether taking part in a study would be beneficial. A detailed consultation with the treating physician, in which all the advantages and disadvantages can be weighed up, is therefore essential.

If you are interested in participating in clinical studies, your physician is the first person you should contact. He/she can assess whether you are eligible to take part in clinical studies and, if so, which ones. Self-help organizations can also help you to find medical centers. You will find a selection of addresses and links for patient organizations starting on [page 60](#).

An overview of studies on multiple myeloma, for example, may be found on the website of the Multiple Myeloma Working Group at:
<https://www.myelom.org/studien/einfuehrung.html>

Additional measures

Additional therapies are very important during the treatment of multiple myeloma. Patients whose bones are already affected may benefit from simultaneous therapy with medications that protect the bones (**osteoprotective**). Your physician will also tell you which vaccines would be beneficial in your case.

Rehabilitation

Medical, occupational and social rehabilitation following the therapy is an important component of your treatment. The aim of the rehabilitation is to support you in coming to terms with the stressful situation you have been through, and to help you get back on your feet. It is also designed to safeguard the success of the therapy and to help you return to everyday life stronger and more confident.

Oncology

[from the Greek onkos = swelling].

Is the study of cancer.

Hematology

[from the Greek haima = blood].

Is the study of blood.

Nephrology

[from the Greek nephros = kidney]. Is the study of the kidneys.

Radiology

[from the Latin radiare = to radiate]. Is also known as radiation therapy.

Who will be treating me?

Multiple myeloma has many aspects and affects various areas of your body. Therefore, it is important that various specialists from different disciplines coordinate your treatment:

- **Oncology/hematology:** The oncologist/hematologist is the most important physician from your perspective. S/he specializes in cancer and will make the decisions on your treatment with you. As these physicians are often specialized in certain types of cancer, it is best to find out in advance which oncologist/hematologist is particularly familiar with the type that you have.
- **Nephrology:** The nephrologist can be consulted in relation to the effects of the disease on your kidneys.
- **Radiology:** The radiologist deals with all types of imaging procedures for diagnostic and therapeutic purposes.
- **Radiation therapy (radio-oncology):** The radiation therapist is your point of contact for radiation therapy.

You can also contact a cancer center. This is where you will find all the important specialist areas “under one roof.”

A relationship based on trust with your physician is important to ensure your treatment is successful. If you have any questions about the diagnosis or your treatment, contact your physician directly. We have given you room to write down your questions at the end of the brochure.

Why is follow-up monitoring so important in my case?

The main purposes of follow-up monitoring are:

- To review how well you are responding to the therapy. It allows your physician to adjust the therapy, if necessary, in order to achieve the best possible outcome.
- To identify a relapse at the earliest possible opportunity. If a relapse occurs, even though the therapy has initially been successful, it can be detected in good time by the follow-up monitoring and further therapy can be initiated if necessary.

It is, therefore, important to remember to keep your follow-up appointments even if you do not have any symptoms right now.



04

Living with multiple myeloma

Accept your illness and deal with it openly. A positive attitude and support will help you achieve much more than you thought possible at the beginning.

04

Living with multiple myeloma

Can I continue to lead a normal life?

A normal life. This includes everyday things such as career, family activities, sports, theater visits, travel and much more. Of course, your life is limited by the disease and the therapy. But that does not mean that you have to do without everything. If you are not sure what is good for you and what is not, contact your physician.

As your immune system may be weakened, you may be particularly susceptible to infections. You should, therefore, avoid crowds and contact with people who have a cold, for example.

Pay particular attention to hygiene (hand washing).

Career:

- Every patient in paid employment must decide individually whether s/he wishes to continue to work. If you are not well, your physician will write you a sick note. In particularly severe cases, applying for early retirement is also an option.
- Talk openly with your employer about the change in your situation.
- There are various models for reintegrating into professional life after an extended bout of illness, that are also supported by the statutory health insurance and pension insurance schemes.

Sexuality and starting a family:

- Discuss problems openly with your partner. It does not help you if you put yourself under pressure. It can sometimes take a while for you and your partner to come to terms with the new situation.
- If you want to start a family, talk to your physician openly and as soon as possible so that s/he can advise you accordingly.

Before traveling:

- Ask your physician to issue you with a physician's letter containing information about the treatment you are receiving and the state of your health.
- Ask your physician if you need special vaccinations before your trip.
- Find out about local specialists.
- Clarify your insurance coverage in advance with your health insurance provider.
- Ensure that your medications are stored under the proper conditions.

Can I do something to help myself?

A variety of factors can contribute to the success of the therapy.

Here are some suggestions:

- Research your disease and your options.
- Make sure that you keep your medical appointments and follow all your physician's instructions.
- Talk to your physician directly about questions and problems and ask for the information you need. Do not hesitate to ask again if there is something you haven't understood.
- Avoid infection risks.
- It's important to take care of your kidneys. So make sure you drink enough water during the day.
- Don't forget about your mental health. There are a number of psycho-oncological services that you can avail of (→*What is psycho-oncological help?, p. 49*). It can also be helpful to exchange information with others in the same situation, for example, in a self-help group (→*How can a self-help group support me?, p. 49*).
- Do things that make you happy. Talk to your physician about your hobbies and keep them up if you can.
- Eat a healthy and balanced diet.
- Stay active, but don't overdo it. If you are not sure whether you can do a certain type of sport based on your findings, ask your physician beforehand.

How can my relatives or friends help me?

Your relatives and your circle of friends can be an important support for you at this difficult time. It is important to find out how you, but also others, can and want to handle the new situation.

Your family and friends can be there to help you in many areas, for example by

- accompanying you to and supporting you during your medical appointments.
- making sure that important questions are clarified for you and that you are aware of or take note of the answers.
- also researching the disease and the therapies with a view to supporting you in making decisions on your treatment.
- helping you maintain a healthy diet and play sport.
- taking over small everyday tasks.



05

Support sources

The diagnosis of cancer affects many areas of daily life. Numerous offers of assistance and opportunities for exchanging information with others in the same situation can help.

05

Support sources

There are a number of people you can contact with your questions. For example, patient organizations for multiple myeloma and cancer counseling centers, which can provide you with more information about your disease, among other things.

Intensive treatment for multiple myeloma can be very time-consuming. The treatment and the potential loss of earnings can also constitute a significant financial burden. So talk to your health insurance provider and your physician about covering the costs of your treatment.

What is psycho-oncological support?

A positive attitude helps you to lead a life that is as normal as possible. Unfortunately, we often tend to neglect the mind, which is a fundamental component of wellbeing and health. If you are depressed, or would like to speak to someone “neutral”, you can get in touch with a **psycho-oncologist**.

Psycho-oncological services are designed to support you and your family members at this exceptional time. Availing of a service such as this does not mean that you are “weak”, on the contrary, it shows that you are ready to take an active role in dealing with your difficult situation.

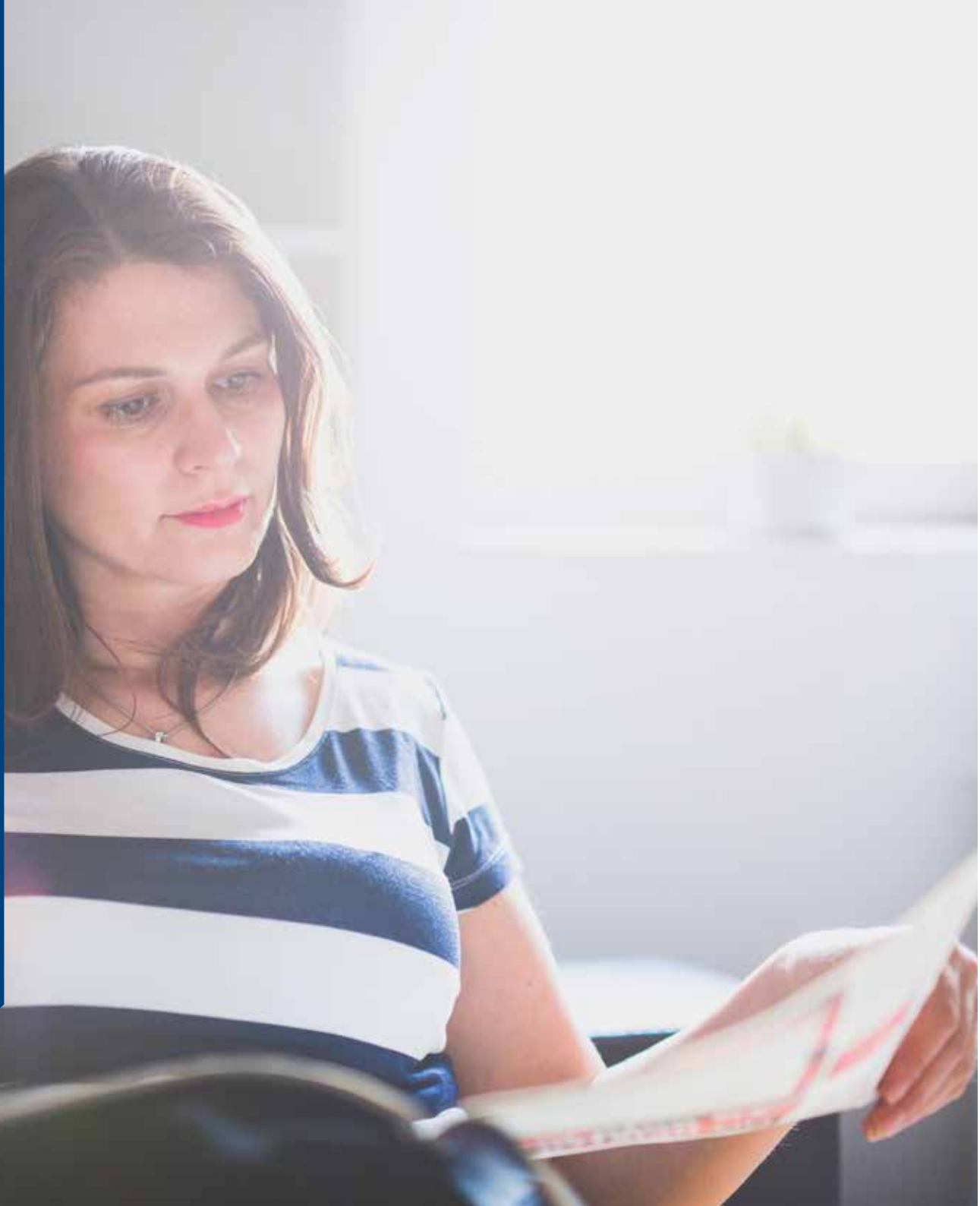
How can a self-help group support me?

Apart from family, friends and psycho-oncological assistance, self-help groups can act as another support mechanism that helps you to deal with the disease better.

Here, you can share information about everyday things with others who have the same worries and questions and you can tell each other about new developments and clinical studies.

When searching for a self-help group, you can contact your physician or do some online research. There is a group in almost every large town or city.

You can find a selection of addresses and links starting from [page 61](#) or at <https://www.krebsratgeber.de/patientenorganisation>



06

Additional information

Avail of the opportunity to do research and to exchange information with others in the same situation. And don't forget to continue to consciously enjoy the wonderful moments in life.

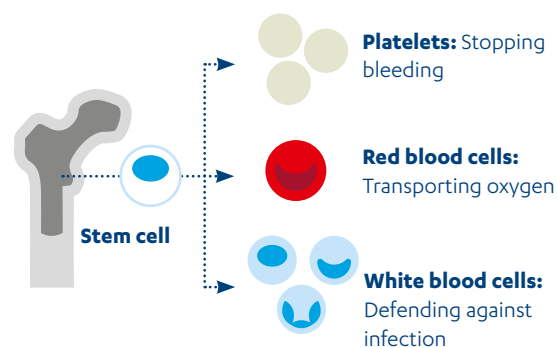
06

Additional information

Blood formation

The body continually generates new blood cells from stem cells in the bone marrow. From there, they enter the bloodstream and assume different functions:

- Red blood cells (erythrocytes) transport oxygen from the lungs throughout the body to the individual cells.
- Platelets (thrombocytes) play an important role in blood clotting and wound healing.
- White blood cells (leukocytes) are an important component of the immune system and protect the body from infections, for example.

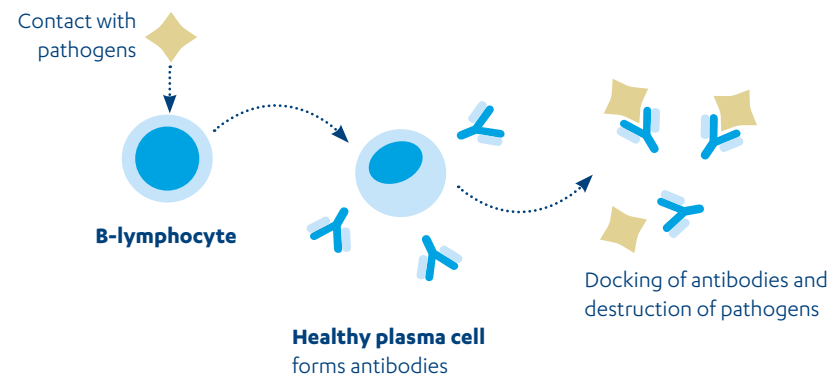


When multiple myeloma is present, the myeloma cells interfere with healthy blood formation. Fewer erythrocytes, leukocytes and platelets are formed, which has a variety of effects on the body.

Immune system

The human immune system consists of many types of cells that are responsible for defending against pathogens such as viruses or bacteria. Some cells “eat” the pathogens themselves, while others call for help from other cells to mount a defense.

White blood cells, also known as leukocytes, are particularly important for the immune system. One subgroup of leukocytes are the lymphocytes, which include natural killer cells (NK cells), T lymphocytes and B lymphocytes. B lymphocytes are cells that use antibodies to mount a targeted defense against pathogens. The B lymphocyte is activated as soon as it comes into contact with the pathogen directly or via the “call for help” from another cell. Following activation, it becomes a plasma cell that produces specific antibodies against this pathogen. This means that these antibodies only fit to this one pathogen, just like a key can only open one lock. The antibodies “dock” on the pathogen, which leads to its destruction.



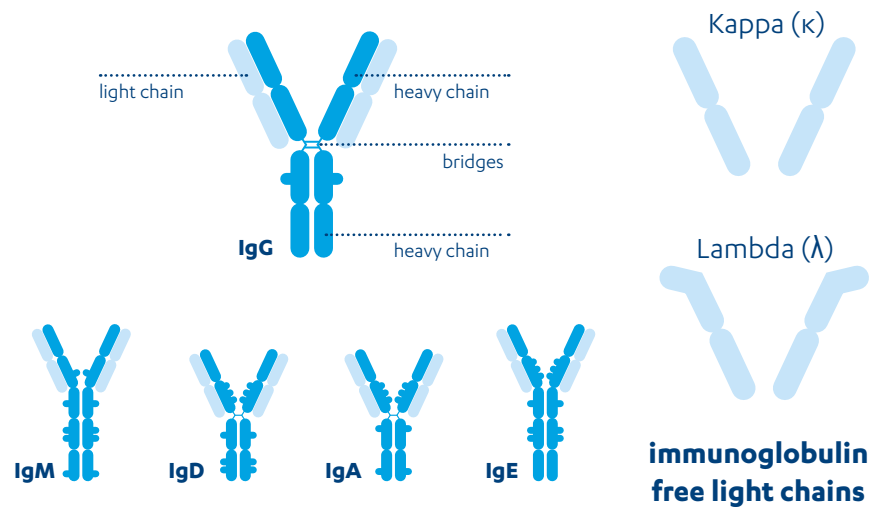
In multiple myeloma, one of these plasma cells becomes abnormal. This single plasma cell continues to multiply in an uncontrolled manner. The abnormal plasma cells (= myeloma cells) constantly produce antibodies or fragments of antibodies without any reason to do so, in other words, without an infection being present that needs to be defended against. It no longer performs its actual role in the immune system.

Antibodies

Antibodies are also referred to as **immunoglobulins (Ig)**. One of their functions is to protect the body against infections by destroying the pathogen. There are different classes of antibody (IgG, IgA, IgM, IgD and IgE), which have different tasks.

The immunoglobulins consist of “light” and “heavy” protein chains. These chains are connected to each other via “bridges” enabling them to form a complete antibody. If the light chains are not connected to the heavy chains, they are known as “immunoglobulin free light chains.” The light chains are divided into two types: kappa (κ) and lambda (λ).

In multiple myeloma, only one type produces an excessive number of antibodies or antibody fragments. These antibodies do not fulfill any function, but can actually harm the body.



My questions and notes

Given the large number of physician’s appointments, it is important that you are well prepared each time. Therefore, it is helpful to write down important questions and points that you would like to address. For your notes, you can use the following page, for example. Alternatively, you can use the checklist starting on page 56, which contains pre-formulated questions to refer to during the consultation.

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Checklist for the consultation at the medical practice

Disease:

- What is multiple myeloma and is the disease curable?
- What is the prognosis for my disease, and what are the chances of recovery?

Diagnosis:

- How will the diagnosis be made?

Tests and procedures:

- What tests and procedures are still pending?
- Can I get a copy of the test results for my records?

Results:

- What do the individual results mean?

Treatment:

- What are my current treatment options?
- Which is the best option and why?
- What exactly does my treatment plan include?
- How long will my treatment last?
- What are the next stages of my treatment?
- How long will it take after my treatment starts before I feel better?
- Which factors can influence the success of my treatment?
- What can I contribute personally to the success of my treatment?
- How will the success of my treatment be monitored?
- Which tests and procedures are necessary and how often will they take place?
- Is participation in clinical studies considered a treatment option in my case?

Checklist for the consultation at the medical practice

Appointment timetable:

- How many appointments will be scheduled?
- Approximately how much time will I need to allow for each appointment?

Side effects:

- Which side effects should I expect to experience during/after the treatment?
- Can these be avoided?
- If so, how?
- What should I do if I experience side effects?

Medication:

- What do I need to remember, in general, when taking my medication (time of day/foods)?

Diet:

- Should I avoid certain foods?
- Should I change my diet?

Support:

- Whom can I contact if I have questions or feel unwell and need support?
- Where can I find other important information and addresses/phone numbers?
- Which self-help groups would you recommend for me?

Everyday life:

- Which changes should I expect in my everyday life?

Career:

- Will I still be able to pursue my career?
- What do I need to bear in mind in this regard?
- How long should I expect to be unable to work?

Sports:

- Can I continue to play sports?
- Which sports would be the most suitable?

Additional information

You can find general information on the topic on the following websites*:

Detailed information on multiple myeloma	www.janssen.com/germany/therapiegebiete/multiples-myelom
Information on multiple myeloma	www.krebsratgeber.de/mm
Information on current medical topics related to cancer	www.krebsgesellschaft.de
DKFZ (Deutsches Krebsforschungszentrum [German Cancer Research Center]) service, providing general information on cancer	www.krebsinformationsdienst.de
Official site of the German Cancer Research Center	www.dkfz.de
Reintegration into professional life and other information	www.einfach-teilhaben.de
Pension office for applying for the severe disability certificate	www.versorgungsaeamter.de
Information on cross-border healthcare	www.eu-patienten.de
Independent Patient Advice for Germany	www.patientenberatung.de

* The respective operator is solely responsible for the content of third-party websites.

Self-help groups and patient association groups



Arbeitsgemeinschaft Multiples Myelom with forum for patients and relatives
www.myelom.org



Myelom.Online e.V
 Phone: +49 (0) 4535 59 11 26
www.myelom.online



Leukämiehilfe Rhein-Main e.V (Leukemia Support Rhine-Main)
 Phone: 06142 3 22 40
www.leukaemiehilfe-rhein-main.de



Myelom-Gruppe Rhein-Main g.e.V (Myeloma Group Rhine-Main)
 Phone: 06142 3 22 40
www.myelom.net

Digital self-help groups



yeswecan!cer and YES!APP Digital self-help group
www.yeswecan-cer.org
www.yeswecan-cer.org/die-yes-app



Your personal companion for all stages of cancer

MY CANCER COMPANION is an internet portal provided by Janssen for cancer patients, their families and other interested parties. The information portal is designed to be a personal companion, providing information and assistance at all stages of the disease.

A summary of the most important information:

- Reliable information on the latest scientific developments
- Valuable everyday tips for living with cancer
- Over 80 videos with facts and practical aids
- Directory of physicians including more than 500 oncology practices
- Contact person at self-help organizations
- A way of sharing information with others in the same situation

You can find more information from Janssen on multiple myeloma at:

www.krebsratgeber.de/MM



www.krebsratgeber.de

Technical terms

A

Albumin

A protein that is primarily present in human blood

Allogeneic stem cell transplantation

Transplantation of donor stem cells

Amyloid

Deposit of abnormally modified proteins

Medical history

Set of questions asked by the physician to clarify the patient's state of health

Antibodies

(→ immunoglobulin)

Antibody class

Antibodies are divided into different classes (IgG, IgA, IgM, IgD and IgE), each of which has a specific function

Antibody therapy

Treatment with antibodies produced using biotechnology, which attack cancer cells directly

Autologous stem cell therapy

Transplantation of a patient's own stem cells

B

Beta-2 microglobulin

A protein on the cell surface of many cells

B-lymphocyte

A lymphocyte that specifically detects and eliminates pathogens. They are also known as B cells

B cell

(→ B lymphocyte)

B-cell lymphoma

A lymphoma is a cancer of the lymphatic system. B-cell lymphoma originates from the B lymphocytes

E

Erythrocyte

Red blood cell. Erythrocytes are responsible for transporting oxygen around the body

G

Graft versus Myeloma

The donor's transplant attacks the myeloma

H

Hematology

The study of blood

HDAC inhibitor

Medication that inhibits histone deacetylase

Histology

Tissue analysis

Hypercalcemia

Excessive calcium content in the blood

I

Immunoglobulins

Proteins produced by B lymphocytes. They specifically recognize a pathogen and are responsible for its elimination

Immunomodulator

Medication that modifies the immune system

C

Calcium

Mineral that is important for bone formation, but also many other functions of the body

Bone marrow

Tissue in most bones. It consists of connective tissue and stem cells

Bone marrow transplantation

Transplantation of stem cells taken from the bone marrow (→bone marrow)

L

Lactate dehydrogenase

An enzyme that is released when cells die

Light chain

Part of the antibody

Leukocyte

White blood cell. Leukocytes are an important component of the immune system

Lymphocyte

Lymphocytes are a subgroup of leukocytes

M

M-gradient

Shows the fraction of paraproteins in serum protein electrophoresis

Monoclonal

Clonality describes the origin of cells or products. Monoclonal cells all originate from a single (= mono) precursor cell

MRI (= magnetic resonance imaging)

Imaging procedure that works with a strong magnetic field and radio waves (= not x-rays).

Multiple myeloma

Cancer that is characterized by uncontrolled reproduction of abnormal plasma cells

Myeloma cell

An abnormal plasma cell

N

Nephrology

Study of the kidneys

O

Oncology

Study of cancer

Osteolysis

Degradation of bone structure

Osteoprotective

Protecting the bones

P

Paraprotein

“Incomplete” antibody (fragment)

Peripheral blood stem cell transplantation

Transplantation of stem cells taken from the blood

Plasma cell

Fully formed B lymphocyte

Plasmacytoma

Plasmacytoma is used as a synonym for multiple myeloma

Proteasome inhibitor

Medication which inhibits the proteasome of the cells

Psycho-oncologist

Provides psychological care to cancer patients

R

Radiology

Radiation therapy

Radio-oncology

(→ radiation therapy)

Remission

Decrease in symptoms or freedom from symptoms. Remission should not be equated with a cure

Relapse

Regression or the reappearance of the disease

H

Heavy chain

Part of the antibody

Serum protein electrophoresis

Diagnostic laboratory procedure for analyzing serum proteins

Solitary plasmacytoma

Solitary plasmacytoma is a type of multiple myeloma in which the tumor cells are limited to one location

Radiation therapy

Treatment with ionizing radiation

T

Thrombocyte

Blood platelets. Thrombocytes are important for blood clotting

C

Cytogenetics

Analysis of the chromosomes in the cell

Cytostatic

Medication which inhibits cell growth

List of references

- 1 DGHO (Deutsche Gesellschaft für Hämatologie und Medizinische Onkologie [German Society of Hematology and Medical Oncology]) Multiple Myeloma Guideline, last revised May 2018, <https://www.onkopedia.com/de/onkopedia/guidelines/multiples-myeloma/@@guideline/html/index.html> (last accessed July 2020)
- 2 Robert Koch-Institut und die Gesellschaft der epidemiologischen Krebsregister in Deutschland e.V.. Cancer in Germany for 2017/2018. 13th edition, Berlin, 2021. https://www.krebsdaten.de/Krebs/DE/Content/Publikationen/Krebs_in_Deutschland/kid_2021/krebs_in_deutschland_2021.pdf?__blob=publicationFile (last accessed May 2022)
- 3 Palumbo A. et al. J. Clin. Oncol. 2015; 33: 2863–2869

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For more details on our
patient engagement:




Scan the QR code to view our
range of support measures

janssen
With Me®

Your website containing information on
diseases on which we are conducting research.
www.janssenwithme.de



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