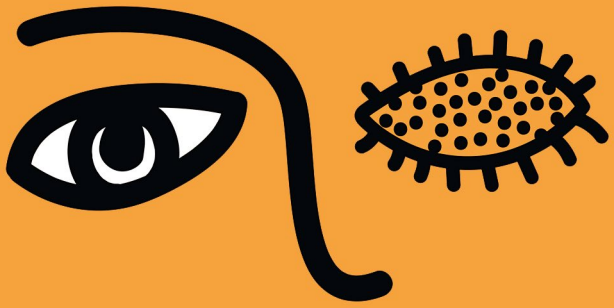
A first-aid kit for navigating the urgent questions that follow a serious diagnosis



Everything's Different Now?

What now?

Will I ever be able to enjoy my hobbies again?

Should I tell my employer?

How worried should I be?

How long will I live?

At first, you *don't have to do anything.* Feeling shocked is completely normal, and it's okay to *give yourself time to process it.*

About this Brochure

Receiving a **serious diagnosis** can make you feel alone, shocked or overwhelmed. New information arrives quickly, while practical questions may suddenly feel urgent. **How do you talk to your family? What should you search for online? Do you need to tell your employer?**

Although every diagnosis and every person are different, many of the first questions are similar. This brochure aims to **provide initial guidance and offer helpful answers** to some of these questions. It was developed from conversations with people living with serious or chronic illnesses, family members, therapists, psycho-oncologists and healthcare professionals.

A quick note: *The final pages of this brochure provide introductory information about polycythaemia vera (PV) and address some questions that may arise following this diagnosis.*

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This brochure was originally developed from conversations recorded for a podcast (more information on page 30). The original podcast is available in German only. Listening to it is not required to use this brochure.

5 QUESTIONS

After a Diagnosis

(Whatever the Diagnosis May Be)

"My husband knew right away, of course, ***but I didn't tell my sons*** *at the time. I simply couldn't bring myself to tell them because they had just started university, and I didn't want to pull them away from that or* ***make them worry about their mother.***"

Ingrid, Patient

Ingrid did not tell her sons about her diagnosis **until a year later,** and only after she realized that the course of her illness was not as severe as initially feared. **Looking back, she says she would handle things differently today.**

01

Should I Tell My Family?

Should you tell your family about your diagnosis? What if your mother is elderly? What if your children are still young? What if you do not expect much support from those around you?

"We often have **an ideal picture of family,** where **everyone can talk openly about everything,"** says Michael Köhler, a therapist who works closely with people living with cancer. "But real life is not always like that."

That is why his answer to the question **"Do I have to** tell my family?" is a very clear **"No."** There is nothing you must do.

For some people, family is the first place they turn to for support. For others, it may **take time,** or they may **first need support from friends, healthcare professionals, or others they trust.**

Sandra Skrebic shares a similar view. She has spent many years supporting people with acute and chronic illnesses, and she says:

"The question I ask is:

What makes it difficult to talk about it openly?"

Perhaps the answers to the following questions may help you **find your own personal way** of talking about your diagnosis and the **worries and fears** that come with it:

- ***Am I not telling someone because I do not want them to feel burdened?***
- ***Do I not want to be a burden to anyone?***
- ***Do I not want to be pitied?***
- ***What am I afraid of? Their reaction? Rejection? Too much concern and attention?***

> *"People often say:* ***I don't want to burden someone I love with this.*** *They tell themselves, I'll keep it to myself for now and see how I cope. But in my experience, the* ***words left unsaid often become a greater burden than the words that are spoken.***"
>
> *Sandra Skrebic, Therapist*

> *"Because of my uncle, I always thought that being seriously ill meant becoming depressed, withdrawing from life, and that life was essentially over. But in the patient group, where everyone shared the same diagnosis, I met people who completely changed that perception. They were living full lives, staying active, and doing well despite their condition."*
>
> *Ingrid, MPN-Patient*

Every diagnosis is a shock at first, and learning how to cope with that shock takes time. Being able to talk with trusted people can help.

Whether your family is the right group of people to talk to is something no one else can answer for you. Wherever you find them, **seek out at least one person you can turn to.** Everything else can happen step by step, at your own pace.

HELPFUL TIP

Patient groups can be extremely valuable. Search online for your diagnosis together with "support group" and your city or region. You may find an online community or local meetings you can attend. The advantage is that the people there have often gone through very similar experiences and may be able to share practical insights that helped them.

02

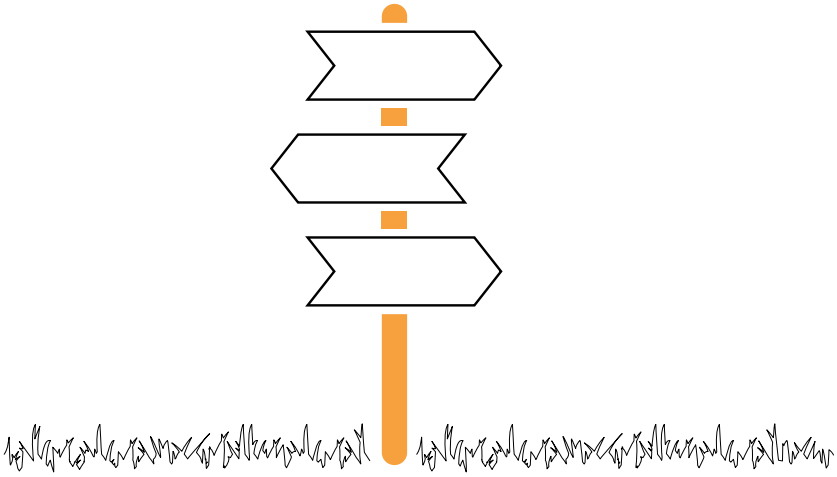
Should I Tell My Employer?

You may wonder whether you must disclose your diagnosis at work. **The answer depends on the laws in your country,** the nature of your job, your employment arrangements and whether your condition could affect your ability to work safely.

Before disclosing medical information, **consider seeking advice** from a local employee representative, occupational health service, patient organisation, social worker or qualified legal adviser.

In some situations, you may only need to provide information about your ability to work or the expected duration of an absence, rather than the diagnosis itself. Specific requirements vary.

If your health could **affect workplace safety or your ability to perform essential duties safely,** additional obligations may apply.



You might ask yourself:

- ***What will the next few weeks look like?***
- ***How demanding will the treatment be?***
- ***How much will the therapy affect my daily life?***
- ***Do I actually know these things, or am I only worried about them?***

Equally important questions are:

- ***What understanding, flexibility or practical support might I need?***
- ***How much information do I feel comfortable sharing?***

Remember:

You can take time to make this decision unless immediate safety or legal considerations require action. You decide how much personal information you wish to share, within the requirements that apply where you live and work.

When talking to others: Pay attention to what feels helpful to you. Often, people try to process what they have heard by telling stories about supposedly similar situations or by expressing their own concerns. If this becomes too much for you, it is perfectly acceptable to end the conversation. You are not responsible for helping others cope with your diagnosis.

The experts' advice: If there are no urgent reasons to do otherwise, give yourself some time before deciding whether to tell your employer. Immediately after receiving a diagnosis, questions about work often feel extremely important. In reality, however, they usually do not need to be answered right away.

Where Can I Find Support?

If you have questions about your rights and responsibilities in the workplace, **seek professional advice.** Employee representatives, social counselling services, patient organizations, and specialized legal advisors can help assess your individual situation.

03

How Do I Find the Best Treatment?

"What is needed is a kind of partnership with the treatment team."

Michael Köhler, Psycho-oncologist

How much do I need to know about my illness? Where can I find reliable information? Am I helping my treatment by becoming well informed, or am I getting in the way? **How involved should I be?**

Research shows that understanding your illness and its treatments can be beneficial. According to a major WHO report, well-informed patients often experience better health outcomes.[1]

But where do we find reliable information?

After a diagnosis, many questions arise. There is often not enough time during medical appointments to address every concern. Some worries or questions only emerge later. As a result, many people search online, even though they know that not everything they find is trustworthy.

Artificial intelligence tools can help patients find information more easily. However, they may provide incomplete, outdated, or inaccurate answers and should not replace information from qualified healthcare professionals.

HELPFUL TIP

Good medical information:
- identifies who produced it and why
- is based on current scientific knowledge
- clearly states its sources
- explains uncertainty
- does not create unnecessary fear
- does not promise miracles or a cure
- does not replace individual medical advice

As human beings, we all have unconscious biases that influence how we process information. **We often trust personal stories more than statistics.** If someone tells me that a friend of a friend's medication caused hair loss, that story may feel more convincing than the scientifically sound results of a clinical study.

So what can you do? It is important to put information into context:

Where does this information come from? What promises is it making? Are they realistic? Who is providing this information, and for what purpose?

You can always seek a second medical opinion. And you should never hesitate to ask questions. Many people find it helpful to write down any medical questions that arise between appointments, prioritize them before their next visit, and bring the list with them to discuss with their healthcare team.

> *"I have had clients who travelled hundreds of kilometres because they found a doctor who truly understood them. Their symptoms improved significantly. Good conversations, guidance, and counselling can be incredibly powerful."*
>
> *Michael Köhler, Psycho-oncologist*

Another important thing to remember is that **you bring valuable expertise to your care:** you are the expert on your own life.

Your doctor is the expert in medicine, treatment options, therapies, and medications. You are the expert on your body, your daily life, and your personal needs. Only you know what helps you feel well, which treatment is realistic for your lifestyle, and how your condition affects you day to day.

The best treatment decisions are made when both forms of expertise come together. That is why it is important to talk openly about your experiences and any challenges you encounter. Even the most effective medication cannot work as intended if it does not fit your life and is therefore difficult to take regularly.

HELPFUL TIP

If you would like to learn more about your condition, look for information from trusted sources such as universities, hospitals, health insurers, cancer information services, or official public health websites. Many universities also run dedicated initiatives that provide reliable information about specific diseases and health conditions.

04

I Feel Terrible. How Can I Get Through This Crisis?

A serious diagnosis can trigger a crisis. You may feel frightened, angry, numb, sad or overwhelmed. **There is no correct way to react, and you do not have to solve everything at once.**

"We tend to go through life with a kind of optimism bias. We assume that things will work out. We follow our routines, rely on our friends and loved ones, and have a sense of direction and order in our lives.

Then suddenly, a diagnosis turns everything upside down. We find ourselves asking: What happened? I did everything the way I always have, and yet something terrible has happened. Coming to terms with that is part of the challenge. The next step is figuring out what strategies can help you move beyond the initial shock and begin coping with the illness."

Michael Köhler, Psycho-oncologist

Proceed step by step:

STEP 1

Identify what is really distressing you

Perhaps you are afraid of dying. Perhaps you are worried about burdening others. Perhaps you miss your work or fear losing your independence.

Try to be honest with yourself: What exactly worries you most? Naming your fears may help reduce their overwhelming power.

STEP 2

Think back to previous challenges

How have you dealt with stress or difficult situations in the past? What helped you then? Looking back can remind you of strengths and coping strategies that may help you now.

STEP 3

Allow yourself to say, "This is really hard"

Nobody wants to be ill. Nobody wants a serious diagnosis. Allow yourself to feel anger, sadness, grief, and frustration. People who acknowledge these feelings often find it easier to notice the positive aspects of their lives as well. Optimism does not mean pretending everything is okay.

This advice comes from Maria Resch, a therapist who works primarily with people living with chronic illnesses.

STEP 4

Do not be afraid to seek support from others

Therapists are there to help people through difficult and challenging times. You do not need to have a mental health condition or commit to long-term therapy to benefit from their support. Often, just a few conversations can help bring greater clarity and make it easier to cope with what you are going through.

Psycho-oncologists are therapists who specialize in supporting people with cancer and their loved ones. They understand the unique challenges that can come with a diagnosis and can help you find ways to cope with the situation.

The availability, referral pathway and reimbursement of counselling or psycho-oncology services vary. Ask your treatment centre, healthcare provider, insurer, patient organisation or local support service what is available to you.

"Fortunately, my family doctor knew a psycho-oncologist who was kind and had time for me. I ended up seeing him twelve times. In Germany, this kind of support is generally covered by health insurance.

There was nothing dramatic about it. It simply gave me the opportunity to reflect on my situation. He would ask questions like: How are you doing? What are you able to do? Have you ever been through a similar crisis before? How did you cope with it? Things like that.

At the time, I kept going back and forth about whether I should stop working. I was 60 years old then. I discussed it with the psycho-oncologist, and he said: Don't think about whether you want to keep working for the next five years. Instead, ask yourself: Do you want to work until Easter? Until Christmas? Until next summer?

It may seem like a small thing, but I found it incredibly helpful. Breaking things down into smaller steps made them feel more manageable. And that's how you gradually find your footing again."

Werner, patient living with a chronic disease

05

How Can I Live Well Despite My Disease?

"You can be living with an illness and still feel healthy. Even when you have a condition that needs ongoing attention, you can still feel well. ***You can still have strength, purpose, and a sense of control over your life.*** *The goal is to find your way back to that feeling."*

Maria Resch, therapist specializing in chronic illnesses

How do you get back to a point where you feel that life goes on?

As Maria Resch explains, this is most likely to happen when several factors work together: **good medical care, emotional well-being, physical activity, healthy nutrition, and a supportive social environment.** The foundation is finding a way to accept your new life situation with the disease. This does not mean giving up. Rather, it means acknowledging: **"This is my situation right now."**

> *"Fighting against my symptoms only used up even more energy. What I learned was to tolerate the feeling of helplessness and to appreciate the things I am still able to do, even if they may not seem like much to others. For example, I can now empty a dishwasher in one go again, and for me that is almost a quality-of-life milestone."*
>
> *Vanessa, patient with a chronic disease*

Vanessa explains that this experience also taught her something important: she learned to recognize and respect her own limits. Looking back, she now sees that life is not about continuing to function at all costs or proving to herself or others how much she can still achieve. Instead, she has learned to manage her energy more consciously and to recognize her limits before she reaches them.

An important step towards regaining quality of life is learning to recognize your new limits and standing up for them.

"Before my diagnosis, I often believed that giving my all meant pushing myself to the limit and beyond. Today, giving my all means doing things in a way that still allows me to live well tomorrow and that does not drain me in the long term. It is not about doing everything I possibly can right now. It is about taking a broader view of my life and making choices that support my overall well-being."

Vanessa, patient with a chronic disease

At the same time, it is important to pay attention to the resources, strengths, and sources of support that are already part of your life. To illustrate this, therapist Maria Resch uses a simple but powerful exercise:

HELPFUL TIP

Picture yourself hosting a **dinner party.** Around the table are all the things that make up your life. Your disease is there too, an uninvited guest.

Yet it is not the only guest at the table. Your creativity is there. Your love of cooking and music is there. The joy of a restful night's sleep, the beauty you can still see in nature, and the places your legs can still carry you to are all there too. Everything that remains part of your life beyond your disease. The **people who matter most** also have a seat at the table: your children, your friends, your family, and others who are important to you.

Sometimes the disease is the loudest guest in the room and seems to dominate the conversation. No one would have chosen to invite it. But it is not the only voice at the table. And with the support of the other guests, you do not have to face it alone.

Try to approach yourself with compassion and realism.

Living with a disease means accepting that some things may change, and some challenges may become greater. At the same time, there is still room to shape your life in meaningful ways. With time, you can learn to identify and make the most of the possibilities that remain available to you.

Consider asking yourself: What can I still do and enjoy despite my disease? What brings me comfort, strength, or joy? Is there something new I would like to explore or experience?

> *"One thing I would like to leave you with is this: stay curious. Over the years, I have learned that no matter how bleak things may seem, there are always choices. You can choose to do something, choose not to do something, or perhaps choose to try something new."*
>
> *Maria Resch, therapist specializing in chronic illnesses*

BONUS

Understanding the Diagnosis Polycythaemia Vera (PV)

Polycythaemia vera, or PV for short, belongs to a group of disorders known as **myeloproliferative neoplasms (MPNs).** These are diseases of the blood-forming system in which certain blood cells multiply excessively within the bone marrow.

PV is a chronic condition that usually develops slowly over many years. This means that it is a long-term companion for those affected. At the same time, PV can now be treated effectively in many cases. Many people live with the disease for decades and, over time, find a good way to manage it. An important part of living with PV is working together with your healthcare team to find the treatment and support that best suit your individual needs. PV is usually caused by a change in blood-forming cells that is acquired during the course of life. In almost all people with PV, a change in the so-called JAK2 gene can be detected.

Over the past decades, PV has been the subject of intensive research. As a result, much more is now known about how the disease develops and how it can be treated. Many healthcare professionals encounter PV only rarely in their daily practice. In addition, some information available online may be outdated or misleading. In this brochure, we aim to answer the most important questions.

Bonus: About the Diagnosis Polycythaemia Vera (PV)

What is happening in my body?

In PV, the bone marrow produces too many red blood cells and often also too many white blood cells and platelets. This can make the blood thicker and increase the risk of blood clots, strokes, or heart attacks. This is exactly why regular medical monitoring and treatment are important.[2]

How long will I live?

PV can now be treated effectively, even though it is not yet curable. **Many people live very long and fulfilling lives with the disease.[2]**

Do I have cancer now?

From a medical perspective, yes. PV belongs to a group of diseases called myeloproliferative neoplasms (MPNs) and is therefore classified as a disorder of the blood-forming system that falls under the category of blood cancer.[2]

The term "blood cancer" can initially cause great fear. Some forms of blood cancer develop rapidly and require immediate treatment. **PV is different. It is usually a chronic condition that develops slowly over many years.[5]**

PV also does not form a solid tumour or cause metastases, as is the case with some other cancers. Therefore, the medical classification of PV as a blood cancer does not mean that it follows the same course as acute leukaemia or another rapidly progressing cancer. Nevertheless, PV is a serious chronic disease that should be monitored and treated continuously.[2–4]

So, the purely medical answer is: yes. For everyday life, however, it is important to understand that PV often behaves very differently from what many people associate with the word "cancer."

Bonus: About the Diagnosis Polycythaemia Vera (PV)

How difficult is life with PV?

Many people with PV have largely normal and fulfilling lives for years or even decades. At the same time, PV is a chronic condition that requires ongoing attention, including regular check-ups, treatment appointments, and coping with symptoms that can sometimes be very bothersome, such as itching and reduced stamina, which in some cases may progress to fatigue (pronounced physical and mental exhaustion).

People living with PV often say that one of the most important things is finding a way to live well with both themselves and the disease. It is possible to live well with PV when it is accepted as part of life. Because this journey is not always easy, support is available whenever needed, whether from psycho-oncology professionals, case managers, or patient support groups.

Be Cautious of Outdated Information

Information about PV has evolved significantly in recent years. As a result, some older websites, forum posts, or personal experiences shared online may be confusing or may present a picture that no longer reflects the experience of all patients today.
If you come across something that worries or frightens you, it is best to discuss it with your treating physician or healthcare team.

Reliable Medical Information:

- is based on the latest scientific knowledge,
- clearly states its sources,
- does not make promises of a cure,
- explains areas of uncertainty,
- and does not replace a personal conversation with your healthcare team.

Bonus: About the Diagnosis Polycythaemia Vera (PV)

Werner's story

In the podcast, Werner shares his experiences following his diagnosis in a very personal and moving way. He was diagnosed with PV in 2011, when he was almost 60 years old. At that time, he received the frightening message that he might have only one summer left to live. Looking back today, this proved to be a very pessimistic assessment and, as Werner's experience shows, it was not accurate. That was 15 years ago. Today, Werner continues to live a full and meaningful life with PV.

Werner's story highlights how deeply an alarming prognosis can affect a person and their loved ones. At the same time, it is important to remember that every patient's journey is unique. One person's experience cannot predict what another person's future will look like.

Many people with PV continue to lead active and fulfilling lives for many years. Thanks to advances in medical understanding and treatment, many patients are able to manage their condition successfully over the long term. At the same time, PV is a chronic disease that requires regular monitoring, appropriate treatment, and ongoing attention to possible symptoms and risks.[2] This combination of realism and hope helps many people feel informed and supported while avoiding unnecessary anxiety.

"Fifteen years ago, shortly after my diagnosis, we were on holiday in Ireland. I woke up early one morning, lying there facing the wall, wondering: What happens now? How is my life going to continue? I couldn't focus on fishing at all. All I could think was: Are these my last days? When we said goodbye to our hostess, I remember thinking: Is this the last time we'll ever see each other? You feel completely uncertain and overwhelmed. That was probably about two months after my diagnosis. Those first months are especially difficult."

Werner, an MPN patient who was diagnosed more than a decade ago and continues to live a full and meaningful life.

Many of the topics covered in this brochure are explored in greater detail in the accompanying German-language podcast. Simply scan the QR code or search for "Ab jetzt ist alles anders?" in your podcast app or on Spotify.



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IMPORTANT: This brochure provides general information and is not a substitute for medical advice. If you have any questions about your diagnosis, treatment, or personal circumstances, please speak with your doctor or health-care team.

MY NOTES

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