

SEPSIS

Information for
patients
and their relatives



deutsche
SEPSIS-HILFE e.V.

Imprint

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For reasons of better readability, the masculine form is used for personal names and personal nouns in this brochure. In the interest of equal treatment, the corresponding terms apply to all genders. The abbreviated form of language is for editorial reasons only and does not imply any judgement.

SEPSIS

Information for
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and their relatives

Greetings

Deutsche Sepsis-Hilfe e.V. is at your service

Dear Sir/Madam,

This information brochure is intended to educate and inform you about sepsis and to help you cope with the consequences of sepsis.

It presents important facts about the meaning, definition, causes, risks, course and therapy of sepsis.

Sepsis is the worst form of infection that can lead to tissue damage, organ failure and death. It can be caused by bacteria, viruses or fungi. Sepsis is a medical emergency that can often be fatal or have serious long-term consequences if not recognised and treated early.

This booklet also contains experiences of people affected by sepsis. You will find examples of seriously ill people who have found their way back to life after the hard time of sepsis - we believe that their stories will give you courage.

The brochure is intended to help you understand the disease in a better manner. In addition, you will also find contact persons so that you and your relatives do not feel alone.

If you have any questions that are not answered by this information booklet, please contact [the office of Deutsche Sepsis-Hilfe e.V.](#)

We will be happy to help you.



Yours, Hubert Grönert

Chairman of Deutsche Sepsis-Hilfe e.V.

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2. Fundamental information

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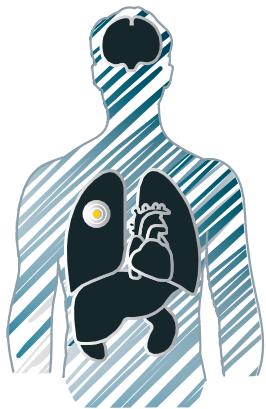
Was ist eine Sepsis?

Sepsis is an acute life-threatening organ failure caused by an **exaggerated or extremely weak immune response of the body to an infection**. This means: Sepsis is always triggered by an infection. The body's own defence system is ramped up, but still cannot prevent the infection from spreading in the whole body.

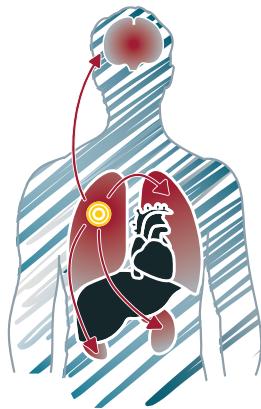
Fact:
Sepsis is always triggered by an infection.

As a result, organs and tissues are not supplied with sufficient nutrients and ultimately organs fail. For example, the lungs can fail. In this case, the patient needs respiratory support measures such as additional oxygen or mechanical ventilation.

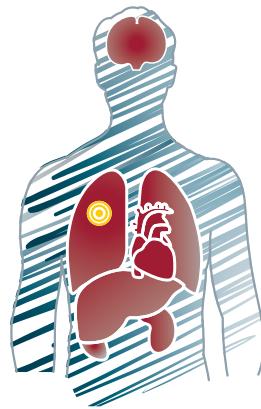
If the blood pressure is still too low (hypotension) despite so-called volume therapy (administration of sufficient fluid as an infusion) and the administration of circulation-supporting drugs (vasopressors) becomes necessary, this is called **septic shock**.



Local infection, such as pneumonia.



Sepsis, the local infection 'jumps' to other organs. Single or multiple organs begin to fail.



Septic shock, the circulation fails and other organs are affected.

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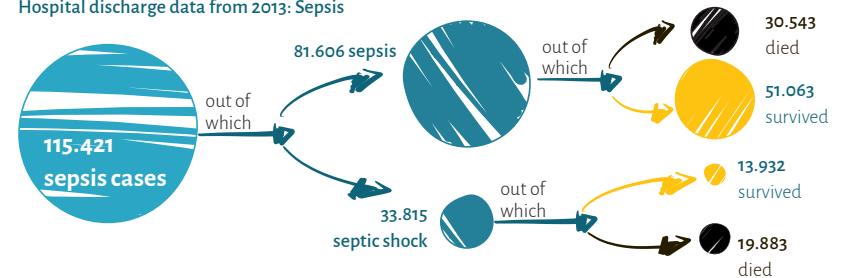
How common is sepsis?

It is difficult to give exact numbers of cases. Over the last few years, numerous scientists worldwide have collected data on patients with sepsis in hospital. However, this often does not include people who were not admitted to hospital or who were not diagnosed at all.

A retrospective survey from Germany based on hospital discharge data showed 81,606 cases of sepsis and 33,815 cases of septic shock in 2013. The hospital mortality rate was 58.8% for septic shock. Approximately 20% of the patients were over 80 years old.

[→ Source: Fleischmann C et al. (2016) Dtsch Arztebl Int 113:159–166]

Hospital discharge data from 2013: Sepsis



Valid, i.e. reliable, data on the epidemiology of sepsis are not yet available - with a few exceptions. In medical jargon, this is monocentric register data collected by means of prospective (forward-looking) active data collection. First long-term results are available for the University Hospital of Jena, where 1,976 patients treated in intensive care were observed, about half of them with nosocomial sepsis. We speak of nosocomial sepsis when the sepsis was acquired in hospital. The hospital mortality was 44.7%, after six months the mortality increased to 58.5% and after 48 months to 74.2%.

[→ Source: Thiel P et al. (2011) Infection 39:S138–S139]

Often, doctors cannot clearly determine whether those affected died directly from the consequences of sepsis or from the consequences of a serious underlying chronic disease such as cancer or cardiovascular disease. It must also be noted that mortality increases significantly with age and that many patients cannot be treated with intensive care or only to a limited extent due to severe previous illnesses, old age or a significantly reduced quality of life.

Who can get sepsis?

Any patient with an infection can get sepsis. However, there are factors that can influence the occurrence and severity of the course.

Risk groups include:

Patients with weakened immune systems, e.g.

- New-borns and young children (mainly affects the first year of life)
- Elderly people (with increasing frequency in those over 60 years of age)
- people who do not have a (functioning) spleen
- People who need to take certain medicines (e.g. to treat rheumatism)
- People who have had an organ transplant
- People with AIDS

People with chronic diseases, e.g.

- Diabetes mellitus
- Cancer
- Kidney or liver disease
- Respiratory diseases, especially those treated with cortisone or the like
- Dependency diseases (alcohol, drugs)

People with ports of entry for pathogens, e.g.

- Open wounds after an operation
- Severe internal or external injuries
- Extensive burns
- People with a catheter or drain in place

What should be considered in case of asplenia?

Asplenia means that the spleen is missing or not functioning.

Estimates show that about one in a thousand German citizens has no spleen. In addition, there are diseases in which the function of the spleen is limited.

Patients with asplenia have an increased risk of contracting infections caused by pathogens that cause meningitis or pneumonia, such as pneumococci, meningococci or Haemophilus influenza. The infections are often particularly severe in these patients.

Vaccination against the above-mentioned pathogens is an important measure to protect asplenia patients.

Patients with asplenia should always carry an emergency passport. You can find more information about asplenia and the current vaccination recommendations on the website of the Asplenia-Net initiative: <https://asplenie-net.org>
There you can also order the emergency passport free of charge.



What are the causes of sepsis?

Sepsis is caused by an infection.

This means that pathogens such as bacteria, viruses or fungi enter the body and multiply there. The most common cause of sepsis is respiratory diseases such as pneumonia, followed by infections of the abdomen (e.g. intestines, gall bladder) and urinary tract infections. But other infections, such as infections of the heart valves, the central nervous system or of bones and soft tissues, can also be the cause of sepsis. In some cases, the source of infection cannot be determined despite extensive diagnostic measures. **Theoretically, any infection can lead to sepsis.**

Can you protect yourself from sepsis?

Basically, anyone with an infection can get sepsis. This means: Avoiding infections reduces the risk of sepsis. Regular, thorough hand washing and careful cleaning of wounds are representative of general and specific hygiene measures.

→ For extended vaccination recommendations for patients without a functioning spleen, see **page 10** „What should be considered in case of asplenia?“

Vaccinations are another way to protect against infections. Examples are vaccinations against seasonal influenza and pneumococci. In particular, chronically ill people and those over 60 should discuss the question of vaccination with their general practitioners.

In addition, there are sensible general recommendations for strengthening the body's defences in the sense of a healthy lifestyle. Recommendations include a balanced, healthy diet, regular exercise, sufficient fluid intake, restful sleep, avoiding permanent stress and a sensible use of stimulants.

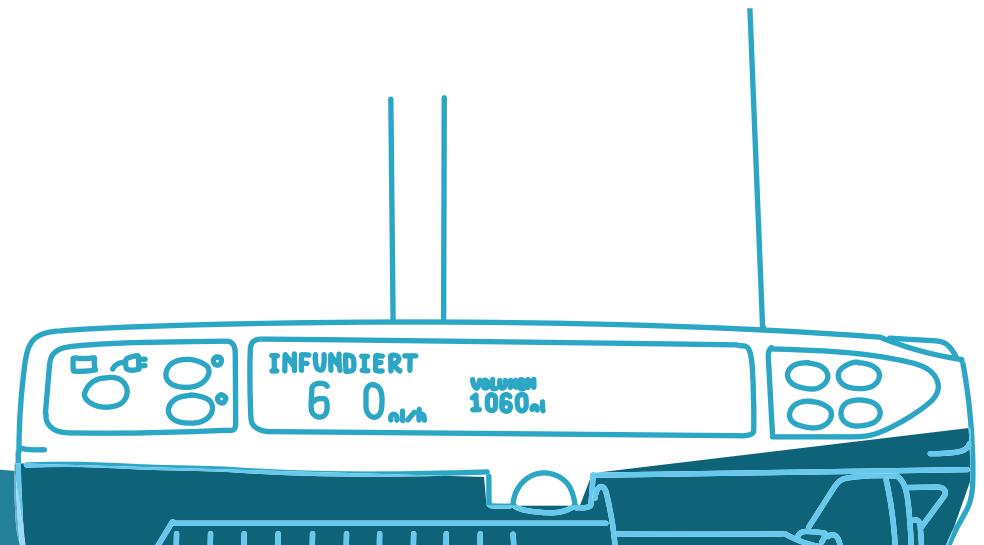
Sepsis can develop outside the hospital as well as in the hospital.

Infections acquired in hospital are called nosocomial infections. They do not automatically equate to treatment errors.

It is estimated that between one third and 50% of hospital-acquired infections are preventable. However, this also means that 50% to two thirds are not preventable. One of the reasons for this is that it is precisely those people who belong to the risk groups who are treated in hospitals.

→ For this, please refer to **page 10** „Who can get sepsis?“

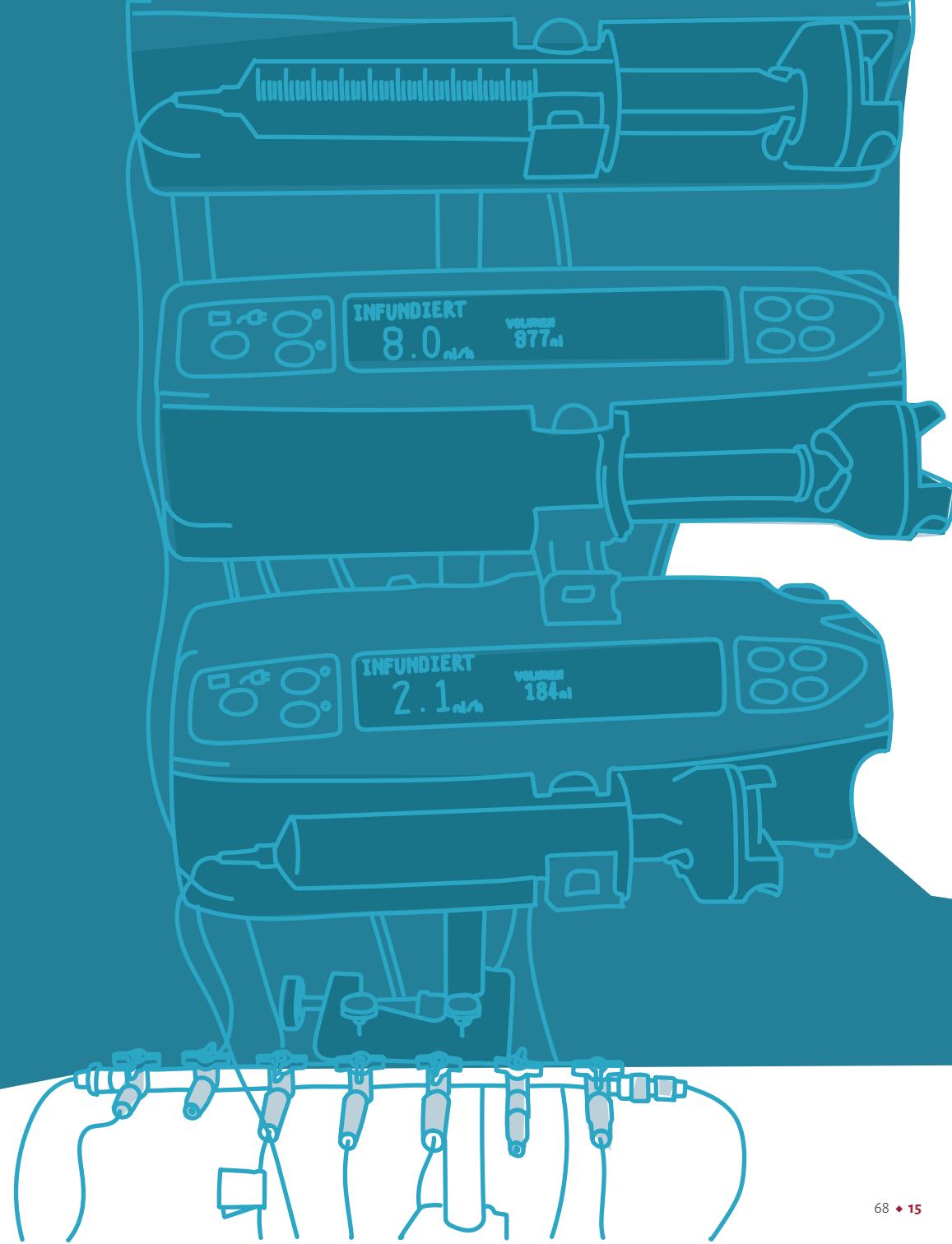
Hand disinfection is the most effective means in the hospital to prevent the transmission of infections. For this reason, the S3 guideline „Sepsis - Prevention, Diagnosis, Therapy and Follow-up“ recommends making the necessary materials for hand hygiene available directly at the place of treatment and establishing further training in the field of infection prevention for all employees in all hospitals.



2. Diagnosis and treatment

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How do you recognise sepsis?

Fact:

Early signs of sepsis are*:

- New onset of changes in consciousness
- rapid breathing (respiratory rate > 22/minute)
- Low (systolic) blood pressure ≥ 100 mmHg

*When an infection is suspected to be present.

The symptoms of sepsis are often non-specific. Fever, chills, palpitations, low blood pressure, confusion and breathing problems are among them. In addition, sepsis can manifest itself very differently in individual sufferers. The symptoms usually do not occur singularly, but in a combination.

In order to detect a life-threatening threat in high-risk patients at an early stage, the S3 guideline „Sepsis - Prevention, Diagnosis, Therapy and Follow-up“ recommends using the Quick SOFA (qSOFA) in patients outside intensive care units who are suspected of having an infection.

This means that a doctor should be consulted if at least two of the following early signs are present and infection is suspected:

- New onset of changes in consciousness
- Rapid breathing (respiratory rate > 22/minute)
- Low (systolic) blood pressure ≤ 100 mm Hg

S3 guidelines

reflect the tested and very well-evidenced state of the art of medicine in diagnosis, treatment and rehabilitation as well as prevention. Guidelines are not legally binding.

How is sepsis diagnosed?

At the beginning of the diagnosis is the focus search: The doctor assesses whether and, if so, where in the body an infection may be present. In order to support the findings, a wide variety of diagnostic procedures are used - always depending on the type of suspected infection: e.g. X-ray or computer tomography (CT) images, ultrasound or laparoscopy (examination of the abdominal cavity).

Blood cultures and, if possible, a microbiological smear from the site of infection are taken to determine the causative agent of the infection and effective antibiotics. Vital signs such as temperature and heart rate as well as inflammatory values in the blood can provide further information on whether an infection is present. To diagnose possible organ failure, the doctor performs a clinical examination of the patient. This includes measuring the blood pressure and respiratory rate. Further laboratory tests follow.

The diversity of sepsis and the problems in differentiating it from other diseases that are associated with similar symptoms make it difficult to make a clear diagnosis.

How is sepsis treated?

Sepsis and septic shock are medical emergencies. The S3 guideline „Sepsis - Prevention, Diagnosis, Therapy and Follow-up“ therefore recommends starting therapy immediately.

Immediate therapy includes the administration of antibiotics and fluids via a venous catheter. In most cases, the first administration of antibiotics is calculated. In this case “calculated” means: Since the results of the microbiological tests are not yet available at this point, the drugs must be chosen to cover the pathogens suspected for the source of infection. As soon as the results are available and it is known which pathogen triggered the infection, this calculated initial therapy can be replaced by a therapy that is specifically adapted to the pathogen spectrum.

The medical team tries to eliminate the cause of the infection. This is called focal treatment. In addition to the administration of antibiotics, depending on the source of the infection, additional surgical sanitation may be necessary, e.g. in the case of an intestinal perforation.

Furthermore, the treatment aims to stabilise or, if necessary, support the individual organ functions. If respiratory function is impaired, this is done by administering oxygen or mechanical ventilation. Blood pressure must be raised with fluids and vasopressors. If kidney function is severely limited, dialysis may be necessary.

In the acute phase, an artificial coma, a long-term anaesthesia, is often necessary. For this, the patient receives medication as in anaesthesia during an operation - usually painkillers and sleeping pills.

Stabilisation of the organ functions is therefore central. But there is more to the treatment of sepsis patients: the prophylaxis of thromboses and stomach ulcers, (artificial) nutrition, the treatment of pain and more.

Treatment in the intensive care unit

Sepsis patients often need to be treated in intensive care. This can take several days to several weeks, depending on the severity of the illness, the underlying diseases present and possible complications. Many of the patients are in an artificial coma for at least some time and have to be artificially ventilated. The duration varies greatly in this case as well.

Treatment in an intensive care unit is an exceptional situation for those affected, characterised by fears, pain and the unfamiliar surroundings. People who are in an artificial coma can often still perceive voices, sounds or even pain. For this reason, relatives should talk to the patient in an artificial coma during a visit and, if possible, also hold his or her hand. This can have a calming effect.

For the relatives, the situation is equally difficult to bear. They know their family member is in a life-threatening situation, connected to machines. Often a person's outward appearance changes due to the severity of the illness. Since the staff in intensive care units have a heavy workload to

Fact:

Recovery is not continuous in most cases.

deal with and both the medical and nursing staff have to take care of many critically ill patients, conversations with relatives are sometimes abundantly brief. This often leads to incomprehension on the part of the relatives and stirs up additional fears.

In order to obtain up-to-date information on the state of health, it is advisable to discuss the procedure with the staff. Designate a person within the family who contacts the attending physicians once a day (by telephone or during a visit) and then shares the result of the conversation with the others. Avoid that each visitor individually asks about the current status. It is also recommended to write down the questions in advance so that nothing is forgotten in the short time of the conversation.

Recovery is not continuous in most cases. **Often, after days of improvement, there are times when no progress can be seen or even regressions or renewed complications occur.** Unfortunately, due to the severity of the disease, even doctors cannot avoid or foresee this. As soon as the patient has overcome the sepsis, he or she is transferred to a normal ward or, if possible, immediately to a rehabilitation clinic.

Viele weiterführende und detaillierte Informationen zu den Vorgängen auf einer Intensivstation sind in der Broschüre „**Zeit auf der Intensivstation**“ aufgeführt, welche Sie kostenfrei bei der Deutschen Sepsis-Hilfe anfordern können.



What is delirium and how can relatives deal with it?

Some patients develop delirium, acute confusion, during their stay. They experience a world that makes no sense to others but seems completely real to themselves. This can be frightening for both the patient and the relatives. A delirious patient may not believe their friends and family when they try to reassure them - even if they recognise them.

Delirium can show itself in two ways: quite obviously to outsiders or more hidden. Some patients are restless and agitated, which is particularly stressful for relatives. Mostly, however, delirium runs its course quietly, it may make patients very sleepy and is difficult for medical staff and relatives to recognise. Delirium is often an extreme condition: Either patients do not sleep at all or they sleep almost all the time; either they are constantly restless or they move extremely little. However it presents itself, delirium is a sign that the person's brain is not working properly because they are very ill.

Reasons for delirium can be infections, side effects of medication or malfunctions of individual organs such as kidneys, heart and lungs. Delirium is usually only temporary. It usually lasts a few days to a week. Sometimes, however, it can take longer before it disappears completely.

There are several ways to help patients with delirium:

- Talk to the affected person, hold his hand, try to reassure him.
- Regularly explain to him that he is in hospital and discuss the situation.
- If the patient is given sleeping pills and you are not sure what to talk about, you can, for example, read from a favourite book or newspaper.
- If it is possible for you, keep a diary in which you write down what happens every day.
- Use a smartphone to say goodnight in the evening. A familiar voice and a familiar face help the sick persons to get their orientation and get to rest.

→ For this, please refer to **page 21** „Intensive care diary“

- Record video messages on the smartphone/tablet that can be shown to the person concerned. Make reassuring, orienting statements, e.g.: You are in hospital. We know about it. The nurses, carers and doctors are taking good care of you. Do what they tell you because they will help you get better. Our thoughts are always with you and we will visit you tomorrow. We love you.”

If you have any questions about delirium, you can contact **Mr. Nydahl, intensivstation@sepsis-hilfe.org** or the office of Deutsche Sepsis-Hilfe e.V.

Intensive care diary

Many patients do not remember the acute phase of the disease. Due to the artificial coma or delirium, they do not perceive the processes in the intensive care unit at all or only to a limited extent or can only assess them to a limited extent.

Their sleep rhythm is disturbed and their ability to perceive things is limited (lying down, partition walls to neighbouring patients, noises from other rooms). Therefore, patients misperceive many things and subsequently build up fears. These fears may continue to accompany them after their stay in hospital. An intensive care diary, which is kept during the acute phase of the illness, can clarify questions in retrospect and thus reduce fears.

Such a diary can help the relatives to structure the processes that have taken place, so that they can later reproduce them chronologically. Often, after longer stays, one no longer knows at what point in time which decisions were made and how the patient's state of health developed over time. If the patient then asks questions later, the relative may not be able to give correct and sufficient answers. As a result, it is more difficult for the patient to process and come to terms with what he or she has experienced.

For this reason, it may be advisable during longer stays of a relative in the intensive care unit to briefly write down a few lines about the course of events every day.

[→ Source: P. Nydahl, S. Krotsetis and S. Köpke: Confusion - delirium in the intensive care unit. Information for relatives of the UKSH University Hospital Schleswig-Holstein]

→ For this, please refer to **page 63** „Contact persons for special topics“

Examples of topics worth noting are:

- Important medical decisions or interventions (E.g.: Was surgery necessary today?)
- Unusual happenings in the room (Interventions at the neighbouring bed, restless fellow patients, etc.)
- What impression did the patient make that day? (Sad, confused, sleepy etc.)?
- What progress or regression was there?
- Were there any important personal, family decisions; What are the relatives doing?

These can only be suggestions. Naturally, it is up to you what you want to note down and report. Taking photos is also a very personal decision.

The nursing staff involved in the treatment can also make entries in the intensive care diary. Many intensive care units in Germany already participate in such an approach.

If you have any questions about an intensive care diary, you can contact **Mr. Nydahl, intensivstation@sepsis-hilfe.org** or the office of DSH e.V.

→ For this, please refer to **page 63** „Contact persons for special topics“

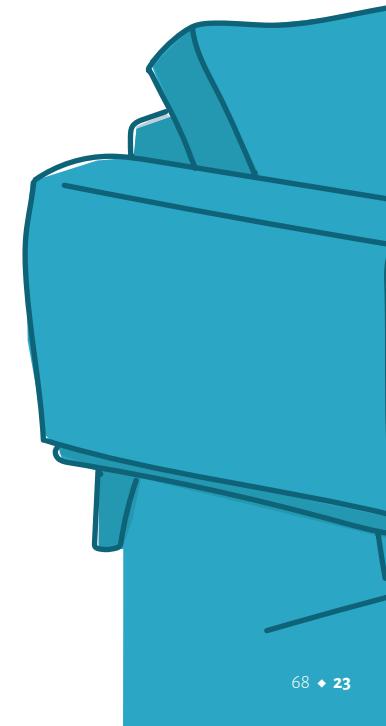


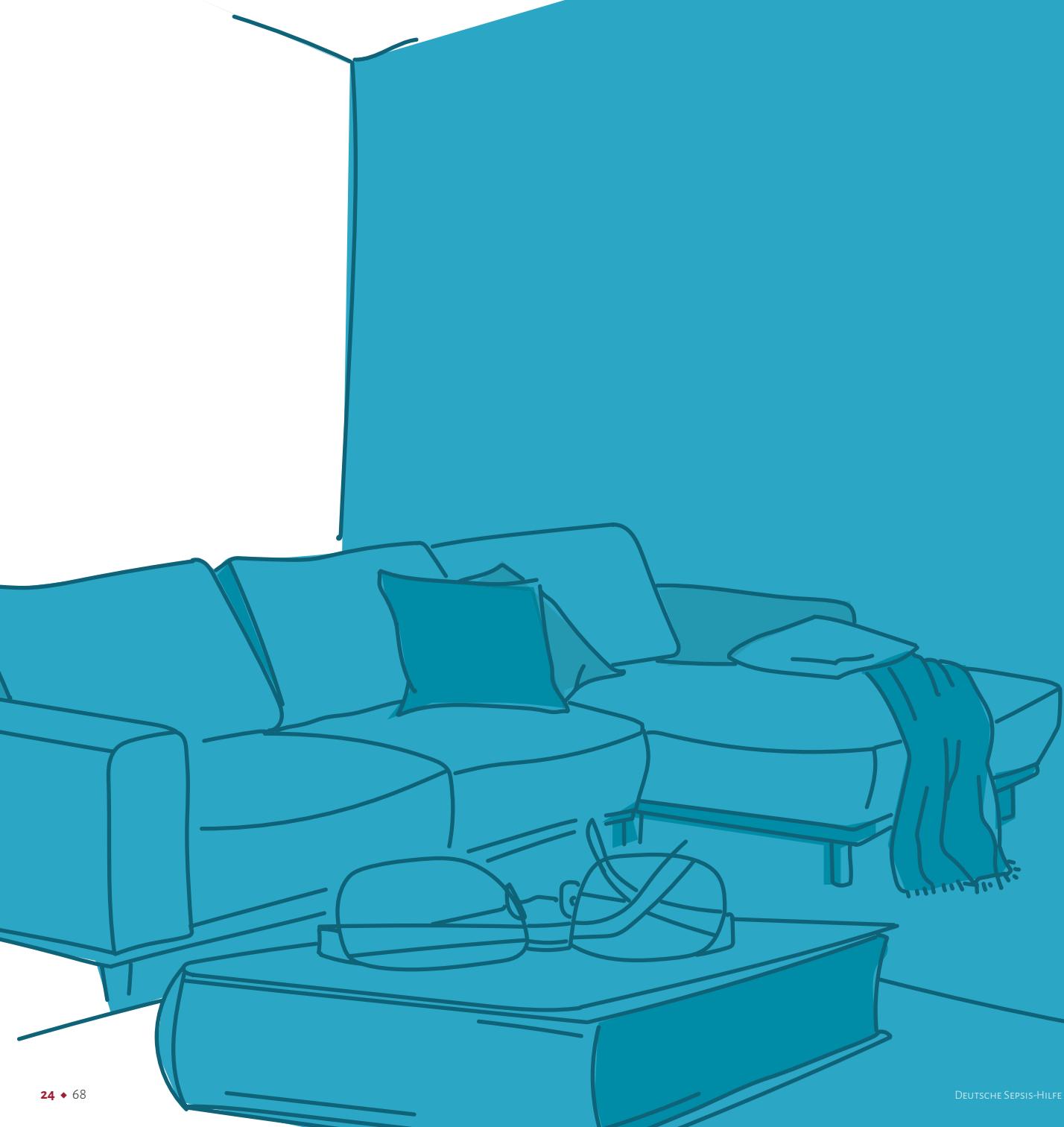
The website **www.intensivtagebuch.de** has many helpful hints and examples on this topic as well as a template for free download.

Treatment in the normal care unit

Not all sepsis patients are treated in an intensive care unit. If the course is easier and the patient is stable, intensive medical treatment is often not necessary.

However, the medical team monitors the inflammation values as well as the vital parameters in order to be able to react immediately to changes. Antibiotics, fluids and oxygen can also be administered in the normal ward. Many sepsis patients spend some time in a normal ward of the hospital after their stay in the intensive care unit before they are discharged home or to a rehabilitation clinic for further treatment.





3. After discharge from a hospital

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Follow-up treatment (AHB)

Many sepsis patients are transferred to a rehabilitation facility for further treatment immediately after hospitalisation or within 14 days. You should discuss whether this further treatment is planned with the attending doctors. The application is usually handled by the social services of the hospitals.



You can find more information at:

www.deutsche-rentenversicherung.de

Enter the following in the search field: **Anschlussheilbehandlung**

In most cases, the German pension insurance is responsible for AHB for **employed persons**, and the health insurance fund is usually responsible for **pensioners**.

At present, there is no rehabilitation clinic in Germany that is specifically specialised in the treatment of sepsis patients. When choosing a rehab facility, it is important that the patient's existing limitations can be treated. Specialist neurological care is often advisable here so that the symptoms mentioned below can be diagnosed and treated.

After sepsis, patients mainly suffer from the following limitations:

- Polyneuropathies - diseases of the peripheral nerves; these lead to e.g. pains, sensory disorders or even relaxation of muscles
- Myopathies - muscle weaknesses
- Neurocognitive dysfunctions - restrictions in attentiveness, memory, etc.
- Post-traumatic stress disorder (PTSD) - anxiety, nightmares, indifference, sleep disturbances, etc.
- Pain

→ For this, please refer to **page 28** „What are the possible late effects of sepsis?“

If there is an additional condition, e.g. kidney damage requiring dialysis, care must of course be taken in the selection process to ensure that the spa clinic can also provide for this condition.

Since many patients suffer from fears and nightmares after experiencing the life-threatening situation in an intensive care unit, psychological support in the rehabilitation facility would be advisable.

→ For this, please refer to **page 40** „What support can you apply for?“

The social workers of the hospitals, if available, or the health and pension insurance funds can give you information about possible rehabilitation clinics.



Die Internetseite: www.rehakliniken.de gibt einen deutschlandweiten Überblick über Rehabilitationskliniken und deren Angebote.

Discharge to home

After their stay in the clinic or rehabilitation facility, patients often return home after weeks of absence. In many cases, they are not yet able to perform activities of daily living as they did before the illness.

In this case, you should discuss further treatment with your general practitioner.

It is conceivable, for example that you could jointly apply for inpatient rehabilitation, if you have not already done so. Outpatient physiotherapy and occupational therapy as well as psychological support are other ways to regain strength, endurance and resilience.

What are the possible late effects of sepsis?

Many former sepsis patients still complain about impairments years after the disease. Possible late effects of sepsis include nerve and muscle damage, pain, cognitive impairment, reduced resilience and psychological disorders.

Cognitive impairments

During sepsis, inflammatory processes spread throughout the body. All organs may get affected. The brain can also be affected. As an indicator of a particularly severe course, the duration of treatment in the intensive care unit is a proven risk factor for the occurrence of brain damage. Not much is known yet about the causes. Also, these long-term consequences do not necessarily appear immediately and are therefore often no longer associated with sepsis.

If the following symptoms are present, brain damage could have occurred in the course of sepsis:

- Reduction in resilience (physical or mental)
- Poor concentration
- Slowing of the reaction capacity
- Attention problems
- Decreased mental receptivity
- Impaired memory capacity
- Reduced mental flexibility and ability to adapt to new situations

Such cognitive impairments are often accompanied by psychological disorders such as anxiety and depression. They are a consequence of the experiences during the illness as well as the long-term effects of sepsis on everyday life and social relationships. They can also be a further characteristic of the functional disorders of the brain.

These and the aforementioned cognitive impairments can reinforce each other in the sense of a vicious circle.

Cognitive disorders can also be the result of a mental disorder. Cognitive disorders may accompany you for the rest of your life. But there are ways to reduce the limitations, to compensate for them and to learn to live with them.

→ For this, please refer to **page 30** „Psychological effects“

Do you have such complaints? Then you should seek neurological or neuropsychological treatment to be examined for cognitive disorders and to discuss further treatment options. Neuropsychological therapy is designed to reduce brain dysfunction and the associated limitations in mental performance, to promote adaptation and to improve your participation in social life again.

You can find more information at: www.gnp.de
Please go to → For Patients / Victims.
There you find → **Outpatient neuropsychological treatment**



Within the framework of occupational therapy, you can take advantage of so-called brain performance training. Concentration and memory games such as riddles, puzzles or Sudoku can be just as helpful as various programmes for independent brain training that can be found on the Internet. Some health insurance companies offer numerous courses that are especially designed to help people cope with stress and promote relaxation.

Perhaps, the most important thing is: Stay active mentally, physically and socially, as best you can, even if you feel like withdrawing. Activity in everyday life is the most important training for your brain.

Would you like to get in touch with former sepsis patients who are also affected by neurocognitive impairments? Then contact **Mr. Köhler, mitte@sepsis-hilfe.org** or the office of DSH.

→ For this, please refer to **page 63** „Contact persons for special topics“

Nerve and muscle damage

Sepsis can cause nerve and muscle damage, which manifests as paralysis, loss of sensation, muscle weakness, coordination problems, difficulty swallowing and pain. This is called critical illness polyneuropathy (CIP) or critical illness myopathy (CIM).

There are many causes, but they are not yet fully understood. For example, machine ventilation, lack of exercise, medication and artificial nutrition may cause the damage. Mild forms of the disease can disappear completely, while only a partial improvement can often be expected in more severe forms.

If you have symptoms and complaints that point to CIP or CIM, it is advisable to consult a neurologist. He or she will discuss further diagnosis and therapy with you, such as occupational and physiotherapies or pain management.

Psychological effects

About 55% of former sepsis patients develop symptoms of increased psychological distress in the first year after discharge from hospital. Similarly, many relatives who may have witnessed a person close to them being exposed to a life-threatening situation suffer from the psychological effects. Particularly depression, anxiety disorders and post-traumatic stress disorder (PTSD) are to be mentioned here. In some cases, the symptoms only appear in the long-term course - i.e. months, sometimes years later.

Die PTBS ist eine psychische Reaktion auf ein extrem belastendes Ereignis, wie es eine lebensbedrohliche Erkrankung sicherlich darstellt. Jeder Mensch reagiert ganz individuell auf Belastungserfahrungen. Schlafstörungen, Alpträume, Stimmungstiefs, Reizbarkeit, Gleichgültigkeit oder ausgeprägte Ängste können die Folge sein. Oftmals stößt die Veränderung in der Persönlichkeit auf Unverständnis im sozialen Umfeld, was wiederum Frustration bei den Betroffenen auslöst. Auch die Beziehung zum Partner kann beeinträchtigt werden.

Studies also show that people who had increased symptoms of PTSD after sepsis also had more severe physical symptoms (fatigue, aching limbs, stomach and heart complaints) than patients who did not have

increased PTSD symptom scores. Since the symptoms can take a chronic course if left untreated, PTSD should be treated through trauma-focused psychotherapy, if necessary with medication support through psychotropic drugs. Make absolutely sure that the psychotherapist treating you has the appropriate qualifications and experience in trauma therapy.

Mental disorders can also be an indication of brain dysfunction. This should be clarified by a neurologist.

Both patients and their relatives often want help to cope better with mental limitations. You can consult the following people:

- **The general practitioner** should always be the first contact person. He or she can clarify whether there are organic causes for the symptoms and refer them to doctors who can treat them further.
- After studying medicine, a **psychiatrist** has completed a specialist training course in which he/she has acquired knowledge of mental illnesses. Psychiatrists are allowed to prescribe medication.
- **Psychological psychotherapists**, after studying psychology, complete additional state-certified training. They focus on the psychological causes of symptoms. Their treatment is based on scientifically proven procedures; they do not use medication. Therapy is designed to help the patient deal with the causes of their mental illness and learn new ways of dealing with it. Psychotherapists can also be consulted without a referral from the general practitioner.

[Sources: Jaenichen D, Brunkhorst FM, Strauß B, Rosendahl J (2012). Physical and psychological long-term consequences after intensive medical treatment of severe sepsis in patients and relatives. Psychother Psych Med 62, 335-343]

→ For this, please follow **page 28** „Cognitive impairments“

[Sources: Hatch R, Young D, Barber V, Griffiths J, Harrison DA, Watkinson P (2018). Anxiety, depression and post-traumatic stress disorder after critical illness: a UK-wide prospective cohort study. Critical Care 22 (1), 310-22]

You can find psychotherapists in your area on the websites of the respective chambers of psychotherapists. Health insurance companies can also provide information about psychiatrists and psychotherapists. It makes sense to ask several psychotherapists, as there are often waiting times. In the first conversation, you should always clarify whether it is possible for the health insurance company to cover the costs.

In addition, psychotherapists offer the opportunity to introduce themselves in a psychotherapeutic consultation and to clarify whether treatment would make sense. Such a consultation usually takes place after an appointment has been made. It is intended to ensure direct access to psychotherapists and to bridge the long waiting times. In addition, appointment service centres of the associations of SHI-accredited physicians, which arrange appointments for consultation hours, should simplify the search for therapists.



Appointment service centre:

www.bundesgesundheitsministerium.de/terminservice-und-versorgungsgesetz.html

In addition to these clinics, there are psychotherapeutic outpatient clinics. They are usually affiliated with universities, training institutes or hospitals.

If the step to psychotherapy is still difficult, psychosocial counselling centres are alternative points of contact. There are often local offers that can usually be found via their website, in the daily newspaper or in the telephone book (under „Counselling“).

Sometimes it makes sense to seek support at short notice, for example if a long wait for an appointment is unavoidable. Self-help groups are also an option. Offers can be found online, for example via the National Contact and Information Centre for the suggestion and support of self-help groups.



Self-help groups: www.nakos.de

Not only the sepsis patients themselves, but also their relatives can get in touch with people who have experienced similar things. The focus is on mutual support.

A call to the telephone counselling service takes even shorter. However, counselling there cannot replace therapy. The numbers 0800 1110111 and 0800 1110222 are free of charge and available around the clock. Counselling is anonymous and open to everyone.



Telephone counselling:

0800 1110111 or 0800 1110222

(free and round-the-clock)

www.telefonseelsorge.de

also offers counselling on chat and mail.

Pain

Chronic pain is one of the long-term consequences that some former sepsis patients suffer from. In the first place, a doctor should clarify whether other diseases are the cause of the complaints. Many large hospitals in Germany have a pain therapy department that specialises in treating chronic pain patients. In addition to the administration of painkillers, the therapy can include physiotherapeutic measures, learning relaxation techniques and psychosocial support.

Amputations

In the course of sepsis, blood circulation is disturbed in the smallest blood vessels. In extreme cases, it is possible that, for example, a finger end limb dies. Amputation of the affected limb may become necessary. In order to cope with such a traumatic event and to deal with the resulting limitations, special physical and psychological treatment is necessary.

→ For this, please refer to **page 63** „Contact persons for special topics“

Discuss the further procedure with your attending physician as well as therapies and rehabilitation options tailored to your limitations. If you would like to get in touch with former sepsis patients who have also had an amputation, please contact **Mr. Trumann: nord@sepsis-hilfe.org** or the DSH office.

Weight loss

Many patients lose weight during their stay in hospital - especially if they receive intensive care for a longer period of time. This often continues in the initial period after discharge from hospital.

Discuss a possible diet plan with your general practitioner. In addition to normal food intake, he or she may consider giving high-calorie sip feeds. If weight loss continues, other triggering factors need to be checked, such as dental problems or swallowing difficulties.

What can you do for your recovery?

After surviving sepsis, life may not be the same. Many patients feel very weak, listless and unable to cope. Some are dependent on the help of others for a long period of time. All this is quite normal, because the body needs a lot of time to regenerate.

Give yourself adequate time.

We have put together some tips to help you cope with your changed daily life despite everything:

- Start with small steps. Challenge yourself, but do not overdo it. Even small activities will lead you to continuously increase your resilience.
- Allow yourself rest breaks, as these are just as important for your body as exercise.
- Increase your activities slowly but steadily.
- Ensure a balanced sleep and wake rhythm.
- Say goodbye to unrealistic goals.
- Adjust your daily routine to the changed life situation.
- Increase self-control over your life and daily routine, but allow for help.

- Forgive yourself for mistakes.
- Did you have to spend a long time in an intensive care unit and can no longer remember this stay? If you want to better understand and come to terms with your time there, it can be helpful to visit the ICU again and have the staff explain the equipment and aids to you.

Despite long recovery periods, many former sepsis patients do not regain the physical and mental capacity they had before the illness. But a whole series of reports show that those affected have learned to accept the changes and build their lives on the new foundation.

Be proud of what you have already achieved.

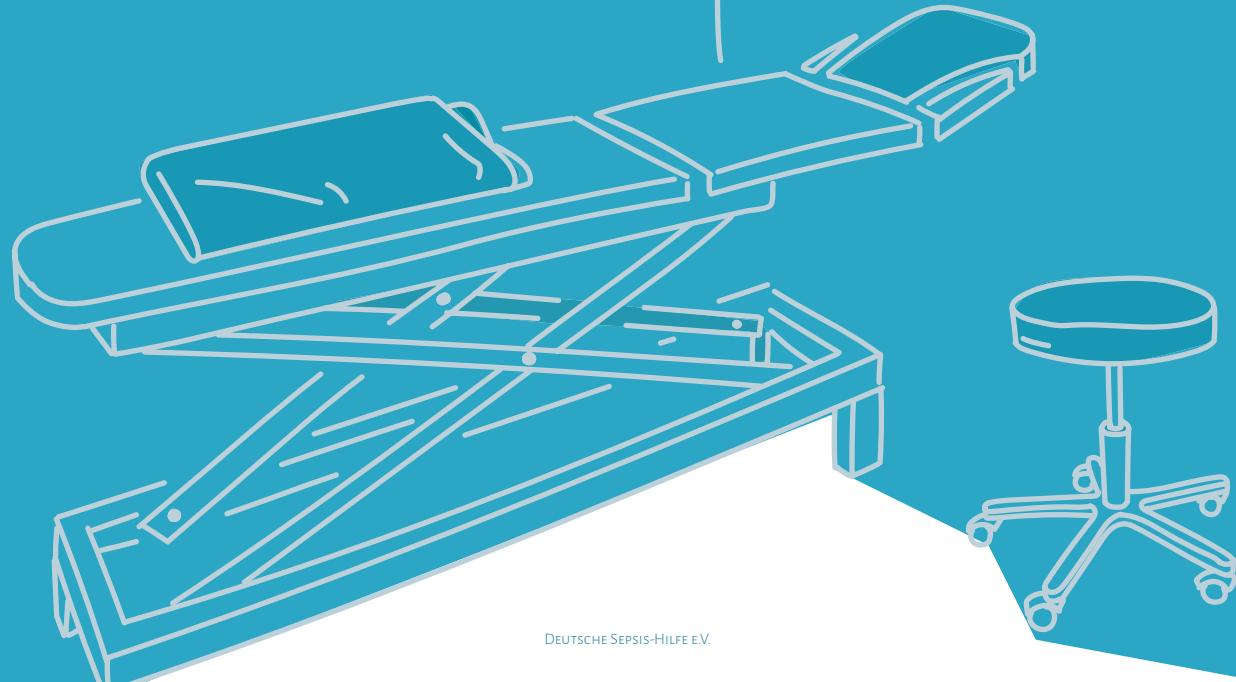


Lisa fell ill at the age of 24.

4. Support

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Important for relatives: Dealing with stress and grief

As already described on the previous pages: Sepsis does not only mean a break for the person affected, but also for life partners and relatives.

During the acute illness, you have been there for the patient, possibly visiting him regularly for months in hospital or in the rehabilitation facility. As soon as the patient is back home, the support continues. Everyday life has to be restructured, doctor's appointments have to be made and care has to be provided. There may also be financial worries and fears about the future. This situation often leads to exhaustion and psychological problems for relatives.

It is important that you also allow yourself rest and time out. It is of utmost importance that you manage your strength, because the recovery process of your relative can take months. If possible, integrate fixed times into the daily schedule that you use exclusively for yourself, for a walk, meeting with friends, etc.

Do not be afraid to ask friends and family for help.

Special support is needed by relatives whose family member is so seriously ill that the dying process is inevitable. In this case, it is advisable to contact local hospice and palliative care facilities.

→ For this, please refer to **page 30** „Psychological effects“

Fact:

Unfortunately, quite a few sepsis patients die both in the acute phase and in the later course.

The loss of a loved one is an exceptional situation and shakes the mental balance. Grief is not an illness, but it can make you ill in the long run if the help and support you need is not forthcoming.

If necessary, there are numerous offers for the bereaved to cope with their grief.

If you feel that you cannot cope with the situation, you can turn to hospice services.

You can find **hospice services** in your area at the following homepage: www.wegweiser-hospiz-palliativmedizin.de

The way in which you can cope with your grief will be discussed individually with the staff. Another possibility would be a bereavement group. You can find appropriate offers online, e.g. via the National Contact and Information Centre for the suggestion and support of self-help groups.

Information Centre for the suggestion and support of self-help groups: www.nakos.de

What support can you apply for?

→ For this, please refer to **page 63** „Contact persons for special topics“

After sepsis, you or your loved one may need support. This chapter is intended to give you a brief overview of existing support. For further questions, you can contact **Mr. Leisgang, unterstuetzung@sepsis-hilfe.org** or the office of DSH.

Severe Disability Law

After surviving sepsis, a disability could exist according to the definition in § 2 SGB IX. This would be the case if the physical function, mental ability or mental health deviates from the condition typical for the age for more than six months with a high probability and therefore the participation in life in society is impaired.

Whether you or your relative has a degree of disability (GdB), and if so, which degree, is determined by the competent authorities.



Please inform yourself about this and the application procedure on the respective websites. You can find it here: **www.integrationsaemter.de** → enter the following in the search field, **‘Pension offices and competent authorities’**

Reports of findings submitted with the application will speed up the procedure. The pension office may also request to inspect, for example, the findings of the treating doctors and discharge reports from the hospital. In individual cases, medical assessments are carried out at the pension office. The medical service of the competent authorities or an expert will evaluate the documents in accordance with the Ordinance on Medical Care (VersMedV).

On this basis, the authority decides on the existence of a disability, the degree of disability and on the corresponding mark (letter in the severely disabled person's identity card which gives an indication of the type of impairment).

If several disabilities are determined, a total GdB is formed. A notice of assessment is issued if the total GdB is at least 20. If the total GdB is less than 20, neither a decision nor a certificate is issued. You can find more information on the GdB, the characteristic signs and the associated compensations for disadvantages on the website of your competent office.

If you do not agree with the decision on your disability, you can lodge an appeal. The legal deadline (within one month after the notification of the decision) must be observed. The objection must be made in writing and must be substantiated.

Fact:

The official procedure is free of charge.

Care Law

For the purposes of social long-term care insurance, whether and to what extent a person is in need of care is determined by the degree of independence and the abilities the person still possesses in the following areas:

- Mobility
- Cognitive and communicative abilities
- Behavioural and psychological problems
- Self-care
- Coping with and independently dealing with demands and stresses caused by illness or therapy
- Shaping everyday life and social contacts

Before you apply for home care together with your caregiver, you should check whether you are entitled to a care level.

The person in need of long-term care's statutory or private health insurance is responsible for long-term care insurance - this is where the application for long-term care should be submitted. In the case of an initial application, you are entitled to a long-term care counselling session within two weeks of submitting the application. If you wish, the counselling can take place at your home.

After the application has been submitted, the expert from the Medical Service of the Health Insurance (MDK) will visit you to determine the need for care and the care level.

Be sure to indicate on the application that the appointment will be coordinated with you.



When you have completed the individual modules under <https://nullbarriere.de/pflegegradrechner.html> the number of points achieved and the corresponding care level will be displayed. **It is advisable to document (print out) the individual module entries for a later MDK assessment.**

How does the MDK visit work and how do you prepare?

It makes sense that the person who mainly provides the care and, if necessary, the carer or authorised representative are present at the assessment. Together, you give the assessor information about the care situation in everyday life - for example, what can still be done independently, where there are difficulties and where help is needed. Present current medical reports, medication overviews and any care documentation from a care service. Think in advance about the questions you have for the expert. You should never „pull yourself together“ during the MDK visit and trivialise or conceal problems out of false shame. If you keep a care diary before the MDK visit or fill out the questionnaire „Care assessment in the home environment“, you will gain more clarity yourself about the circumstances and effort of the care. This way you are well prepared for the MDK visit. .



You can find more information on the MDK homepage:

www.medizinischerdienst.de

https://www.medizinischerdienst.de/fileadmin/MD-zentraler-Ordner/Downloads/01_Pflegebegutachtung/Pflegeflyer_A4-VERSION_2022_ENG_01_UA.pdf

Has a care level been recognised?

Then you can choose between care allowance and benefits in kind or a combination of both from care level 2.



For more information on the care level and possible services, go to:

www.bundesgesundheitsministerium.de

Go to → Service → Publications → Care

Preventive care

You care for your relative at home and are prevented from doing so, for example because of a holiday or illness? Then the long-term care insurance fund currently pays a maximum of 1,612 euros from care level 2 for a maximum of six weeks a year to continue to provide care at home.

If close family members take over the preventive care, they receive 1.5 times the care allowance for up to six weeks.

Short-term care

Short-term care is available for longer absences of the caregiver, for example during a cure or a holiday. The person in need of care can then be accommodated in a facility that offers short-term care places - also in a rehabilitation clinic if the person in need of care is participating in a rehabilitation measure there.

Short-term care may also be necessary if the transition to home care has to be arranged following a hospital stay. The long-term care insurance benefit is available to all persons in need of long-term care with care levels 2 to 5 in the same amount. The amount of the benefit is currently up to 1,612 euros per year for up to eight weeks per calendar year.

Time off work for carers

Under certain conditions, carers can take partial or full leave from their work to temporarily devote themselves to caring tasks. More detailed information can be found on the website of the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth.



You will get **more information about care** on the web pages of the Federal Ministry of Health:

<https://www.bundesgesundheitsministerium.de/themen/pflege/online-ratgeber-pflege/leistungen-der-pflegeversicherung/leistungen-im-ueberblick.html>

You can **download** the following **helpful brochures** from this site:

<https://www.bundesgesundheitsministerium.de/service/publikationen/details/ratgeber-pflege-englisch.html>

<https://www.bundesgesundheitsministerium.de/service/publikationen/details/pflegeleistungen-zum-nachschiessen.html>

Nursing aids

Nursing aids are devices and materials that are necessary for home care. They facilitate care and alleviate the complaints of the person in need of care or contribute to enabling him or her to lead a more independent life.

- Technical care aids are usually provided by the long-term care insurance fund in part or against a co-payment.
- Consumable products, e.g. disposable gloves, bed pads or disinfectants, must be purchased by the person in need of care. He or



www.bmfsfj.de/bmfsfj/themen/aeltere-menschen/vereinbarkeit-von-pflege-und-beruf/familienpflegezeit/die-familienpflegezeit/75714

she receives a reimbursement from the long-term care insurance fund of currently up to 40 euros per month at all care levels (1-5).

Other help

Housing assistance

Housing assistance is financial support for the purchase, furnishing or maintenance of a home suitable for the disabled. Different service providers may be responsible, e.g. long-term care insurance funds, accident insurance funds, pension insurance funds and the Employment Agency, but also the Integration Office. Furthermore, there are housing assistance programmes of the individual federal states.

An important tip on how to proceed: First get advice, then submit the application and wait for approval. If you rebuild first and then apply, you are not entitled to financial support.

You can find more information at:

www.bundesgesundheitsministerium.de/leistungen-der-pflege/pflegehilfsmittel.html



Motor vehicle assistance

You may need to purchase or convert a vehicle or incur costs for a driving licence. The Motor Vehicle Assistance Ordinance regulates corresponding benefits.

What does a health care proxy, care proxy and living will mean?

This chapter briefly explains the terms health care proxy, care proxy and living will. It is advisable for everyone to think about issuing these documents while they are still healthy and to discuss the contents with their family and possible proxies. This is the only way to ensure that in the event of illness, action is taken in the patient's best interests and legal and financial matters can continue.



Information can be found at: www.bmjv.de/DE/Themen/VorsorgeUndPatientenrechte/Betreuungsrecht/Betreuungsrecht_node.html

- **Health care proxy** – as a health care proxy, you can specify who may manage your affairs and make decisions for you if you are no longer able to do so yourself. It makes sense to write the power of attorney in as much detail as possible. A neutral person should testify that the person concerned is in full possession of his or her mental faculties at the time the power of attorney is granted.
- **Care proxy** – if a person suddenly needs care and there is no health care proxy, relatives are not allowed to conclude legal transactions on behalf of the person to be cared for. The guardianship court then appoints a legal guardian. This is subject to a fee. However, if it is decided in advance through a care proxy who is going to take over the legal guardianship in case of need, the guardianship court is bound by this decision.
- **Living will** – with a living will, you can specify what may be done medically if you are no longer able to express yourself on this, or if you can no longer give your consent.



Helpful websites:

German Pension Insurance:

- Follow-up treatment: www.deutsche-rentenversicherung.de

Integration offices:

- Application: www.integrationsaemter.de → enter the following in the search field: 'Pension offices and competent authorities'.

MDK www.medizinischerdienst.de

- https://www.medizinischerdienst.de/fileadmin/MD-zentraler-Ordner/Downloads/01_Pflegebegutachtung/Pflegeflyer_A4-VERSION_2022_ENG_01_UA.pdf

Federal Ministry of Health:

- **Appointment service centre:** www.bundesgesundheitsministerium.de/terminservice-und-versorgungsgesetz.html

Care level and possible services:

- www.bundesgesundheitsministerium.de
Go to → Service → Publications → Care
- <https://www.bundesgesundheitsministerium.de/themen/pflege/online-ratgeber-pflege/leistungen-der-pflegeversicherung/leistungen-im-ueberblick.html>
- <https://www.bundesgesundheitsministerium.de/service/publikationen/details/ratgeber-pflege-englisch.html>
- www.bundesgesundheitsministerium.de/service/publikationen/details/pflegeleistungen-zum-nachschlagen.html

Federal Ministry for Family Affairs, Senior Citizens, Women and Youth

- <https://www.bmfsfj.de/bmfsfj/themen/aeltere-menschen/vereinbarkeit-von-pflege-und-beruf/familienpflegezeit/die-familienpflegezeit-75714>

Federal Ministry of Justice and Consumer Protection:

- <https://www.bmjv.de/SharedDocs/Publikationen/DE/Betreuungsrecht.html>

Self-help groups: www.nakos.de

Outpatient neuropsychological treatment: www.gnp.de

- Please go to → For Patients/Victims
→ Outpatient neuropsychological treatment

Telephone counselling:

0800 1110111 or 0800 1110222 (free and round-the-clock)

www.telefonseelsorge.de Counselling through chat and mail

5. Victims tell their story

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Sepsis from the perspective of a former patient

In the summer of 2012, Steffi A., then aged 49, narrowly survived a severe septic shock. An event that changed her forever. Since then, her life has been divided into before and after, into an old and a new era. She describes her view of things.

It was an incidental finding during a routine examination: About eight years ago, I was found to have gallstones, which, according to the information, were small and completely non-irritating in the gallbladder and posed no danger. I was advised that as long as I had no complaints, it was best not to touch them - especially because of my liver, which was greatly enlarged due to a congenital blood disorder.

But the typical symptoms (such as certain food intolerances, severe nausea and colic-like discomfort) were not long in coming. The intervals between these „attacks“ became shorter and shorter, so that I had to be admitted to hospital in July 2012. After various examinations, the decision was finally made to remove the gallbladder. However, I was told that the operation could only be performed after the inflammation had subsided. That is why I was allowed to go home, went back to work, and even wanted to travel again (with the doctor's approval) before the operation, which was planned for September and which I was looking forward to without any fear.

But all this was not to come to pass ...

Just three weeks later, my condition deteriorated dramatically. After a night of severe nausea and almost unbearable „belt-like“ abdominal pain, the general practitioner who had been called alerted the ambulance service immediately and had me brought to the rescue centre of the nearby hospital under emergency medical escort. Despite the almost unbearable pain, I felt dizzy and sleepy at the same time, but - for reasons that were inexplicable to me at the time - intuitively felt an indescribable fear of what might come. Mortal fear ...

The emergency doctor who had knelt by my bed at home and administered painkillers was to remain my last memory for a long time. The next were the frightening sounds of the intensive care unit. That was several weeks later.

On 3 August 2012, I was admitted to an ICU at the hospital with prognoses that were merciless and devastating. Triggered by supposedly „harmless“ gallstones, a necrotising pancreatitis had developed – the cause of a severe septic shock that led to multi-organ failure within a very short time and made immediate organ replacement therapy necessary. My relatives were told that it was not foreseeable whether I would survive the next two hours, and my son, who had left two days earlier for a semester abroad in Sweden, was asked to return immediately on the advice of the attending senior physician to see his mum once more - and to say goodbye to her.



Photograph of a patient with septic shock in the intensive care unit

But I only found out about all this later ...

In between, there were many weeks in an artificial coma, tracheotomised and ventilated, with several operations on an abdomen kept open from the sternum to the pubis, covered only with sterile foil.

All kinds of complications occurred, including complete coagulation failure, the spleen had to be removed because of necrosis and existing splenic vein thrombosis, capillary leak syndrome, septic encephalopathy and critical illness polyneuropathy and polymyopathy developed. All this left me in absolute danger of losing my life over a long period of time, which was only made clear to me much later. It is still difficult for me to really realise it - even today.

The worst thing, however, were the fears, nightmares and hallucinations I had to go through in the artificial coma and during the slow „winding down“ of the medication - a condition that doctors certainly do not compare to drug withdrawal without reason. I never want to have to endure anything like that again.

I lost 18 kg in the six weeks I was in intensive care unit. I no longer recognised myself in the mirror that was held up to me there at some point when I „woke up“ again. **Everything that one normally takes for granted - breathing, eating, swallowing, speaking, later sitting, one day standing and walking - I had to learn all over again.** And I had to realise that nothing, absolutely nothing, is „normal“ after a sepsis.

As there was no rehabilitation place available at first, I was transferred from the ICU to an IMC ward. From there, after another ten days, I was finally taken to early neurological rehab, which I started in a wheelchair on a ward for the severely disabled and left on my own two feet after seven weeks. A long and endlessly arduous path ...

After one year and three months, I was able to start a gradual reintegration into my profession, which I am doing again today - contrary to all forecasts - to the full extent (in a two-shift system, with weekend and holiday services as well as night-time on-call duty). This takes a lot of my energy, which usually stays completely at work. The rest of my daily life also often pushes me to my limits, I am quickly exhausted and less able to work under pressure, sometimes I suffer from concentration and memory problems as well as sensory disturbances in my hands and feet due to the polyneuropathy. Another remnant of the severe sepsis is a very large focus of necrosis in the liver, which I notice through a constant feeling of pressure in the upper abdomen, which has to be monitored regularly and of which no one knows whether there is any danger.

But I am alive and infinitely grateful for it!

I was very lucky to have been in the right place at the right time and to have been in the very best hands there: in an intensive care unit that had been a kind of „role model ward“ for me long before, without suspecting that one day I would have to experience being a patient there myself in „my own“ hospital. Perhaps I should mention at this point that I work as a medical-technical assistant in the department of medical microbiology at this hospital, so sepsis is exactly „my“ topic professionally as well. But EVERYTHING changes when you suddenly find yourself on the other side and lying helpless and at the mercy of the sickbed.

I owe my survival to the prudence of my general practitioner, but above all to the great commitment of the then senior physician of a really very special intensive care unit. Not only to his high level of medical knowledge and skills, but also to his assertiveness and tenacity, with which he always believed - even against some other opinions - that I could make it.

Last but not least, I would like to mention the support of my family and colleagues and the tireless and loving care of the nursing staff, without whom I would have been lost.

Even today, I regularly visit „my“ ITS once a year - always on 3 August. When I was transferred, I had to promise the doctors and nurses that I would treat this day as my second birthday from now on. And it is simply indescribable to experience how happy everyone there is to see me again. To this day, it is not easy for me to stand in front of that door again, ring the bell and take in the oppressive atmosphere with all its frightening sounds. Each time it feels as if I am suddenly catapulted back into the situation of that time. Maybe you could call it a form of processing or a kind of „confrontation therapy“.

Of course, people and the way they deal with such an experience are very different. It may be that many survivors of sepsis (and their relatives) only want to look forward, preferring not to think about it anymore, but to put all the difficult memories behind them. Of course,



Steffi A. after surviving septic shock



I completely understand and respect that! But I am not one of them. For me, that would be the completely wrong way, because I think it is important to process and fathom what I experienced and to deal with it - even today.

Since such a severe and existentially threatening illness, which is literally a borderline experience, leaves deep marks not only on the body but also on the soul, I would have wished for psychological

support after some time, which unfortunately never existed in my case. Only much later - last year - did I have the strength to get help myself. Unfortunately, the people around me (including myself) often react increasingly incomprehendingly and annoyed over time when you feel the need to talk about what you have experienced - with the argument that it should „finally“ be over - but it never is.

And today I know that the strongest and bravest thing is to seek help! This is one of the reasons why I decided to become a member of the Deutschen Sepsis-Hilfe (German Sepsis Aid).

Sepsis from the perspective of relatives

Lisa fell ill with sepsis at the age of 24. Due to the severity of the disease, both of her lower legs had to be amputated and her spleen removed. Her parents, Astrid and Rainer, describe how they each experienced the situation.

Rainer: The news that our 24-year-old daughter was ill was brought to us by a police officer at 3 hours on a Sunday. When I spoke to the doctor in the intensive care unit on the phone and the word sepsis was mentioned, I could not understand the term at all. But the statement that we should leave as soon as possible made it clear to me that our daughter was seriously ill.

Astrid: On the drive to the hospital, we spoke very little. Each of us tried to understand the situation somehow. In my mind, I was already thinking about how the funeral would go and what would be in our daughter's best interest. We had never talked about it with her before. I was afraid of having to make final decisions for her, such as turning off the machines that were keeping her alive

Rainer: After a four-hour drive, we finally arrived at the hospital and were briefly explained by the doctor. But little had I understood by then. The fact that our daughter was in an artificial coma made it clear to us that the disease was life-threatening. Despite the preparation, the sight was frightening, as she was very bloated due to the treatment. **That was when I first prayed.**

Astrid: In the course of the day, our other children came by despite the distance, which helped us a lot. More conversations with doctors followed, who gave us more information about the treatment. The first glance when entering the hospital room went to the vital signs and became a sad routine. Our four-year-old son was taken by our adult children to look after him for a few days so that my husband and I could support each other.



Lisa im künstlichen Koma



Rainer: The first night was marked by interruptions where I had to constantly look at my mobile phone. But we were glad that there was no call from the hospital, which would certainly not have been good news. This also marked the next nights. Monday began with a deterioration in our daughter's condition. We were told that the increase in medication was increasing the risk of limb loss. But we felt that our daughter was in very good hands and trusted the doctors. When the first improvements in the vital signs appeared on Monday evening, cautious optimism set in.

Astrid: The worst part of the situation for me was not being able to do anything. All we could do was stand at the bedside, stroke our daughter, talk to her without knowing if she was even aware of anything.

Rainer: On Tuesday, our daughter was slowly getting better, but remained critical. We had to agree for her spleen removal. An unusual decision over the head of an adult daughter. I then had to go home to take care of our little son. Inside I felt a certain confidence.

Astrid: After the next few days were marked by a slow improvement, the anaesthetic was reduced on the 5th day to end the induced coma. This raised the concern whether and how our daughter would wake up again or whether she would remain in a coma. We were all the more relieved when she looked at us on the 6th day. Since she could not speak due to the ventilation, communication was not yet possible, but we had made a big step. The second step was that urine came out of the bladder catheter. I have never been so happy at the sight of urine, but it meant that the kidneys would resume their function and our daughter would be spared dialysis.



Lisa wakes up after the induced coma. Finally.

Rainer: On day 7, Lisa was finally able to speak and we could talk. We were now grateful for how quickly the recovery process was going. But the struggle for hands and feet began now. The fact that one ear was deaf did not mean much at this point. The main thing was to survive. The second week was filled with the first hand operation, as the enormous water retention had damaged the nerves so badly that she was paralysed. The reduced blood flow to her feet caused them to become discoloured. The decision in which hospital to continue treatment had to be made so that Lisa's friends could also visit her. It was not easy to get operating theatre capacities in the Ruhr Area, but we succeeded.

Astrid: Now it turned out that it was good that I was with our daughter during the day to plan together with Lisa. Parallel to the first steps of recovery, I could now finally take over tasks for my daughter: Serving food and drink, brushing her teeth, applying lotion, washing and brushing her hair, etc. In this way, I was able to support the staff in the intensive care unit well and we became a really good team together.

Rainer: The transfer to the Ruhr Area changed little for me, except that the journey to the hospital was reduced from four to one hour. Through the phone calls with my wife, I realised how important it was for me to take care of our five-year-old son alone, so that my wife could be there for our daughter all the time. Nevertheless, as a single father I often reached my limits. The visits to the hospital were stressful for our son because he only ever saw his mother briefly. His question whether his mother would come home at all again showed how the situation affected him. It was a burden for me to see my daughter, who had just been amputated on both lower legs, because it made me realise how drastic the permanent restrictions caused by the sepsis were.



Lisa is regaining her abilities - for example, completing crossword puzzles with her left hand.



Astrid: The time was now very intense because I slept in the room with my daughter. It was a great help for her that I could be there around the clock and that the nursing staff did not have to take over all the tasks. For me, this time meant being able to participate intensively in all the processes of change and recovery of our daughter and to have important conversations that she was mentally and emotionally unable to have. But it also meant having no space to retreat and no real balance for myself. I functioned as long as I had to. It was only when I returned home that I realised how broken I was and what was now no longer working.

Rainer: My wife's return after nine weeks meant a relief, but it took time for the relationship between our younger son and her to settle down again. Only a short holiday brought some normalisation. Due to the extreme stress, we applied for a mother/father-child cure, which we were thankfully allowed to take at the same time as our sick daughter's rehab. Nevertheless, we still feel the effects of the extremely stressful time today, even though we can gratefully accept our daughter's rapid progress.



After her discharge from the hospital, Lisa is taking riding lessons again.



6. Deutsche Sepsis-Hilfe e. V. – our support services for you

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Die Deutsche Sepsis-Hilfe e. V.

Deutsche Sepsis-Hilfe e. V. (DSH) is the world's first organisation for people suffering from sepsis and their relatives or survivors. It was founded in 2007 by a group of people affected by sepsis. With our more than 350 members, most of whom are affected persons, relatives or surviving dependants, we have a nationwide network that provides psychosocial support. All our members have been in similar situations and have sought and found a connection with us.

What support can the Deutsche Sepsis-Hilfe e.V. offer you?

We offer a variety of services to support those affected and their relatives. These are independent of membership in our association.

Consultancy

Every year, the Sepsis-Hilfe receives about 300 enquiries from affected persons, relatives and interested parties. The main focus is on questions concerning the recognition and avoidance of sepsis, the acute phase, late effects and rehabilitation possibilities. Often the wish for contact to other affected people is expressed.

Do you also have questions about sepsis? You are welcome to contact us. We will try to answer your questions. Please use one of the following options:



Sepsis hotline: 0700 7377 4700

You can contact us on weekdays from 08:00 to 21:00 and on weekends/holidays from 09:00 to 21:00. During regular office hours, you can reach the office staff at the specified number. From 16:00 and on weekends/holidays, our volunteer members are available to offer advice to affected persons, relatives and those seeking help.

Enquiries by email

You are also welcome to send us your request by email at info@sepsis-hilfe.org. We will try to process your request as quickly as possible.

Contact option via our homepage: Another way to contact us is via our homepage.

Please use the **contact form** at:
www.sepsis-hilfe.org/de



Contact persons for special topics

Do you have special questions? Members of our association with special knowledge on specific topics are available to answer your questions.

- For questions regarding **delirium** and intensive care diary, please contact **Mr. Nydahl**: intensivstation@sepsis-hilfe.org
- For questions regarding **neurocognitive impairments**, please contact **Mr. Köhler**: mitte@sepsis-hilfe.org
- For questions regarding **amputations** after sepsis, please contact **Mr. Trumann**: nord@sepsis-hilfe.org
- For questions regarding **severe disability and care law**, please contact **Mr. Leisgang**: unterstuetzung@sepsis-hilfe.org
- **If you have any further questions**, please do not hesitate to contact the office: info@sepsis-hilfe.org

Regional groups

In recent years, Deutsche Sepsis-Hilfe has continuously worked to expand its services regionally. Currently, there are contact persons in various regions of Germany and in some of them there are already active regional groups.

You are welcome to contact the person responsible for your area.

Our regional groups and your contact persons

Contact person for the North

Region: Arne Trumann

(Contact person for questions regarding amputations)

nord@sepsis-hilfe.org

Regional group - West:

Marc Dubreuil

west@sepsis-hilfe.org

Regional group - Franconia:

Bernhard Leisgang,

Stefan Müller

franken@sepsis-hilfe.org



Regional group - Berlin:

Petra W., Maria K.

berlin@sepsis-hilfe.org

Regional group - Mitte:

Frank Köhler

(Contact person for questions regarding cognitive impairments)

mitte@sepsis-hilfe.org

Contact person for the South

Region: Rita Wegmann

sued@sepsis-hilfe.org

Personal meetings

Self-help lives above all from personal conversations and getting to know each other. Exchange, training, support, help, common ground - these are central concepts in our modern self-help.

Get in touch with others - you are not alone!

Information about upcoming events can be obtained from the office or our homepage <https://sepsis-hilfe.org/de/>.

General meeting of members: Every year in spring, we hold our big association meeting to which all members are cordially invited. Even if you are not a member of our association, participation as a guest is possible by prior arrangement. Get to know us personally and benefit from the exchange with other affected people. We look forward to seeing you..

Regional group meetings: Not everyone can undertake long journeys after sepsis, even if they would like to. For this reason, we also try to offer regional meetings. You are also welcome to attend these meetings as a guest.

Nationwide events on the topic of self-help: Visit the Deutschen Sepsis-Hilfe booth at nationwide events on the topic of self-help.

Contact with other people affected

Would you like to get in touch with other people affected by sepsis? We will try to put you in touch with other people affected, if possible from your region. Please contact the office.

Information material

Would you like more information? We will be happy to send you our free information material. Please contact the office.



You can find a lot of information about sepsis and about our association on our homepage www.sepsis-hilfe.org
Our Facebook page www.facebook.com/deutsche.sepsishilfe offers you further contributions on the topic of sepsis.

Become a member of Deutsche Sepsis-Hilfe e.V.

For 30 euros (individual membership) or 40 euros (family membership) per year, you will find support in the association and access to all membership benefits. In addition to the offers outlined on the previous pages, membership includes:

- Receipt of the **biannual association newsletter**
- **Access to** internal member area of our website **containing information about events, dates, minutes, forum, etc.**
- Opportunity to **work and assist in individual regional groups**
- Possibility of **supporting our telephone service**

You can obtain the current membership application form from the office or on our homepage:

www.sepsis-hilfe.org

We would be pleased to welcome you as a new member of our association.

We need your support

Deutsche Sepsis-Hilfe e. V. is independent and only committed to its members.

We are financed exclusively by donations, membership fees and funding from health insurance companies. We refrain from funding by pharmaceutical companies or other institutions where this could cause a conflict of interest.

Please support us and donate to Deutsche Sepsis-Hilfe e. V.!

Your donation helps us to continue our charitable work and to continuously expand our assistance.

Donation account

Bank für Sozialwirtschaft Leipzig

IBAN: DE9886 0205 0000 0155 1501

BIC: BFSWDE33LPZ

You will get more information about donation options on our homepage: www.sepsis-hilfe.org



Sepsis patients and their families often experience an arduous journey back to life. We want to support them in this..

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With our more than 350 members, most of whom are affected persons, relatives or surviving dependants, we have a nationwide network that provides psychosocial support.

They have all been in similar situations, have sought and found a connection, and now regularly exchange information about problems and help.

Independence is important to us!

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