Supplementary Online Content 2

Schmidt K, Worrack S, Von Korff M, et al. Effect of a primary care management intervention on mental health–related quality of life among survivors of sepsis: a randomized clinical trial. JAMA. doi:10.1001/jama.2016.7207.

Sepsis Help Book
Sepsis Monitoring Checklist
Sepsis Case Manager Training Manual
Sepsis PCP Manual

Effect of a primary care management intervention on mental-health-related quality of life among survivors of sepsis: a randomized clinical trial

Sepsis Help Book

Sepsis survivors Monitoring and cOordination in OutpatienT Health care

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1 Introduction

This manual is specifically written to help you to recover from your severe illness. It is based on scientific knowledge and the long experience of physicians, specialists, and other patients who have overcome your illness.

1.1 What is this manual about?

First the manual describes symptoms and causes of sepsis so that you get a better understanding of what happened to you in the first place. The next part is about after-effects that may occur after a sepsis. Of course you won't have all these after-effects – simply skip those that don't apply to you and read only those that interest you. The sections highlighted in orange summarize the most important points. In addition, this manual offers a lot of information and assistance for treating and providing self-help for your sepsis consequences.
In the last part, you will find information on how to apply for social welfare benefits, like level of care, staying at a rehab center, or a degree of disability. Your family will find useful advice, too.
Of course this manual does not replace talking with your family doctor. Only your doctor knows you, your medical history, and your diseases and can assess your situation completely to give you the best advice.

1.2 What is this manual good for?

● It can answer some of your important questions.
● It can help you and your family better understand what happened to you over the last months.
● It offers simple exercises and practical advice for your recovery and return to a good everyday life.

What does this manual teach?

- We want you to get an overview of the symptoms and causes of sepsis so that you better understand your own symptoms and the treatments you went through.
- You'll learn different after-effects of sepsis, including symptoms and possible therapies
- You'll get some suggestions for coming to terms with your illness.
- We'll offer some practical advice on how to apply for social welfare benefits.

But the main objective of this manual is to show you how to help yourself. Together with your doctors and therapists, you can indeed do a lot for your health. Taking good care of yourself always promotes self-healing. For example preparing for visits to your doctor or keeping a small

diary of your good and bad experiences can help you and your doctor to discover together many ways to help improve your health and feel better.

After your difficult time in the hospital, we hope we can help you and your family to start a new chapter in life that is happy and full of confidence.

1.3 The SMOOTH study at a glance

SMOOTH is an acronym for “Sepsis Survivors Monitoring and Coordination in Outpatient health-care.” In German it’s “Strukturierte Langzeitbegleitung für Patienten nach Sepsis.” This study has introduced long-term care for patients after sepsis for the first time. Your family doctor is involved in this study and is the key contact person for your care.

At first, we help coordinate your discharge from the hospital. This means we talk to you and your family doctor to find out if you will need help in your everyday life and if something needs to be organized before your discharge from the hospital.

When you are discharged from hospital, you and your family doctor will get training on sepsis and its after-effects. For this training, we will meet you either at your family doctor’s practice or at your house. You will get tips for everyday life and advice on how to support your recovery. In addition, we will ask you about current problems so we can meet your individual needs during future telephone trainings. Your family doctor is the main person in charge of your treatment. Your doctor is the one who knows you and your medical history best and together you can make the decisions about your care that are best for you.

Another part of this study is what we call “case management.” This means that the Institute of General Practice continually supports you and your family doctor. This includes regular interviews about your needs and your well-being. For these interviews, we will contact you once a month by phone and ask you some “monitoring questions.” Your case manager, a trained study nurse who interviews you, will contact the study physician at our institute after each interview. This study physician is in close contact with your family doctor and they will work hand-in-hand. However, it’s your family doctor who is responsible for your therapy.

These monitoring interviews will take place over one year. In the first six months, your case manager will contact you once a month; in the second six months, once every three months.

Your participation in the SMOOTH study involves:

- A phone call at the rehab center for organizing your transfer into your family doctor’s care
- A one-hour training session after your discharge from hospital or from the rehab center
- First monthly and then quarterly phone calls to assess your current problems and provide brief refresher trainings in the first year after your discharge

- A longer at-home interview after six months
- And a further contact after one year and two years to ask you about your quality of life

This manual is part of the study and of your training program. It is yours to keep.

Best regards,

Your

Smooth study team

2 Sepsis

You have overcome a sepsis. Sepsis is a severe disease and its after-effects might still affect your well-being. This manual aims to help you to understand what a sepsis actually is and gives suggestions that can help you return to an active everyday life.

Anyone can get a sepsis. Hospitalized patients who are already severely ill are at a higher risk of getting a sepsis. This is because their bodies and immune systems are weakened and can no longer fight off the infection sufficiently. The same applies for elderly people and babies with their not-yet developed immune systems.

If you want to learn more about your individual medical history and how your sepsis started, please ask your family doctor.

2.1 What is blood poisoning (Sepsis)?

Sepsis is an inflammation of the whole body. Starting from a certain location, such as a urinary tract infection or any kind of wound, pathogens enter the bloodstream and infect one organ after another until the whole body is affected. In principle, any infection can cause a sepsis. That's why patients with wounds or artificial access points to their bodies, like vein cannulas, urinary catheters, or wound drainages, are at risk.

Sepsis, sometimes also called blood poisoning, should not be confused with the well-known red stripe that runs from a wound towards the heart. This stripe is rather a symptom of an infection of the lymphatic system which, of course, also needs treatment.

Sepsis affects the whole body. Severe sepsis can lead to collapse of all processes in the body and, in the worst cases, even result in death. Therefore it's not surprising that a severe sepsis must be treated in hospital with drastic medical measures.

Simple sepsis

A simple sepsis is often caused by an infection of the gastro-intestinal tract or by respiratory diseases. Pathogens are detected by a blood test. Treating normal sepsis requires antibiotics, but needs no intensive medical care.

Severe sepsis

A severe sepsis happens if, in addition to normal sepsis symptoms, at least one organ failure occurs (brain, lung, heart, kidney, liver, blood clotting, metabolism, etc.).

Severe sepsis needs immediate intensive care because it is life-threatening. In such cases, more and more organs will be affected by the infection and are in danger of collapsing. That's why swift action is key.

Septic shock

A septic shock is the worst degree of sepsis. Septic shock is a severe sepsis combined with extremely low blood pressure. Organs are no longer sufficiently supplied with oxygen. Patients in septic shock are extremely ill and often die in spite of maximal intensive care medicine efforts.

Source: ACCP/SCCM Consensus Conference Committee. Crit Care Med 1992; 20(6): 864-874

2.2 How dangerous is a sepsis?

In Germany, sepsis is the third most common cause of death after cardio-vascular diseases. Every day two people die of AIDS in Germany, but 162 people die of sepsis.

Source: Die Zeit; Trias; Kranke ohne Lobby; 1. Aufl. 2006;108 S., 30 Abb., kartoniert, ISBN-10: 3830433522; ISBN-13: 9783830433521

Source: Engel C, Brunkhorst FM et al, Intensive Care Med 2007;33:606-618

2.3 Which symptoms indicate a sepsis?

These are the symptoms your doctor watches out for:

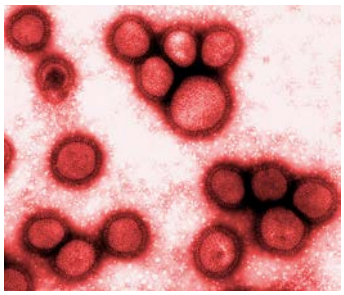
- At first, sepsis causes a fever of 38°C or more, but it can also involve lower than normal temperatures (less than 36°C), especially in old patients or children.
- The patient suffers from respiratory distress which causes breathlessness or hyperventilation (an increase in deep breathing)
- The heart rate is higher than normal (more than 90 beats per minute).
- The skin can be hot or a skin rash occurs.
- An obvious sign of sepsis is confusion or anxiety in a patient or a decline in consciousness.
- Falling blood pressure and reduced urinary excretion indicate an advanced sepsis with organ failure.

Source: (ACCP/SCCM Consensus Conference Committee. Crit Care Med 1992; 20(6): 864-874)

2.4 What does the physician do in case of a suspected sepsis?

Physical examination

If a physician suspects a sepsis because of the patient's clinical symptoms, blood samples can help clarify the diagnosis.



Laboratory findings

Sepsis patients show either an extreme increase or decrease of white blood cells. Other inflammatory markers are almost always increased as well. As this is also the case in other diseases, further examinations are necessary.

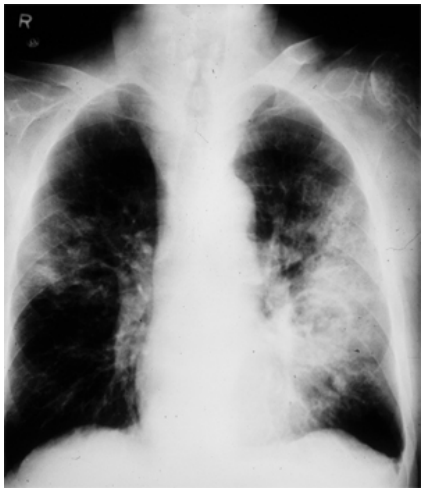
Source: rev. Guideline „Prävention, Diagnose. Therapie und Nachsorge der Sepsis", Deutsche Sepsis-Gesellschaft 2010

Identification of the pathogen

The blood test helps identify the pathogen that has caused the sepsis. Different antibiotics are tested on the artificially grown pathogen in order to find out which has the best therapeutic effect and to which antibiotics the pathogen is resistant.

Finding the source of infection

Knowing the source of infection is crucial for the right treatment. Therefore medical imaging can be necessary, such as an x-ray of the lung, computer tomography, or an ultrasound image. Examination of saliva, urine, or a wound smear can also help to discover the pathogen.



2.5 What exactly happens in your body?

Starting from the location of primary infection, the pathogen enters the bloodstream and spreads to the whole body. As a reaction to this, the immune system releases large quantities of white blood cells (leukocytes) to destroy the pathogen. Unfortunately, this affects the blood vessels, allowing fluid to escape from the bloodstream into tissues. As a result, water accumulates in the limbs causing so-called “edemas”.

The heart tries to compensate for the fluid loss in the blood vessels by beating faster, which lowers the blood pressure. As a consequence, the organs stop getting enough oxygen and are in danger of failing. Lungs, kidneys, liver, and heart can stop working and multi-organ failure (the collapse of several organs) is a consequence.

2.6 What happens during organ failure?

Lung: Lung failure involves severe respiratory distress with danger of suffocation. The patient needs medical ventilation with a tube. In case of long-term ventilation, this tube is inserted in the trachea via a small incision.

Kidney: Kidney failure begins with a drastic decrease in urine production. The kidneys fail to filter waste products from the blood properly. The patient gets a permanent catheter so that urine can be released and urine output can be controlled. In case of total kidney failure, blood purification (dialysis) is absolutely necessary. In which case, a machine (an “artificial kidney”) purifies the patient’s blood.

Perfusion and blood clotting: The coagulation system regulates the body’s fluids – keeping them neither too thick nor too thin. In sepsis patients, this coagulation system is often disturbed. Blood will clot or clump in the smallest blood vessels, blocking blood flow and preventing organs from getting a sufficient oxygen supply.

Central nervous system: The central nervous system is especially sensitive to low oxygen and other metabolic disorders. Sepsis patients often find their perception and consciousness affected by an impairment of the central nervous system. These patients become restless, confused, and sometimes become disoriented.

Liver: The liver is an important metabolic organ. Sepsis often impairs hepatic (liver) function. The liver can no longer filter waste products and skin can become yellowish (which is called “jaundice”).

Metabolism: Sepsis can affect the blood sugar making it either too high or too low. If the patient's sugar level is too low (hypoglycemia), it can cause confusion and disorientation. If the sugar level is too high (hyperglycemia), patients might need insulin – even if they are not diabetic. In addition, high blood sugar can damage nerve pathways. This is called neuropathy and often occurs in patients after sepsis.

2.7 The therapy at a glance

Patients suffering from severe sepsis or septic shock need intensive care treatment and antibiotics right away. The sooner treatment starts, the better the chance of recovery.

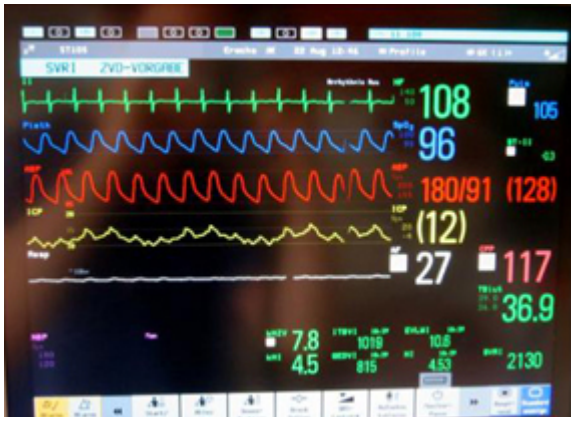
Source: Kumar A. et al. Crit Care Med 2006;34(6)1589-1596

In these cases, two steps are necessary:

1. Doctors must find the source of infection so that they can treat it.
2. And the patient needs liquids, given through a venous catheter.

These liquids contain:

- essential nurients if the patient can no longer eat
- drugs to control blood pressure
- pain or sedative drugs if necessary
- and, most important, antibiotics.



In addition, medical treatments, such as mechanical ventilation or blood purification, will support the work of damaged organs.

Source: Reinhart K, Brunkhorst FM: Prävention, Diagnose, Therapie und Nachsorge der Sepsis; Thieme Verlag; ISBN 978-3-13-137361-8

2.8 Summary - Sepsis

- Sepsis is an inflammation of the whole body; it can affect all organs.
- There are several risk factors for sepsis, however, in principle anybody can develop a sepsis.
- Sepsis is a common disease.
- Treatment of sepsis requires strong drugs and often mechanical ventilation. Usually patients are treated in the Intensive Care Unit.

Many people have suffered or died of sepsis because the disease was not detected and treated in time. Here are some prominent examples:

Source: Deutsche Sepsis Hilfe e.V. http://www.sepsis-hilfe.org (letzter Zugriff 28.02.2011)

But many others have survived a sepsis! For them, chances are good that they will soon regain control of their life!

3 What happens after a sepsis?

3.1 Recovery often takes a long time

In Germany, around 60,000 people survive a sepsis each year. However, recovery often takes a long time – up to a year or more. As a rule of thumb you can say: *One day in the ICU (intensive care unit) requires one week of recovery.* This shows the level of stress the body and mind experience in intensive care. So be patient!

Some patients suffer from secondary diseases or after-effects from the sepsis. How long these will last can vary widely. The following text tells about these secondary diseases:

3.2 Loss of weight and muscle atrophy

It is very important that patients pay attention to their weight and their diet after a sepsis. Sepsis causes considerable stress in the body and requires a lot of energy. Normal eating cannot supply this energy need. For this reason, the body has to use its own reserves, which leads to muscle atrophy (see below) and loss of weight. Reduced appetite can cause weight loss too.
Loss of weight can cause complications that impede the healing process. For your recovery it is important that you maintain your weight and avoid further weight loss. You need your muscles; you need your strength!

If your body is malnourished:

- you will be vulnerable to infections because your immune system is weak;
- you will feel tired and exhausted and your physical strength will be poor;
- you will suffer from bad wound healing and maybe even from bedsores because you don't have "padding;"
- and ongoing muscle atrophy can even cause organ/bone marrow failure.

Source: Intensive care recovery manual v3, Jones et al, 22/6/2009, St Helens and Knowsley Hospitals, NHS

Buy a bathroom scale if you don't have one. The "body mass index" (BMI) can show you if your weight is within a normal range. In your patient manual you will find a measurement disc to help you calculate your BMI.

If you suffer from lack of appetite, these tips might be useful:

- Have small but frequent meals.
- Have nourishing snacks and high-protein drinks at hand between meals.
- Eat your favorite dishes as often as possible.
- Avoid heavy and greasy dishes if they cause digestive problems.
- Take your time! Eat slowly and relax for a while after your meals.
- If you feel full early, avoid juices and broths during the meal. You should drink after you've finished your meal.
- High-protein drinks are a good additional source of energy between meals.

Source: Intensive care recovery manual v3, Jones et al, 22/6/2009, St Helens and Knowsley Hospitals, NHS

3.2.1 Summary nutrition

- High protein food is important for building muscles and helps improve wound healing. Particularly good choices are foods such as meat, fish, eggs, and dairy products.
- Discuss with your family doctor some nutrition objectives that are sensible and feasible (x kg in x weeks). It can make sense to keep a dietary record for some days.
- Nutrition counseling can help you plan a balanced diet.
- In case of significant weight loss, the so-called "astronaut's diet" can help. This is a high-caloric nutritional supplement, normally available in small bottles.

3.3 Effect on nerves and muscles

Polyneuropathy – a disease affecting the nerves

Unfortunately, damage to the nerve fibers is a common complication after diseases that required intensive care (like sepsis). This is called polyneuropathy. The inflammation affects nerve pathways in the body and damages them. Metabolic imbalances, like hyperglycemia, or drugs like cortisone can also cause polyneuropathy. After three days, 70% of all patients with septic shock show some form of damage to the nerve pathways.

Source: Tepper Neth J med 2000.

If nerves no longer work as they should, incorrect signals like numbness, pain, or tingling can reach the brain.

Myopathy – a muscle disease

If the nerves no longer move the muscles the muscles start declining, which causes muscle atrophy. Some patients suffer from temporary or permanent reductions in strength and mobility, affecting everyday activities and quality of life, as well as the time needed for recovery.

Neuropathic pain

In some patients, nerves damage shows up as pain. This pain differs from other sorts of pain because it often appears without any external stimulus. It can happen either in sudden attacks or persistently. In most cases, patients experience burning or pricking sensations (like needles). Tingling (like ants crawling) and itching can be symptoms of neuropathic pain as well. This pain can even be caused by light touching (such as from clothes) or by cold or heat.

Diagnosis

To detect polyneuropathy, the physician examines muscle power and reflexes as well as pain, temperature, and touch perception. In addition, a neurologist (a physician specialized in nerves) can measure nerve conduction velocity and muscle function.

Source: http://www.schmerzliga.de/dsl/hilfen_tipps/ihr_eigener_schmerzmanager.htm (last access: 28.02.2011)

Therapy

Physiotherapy/ ergotherapy

Physical activity is one of the best treatments for polyneuropathy. Physiotherapy and ergotherapy are excellent ways to re-establish agility and counteract muscle atrophy. Both methods aim at easing pain, at correcting poorly adjusted movement sequences, and maintaining functionality. Rehabilitation sports can also be helpful. Discuss which therapies are best for you with your family doctor.

Medicines

A variety of different medicines are available to treat neuropathic pain. Working together with you, your family doctor will figure out which drug is best for you. Most medicines need 2 – 4 weeks to take full effect, so even if your medicine doesn't work immediately, don't stop taking it. Different kinds of substance can help treat neuropathic pain. For this reason, your doctor might prescribe drugs that are normally used against epilepsy or depression.

Non-medical treatments

There are many other therapies than just drugs. Application of a TENS-device is one example. This portable device stimulates the nerves for therapeutic purposes using electric pulses. The physician shows the patient how to connect the electrodes to the skin. These light electrical impulses produced by alternating current aim at reducing pain by producing a light tingling.

If you suffer from neuropathic pain, it might be worth trying alternative methods like Qi-Gong, Tai-Chi, Yoga or acupressure/acupuncture. However, although these methods might be helpful, they should only complement a basic therapy with drugs or physiotherapy. Please discuss with your physician which therapies are best for you.

Psychotherapy

Pain perception takes place in the brain and not in the hand or the foot. That's why two different people experience the same pain trigger completely differently. The individual attitude to life, as well as social activities and relationships, can influence pain perception significantly. For this reason, pain often gets worse if patients stay at home all the time and shut themselves away. Talking to your family doctor or to a psychologist can help you to detect pain intensifying behavior, reduce avoidance behavior and anxiety, and learn pain coping strategies.

It might be beneficial to use relaxation techniques such as autogenic training, progressive muscle relaxation like Jacobson's techniques, or yoga in addition to the basic therapy.

3.3.1 Summary: Nerve damage

- Because of the inflammation, a sepsis can lead to damage of the nerves and muscles.
- Symptoms of this so-called "neuropathy" can be pain, muscle weakness, or unpleasant sensations like tingling.
- Physical therapy is important for maintaining and improving mobility and functionality.
- Pain and impairment of mobility always also impact the mind and social relationships. Psychological therapy can help you get back to feeling better.
- TENS-devices and alternative methods can helpfully complement basic therapy.
- Don't be afraid to request help with your everyday life!

3.4 Pain

Pain has many different faces, but one aspect is common: Pain is always a burden and worsens quality of life. However, acute pain is quite useful because it shows us acute damage to the body. Acute pain is a wake-up call, mostly limited to the part of the body that is affected by a trauma or disease. This kind of pain disappears when its cause is treated successfully.

But what if the pain persists?

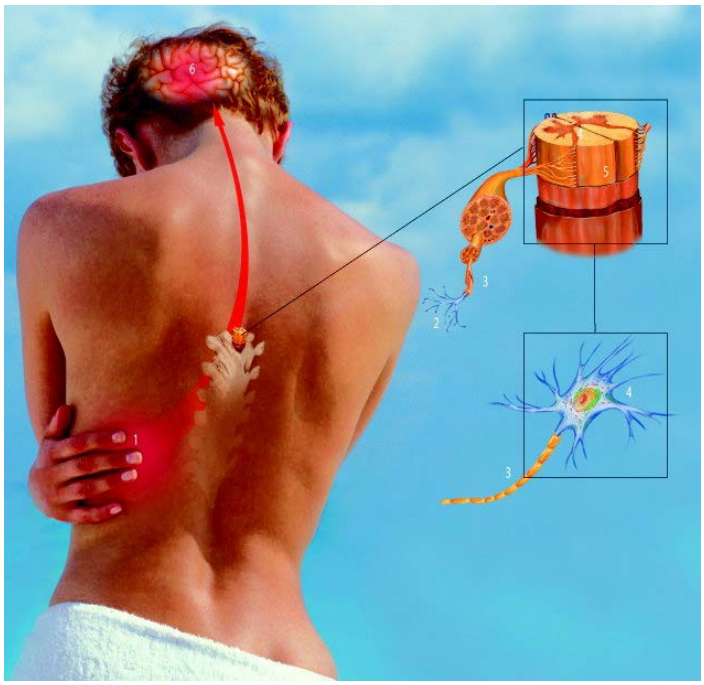
Chronic pain is pain that persists for 3 – 6 months or longer. This kind of pain no longer has an alert function and makes patients suffer permanently; in some cases the cause is even unknown. Chronic pain can be seen as an independent disease that impairs the patient's life considerably. On the one hand, this pain can physically affect a patient by loss of mobility and functional impairment. Psychologically, it can affect mood and thoughts. Pain has also a negative social impact as patients often withdraw and stop taking active part in life. After a sepsis, many patients suffer from chronic pain caused by damaged nerve pathways. (See above)

Chronic pain may have a lot of negative impacts but modern pain therapy provides a large variety of treatment options:

Source: http://www.schmerzliga.de/dsl/hilfen_tipps/ihr_eigener_schmerzmanager.htm (last access 28.02.2011)

Medical treatment

In most cases, treatment with drugs is necessary to make other therapies like physiotherapy or therapeutic exercise possible in the first place. Depending on the type of pain, different drugs can be used. Pain therapy – even for little pain – can reduce symptoms in the long run because it prevents an early "recording" of pain in the pain memory that can increase perception of pain in the future.



The next section is about different classes of drugs. Please discuss with your family doctor which are suitable for you. Your family doctor knows you and your medical history, knows all the drugs you take, and can recommend the best drug for you. Your family doctor will also inform you about side effects and limitations of use.

Nonsteroidal anti-inflammatory drugs or NSAID

”Nonsteroidal anti-inflammatory drugs” or “NSAIDs“ like Diclofenac, Ibuprofen, Naproxen, or Aspirin provide not only analgesic (pain killing) but also anti-inflammatory effects. As this class of drugs can affect the stomach mucosa, patients should combine these with drugs to protect the stomach in case of long-term use.

Opioids

Opioids like Tramadol or morphine work directly in the brain, i.e. at the place that perceives pain. These drugs are very potent, but don’t work for all patients or all types of pain. The extended-release form of Tramadol provides around-the-clock treatment of pain – avoiding the feared feeling of addiction. Pain patches have the same effect. As these substances often lead to constipation, patients should also take a laxative in case of long-term use. You shouldn’t drive a vehicle after taking opioids.

Antidepressants

Sometimes drugs that are normally prescribed for treating depression are used in pain therapy too. In low doses, they influence pain processing and pain transmission in the body.

Anticonvulsives

Drugs that were initially developed for treating epilepsy can help treat pain, especially neuropathic pain.

Physical therapy

In the past, it was commonly thought that people suffering from pain should rest a lot. Today we know that moderate exercise is one of the best therapies! Physical activity releases endogenous substances that reduce pain (endorphins).

Under the guidance of a physiotherapist, physiotherapy supports muscle building and prevents incorrect postures that might increase pain. Due to the physical activity, tendons and joints regain functionality. Manual therapy uses the same approach: massages can help loosen tension and improve circulation.
Provided that there is no pressure to perform well, many other types of sport can help too.

Cold and heat therapies (such as ice or fango packs) can ease pain as well. They reduce inflammation processes and. stimulate circulation. Moreover, electro- or ultrasound treatment can also help treat pain.

Psychological therapy

Chronic pain always impacts the mind as well as the body. This impairment can intensify pain and make it last even longer.
Pain perception takes place in the brain, not in the hand or the foot for example. That's why two different people experience the same pain trigger completely differently! The individual's attitude to life, as well as social activities and relationships, can influence pain perception significantly. For this reason, pain often gets worse if patients stay home all the time, shutting themselves away.

Psychological pain therapy is at least as multi-faceted as medical therapy. One approach is cognitive-behavioral therapy. This method aims to provide a better understanding of one's own pain perception which can reduce fears and anxieties. This method starts by addressing the patient's behavior. It tries to to detect pain intensifying behavior, to reduce relieving postures and avoidance strategies, and to learn pain coping strategies. In addition, relaxation methods can support stress management and ease muscle tension which often increases pain.
Possible methods are progressive muscle relaxation using Jacobson's techniques, autogenic training, as well as hypnotherapy and a variety of imagination, breathing, and meditation techniques.

Acupuncture

Acupuncture has become more and more important in pain therapy. In certain cases it is covered by medical insurance. Specially trained physicians can provide acupuncture successfully.

Complementary approaches

Examples of approaches that can help many patients include Far Eastern techniques like Tai-Chi, Qi-Gong, or yoga. Most of the time, patients try these therapies in parallel with medical and physical therapy.

However, no therapy works if the patient does not join in! The following recommendations can help you to treat your pain yourself.

Become your own pain manager!

- **Take over responsibility:** Trusting physicians and therapists is a good thing. But you can contribute a lot to your own pain management if you take an active part in your recovery and become your own pain manager.
- **Formulate objectives:** Bring your worries and problems to your mind and formulate objectives in order to overcome these problems one by one.
- **Monitor your progress:** Write down what eases your pain. By doing so, you can assess what works for you.
- **Get physically active:** This is not about top performance, but about regularity. Your body and also your soul benefit from any kind of physical activity. Activity helps control pain!
- **Look for stimulation:** Just as the body needs activity for staying fit, your mind needs training too. New activities and inspirations divert your attention from pain.
- **Find your own balance:** A healthy balance of activity, hobby, family life, recreation, and peace is very important. If you are stressed or bored, pain can get the better of you.
- **Seek and accept support:** Friends and family can encourage you to pursue your objectives. They can give you support if things are going badly for you.
- **Do what you enjoy doing:** If you see that you enjoy a certain activity (and this activity is good for you), do it more often.
- **Invest in personal relationships:** Don’t shut yourself off. Contacting other people is at least as important as a healthy diet and physical activity. Joining a self-help group can help to break isolation.
- **Brace yourself for setbacks:** Setbacks can occur frequently. You should consider on good days how to deal with bad days
- **Treat yourself:** Each time you move a step closer to your objectives or you have

successfully applied a certain strategy you should allow yourself a little reward. This boosts your positive development.

Source: http://www.schmerzliga.de/dsl/hilfen_tipps/ihr_eigener_schmerzmanager.htm (last access 28.02.2011)

3.4.1 Summary pain

- Chronic pain can have many causes. It is defined as pain that goes on for more than 3 – 6 months.
- Pain can be treated with drugs. Don't be afraid of asking your physician. Pain is recorded in the pain memory and intensifies pain perception. For this reason, an early and effective pain treatment is very important.
- Physical therapy and additional therapies (heat, cold, etc.) can help reduce pain promoting movement patterns.
- Pain always carries emotional burdens and affects social relationships. Pain perception and processing is very different between individuals. Talking and trainings can help to reduce pain promoting behavior and thought patterns.
- If it helps, give alternative methods like Tai-Chi, Qi-Gong, acupuncture, or relaxation techniques a try.

3.5 Deep sadness (Depression)

Many patients who have suffered from a severe illness experience a general feeling of sadness. This gloomy mood often gets better as time passes. Few patients suffer from it permanently. We talk about a depression if the patient suffers from an ongoing feeling of sadness. Further symptoms are loss of interest or less interest in activities or things the patient liked before falling ill. Some patients also report lack of energy or power, waking early in the morning or sleeplessness, as well as unusually reduced or increased appetite.

- A depressive mood is common after severe illnesses. One in five people suffer from long-lasting depression at least once in life.
- Sadness, lack of motivation or sleeplessness can be symptoms of depression.
- Moderate depression often disappears spontaneously. You should talk with your family doctor about it.

Depression is not destiny! It is easy to treat nowadays. Therapy to treat depression has several parts:

Psychotherapy

Psychotherapy helps to reduce negative thought patterns (thought loops).

There are different approaches, including “analytic therapy,” “talk therapy” and “cognitive behavioral therapy” to name but a few. For treating depression, cognitive behavioral therapy especially has proven very effective. It concentrates on the patient’s current situation by addressing and weakening concerns that are a burden. To that end, this therapy first looks for depression-promoting behaviors and warnings. After that, the patient and therapist together develop strategies for dealing with them. Patients learn how to stop the constantly recurring negative thought loops (brooding) and to try new ways of thinking.

Pharmaceutical therapy

Drugs help. They help you to get off the ground again. These drugs are not addictive. If you are patient, they are effective in most cases. Afterwards, you should discuss with your physician

how to proceed.
In more than half of patients, treatment with drugs is successful after no more than 12 weeks. However, it is not always clear if this success is only due to the drug. In the end, the effect has to be tested again in each case. Patients should take the drug for at least 6 months so that the body has enough time to adapt to it.
Different active ingredients are available. Please discuss with your physician which one is the best for you. Knowing your medical history and all other drugs you take, your physician can decide which drug is best for you. So-called selective serotonin re-uptake inhibitors, for example, treat a lack of the messenger substance serotonin in the brain which often exists in depression.

In treating mild depression, St. John's wort may be helpful. It is important that you tell your doctor if you use it, because it might be poisonous if mixed with other drugs. Check if St. John's wort really helps you; if not, you should stop taking it.
Please inform your family doctor whenever you buy drugs for yourself without a prescription. Many patients take "over the counter drugs" – which is okay. However, your family doctor needs to know to be able to adjust your other medication.

Every drug has side-effects. This is also true for anti-depressants. Often side-effects can occur even before the desired effect takes place. Please be patient and inform your family doctor about anything you consider unusual.

Additional supporting activities
Establish fixed plans and regular activities for each day and week. Have meals regularly, go shopping at regular intervals, etc. Schedule small "enjoyment objectives" to help you remember to have fun. It is a proven fact that they speed up your recovery. You are the person who knows best what is good for you.
Physical activity, ergotherapy, and sociotherapy support treatment of depression.

- Moderate physical activity (walking, cycling, swimming, etc.) alone is not sufficient to treat depression, but it boosts other treatments and improves your general well-being.
- Ergotherapy (occupational therapy) helps you to cope with everyday life. If needed, you can learn about topics like self-management, housekeeping, financial planning, and occupations. You can receive ergotherapy within the framework of in-patient psychotherapy, or in ambulatory therapy, and it is covered by medical insurance.
- Sociotherapy helps you in dealing with other people or groups. After a severe disease, many people have difficulty getting in contact with other people or administrative bodies. Sociotherapy supports you in re-gaining your independence.

Things you can do to help yourself

In this section you will find tried and tested advice from patients who have overcome a depression (members of self-help groups):

- A visit to your physician or your psychotherapist is the first step. It is helpful if a relative or a friend you trust comes with you. Your friend will support you and can describe changes in your mood or your condition "from an external point of view."
- Expect that your treatment will take some time. Your troubles will not disappear after the first tablet or the first therapy session. Sometimes it takes 4 weeks before you can see the effect of a drug. It may take up to half a year until your depression is over. It is likely that you'll experience depressive episodes during your therapy. But your condition will improve bit-by-bit over time.
- You can support your own treatment. We already mentioned the importance of physical activity. This should, of course, be at a level at which you are comfortable. No top performances are needed. Try to set up small, easy to reach goals: an outdoor walk, a short bike ride. Find out what you like doing. If you have difficulty doing it alone, ask someone for help. Motivation is much easier when you are not alone.
- Enjoyable little everyday activities, "enjoyment objectives," alone or together with others can help. Often friends are much more reliable than you would expect. Calling a friend, meeting someone, going to the hairdresser's, or cooking a nice meal has beneficial effects. At the moment, it might be difficult to motivate yourself. But making a weekly schedule listing possible activities – not as an obligation, but as a reminder and encouragement– is useful. Overcoming crises is easier if someone supports you. Accept offers from your partner, your family, or friends for talks or support. Sometimes a professional therapist is helpful too.
- Examples of "enjoyment objectives" are: walking, going shopping, reading the paper, cooking (for yourself and also for others), helping children do their homework, taking care of a dog, etc. Use your imagination and figure out what is best for you.
- It is also helpful to talk to other people who have or have had the same problem. They have had similar experiences and understand how you feel now. Approach a self-help group. You will find a ready welcome at these groups. People share experiences, encourage one another, and give concrete advice and information. Talking helps!

Source (last access 28.2.2011):

http://www.versorgungsleitlinien.de/patienten/pdf/NVL-Depression-Patienten-Konsultation-1.0.pdf

http://www.degam.de/leitlinien/pat_info_muede.pdf

3.5.1 Summary sadness (depression)

- A depressive mood is common after severe illnesses. You are not alone! One in five people suffers from long-lasting depression at least once in life.
- Sadness, lack of motivation, or sleeplessness can be symptoms of depression.
- Get active! By asking for help you have already taken the first step to face your disease. Do sports, cultivate contacts, ask family and friends for support, do whatever is good for you.
- Psycho-therapy can help break up old thought patterns and develop helpful techniques. Medicines provide support too. They can help you to get going.
- Depression is easy to treat. It's not destiny. Play your part in fighting it!

3.6 Forgetfulness and confusion (memory and concentration)

After a sepsis, sometimes you can feel uncertain about your own memory and ability to concentrate. Forgetting a phone number occasionally is no cause for alarm. However, it is possible that your cognitive performance may indeed have deteriorated compared to its level before the sepsis. You might have difficulty finding things, or abstract thinking may suddenly be a problem. Many patients report difficulties in doing activities they are used to, such as washing or cooking.

These symptoms often show up, particularly if patients are elderly or have a medical history of stroke or alcoholism.

There are several possible causes:

- Heavily fluctuating blood sugar levels during intensive care treatment can affect brain capacity.
- Low blood pressure associated with a possible undersupply of oxygen to the brain can cause cognitive issues.
-Often brain perfusion (the flow of blood to the brain) is already affected due to pre-existing diseases and is worsened by the sepsis.
- Genetic factors are also a possibility.

Exercises to boost attention and concentration can help you regain your cognitive abilities. This "brain jogging" can improve your memory performance. There are many valuable books and courses available on this topic. Explore this literature yourself and ask your general physician about it. Avoid everything that disturbs your concentration – like bad lighting and noise. Physical activity is very helpful! Go for a walk. Do exercises. In many cases, ergotherapy and physiotherapy can help you train for everyday activities.

It is important that you structure your life. Introduce regularity by always doing certain activities at the same time and on the same days (such as phoning a friend each Wednesday afternoon at 3 p.m.) Put everyday objects (like keys) always in the same place. Check more than once if you switched off the stove. Include your family and friends and don't be afraid of accepting help.

Don't isolate yourself. Try to take an active part in life. Look for activities within your family or do some volunteer work. You could dance, paint, walk – whatever you like! But don't ask too much of yourself. Do only things you feel able to do – otherwise you might get frustrated.

sources: (last access 28.Feb 2011) - Hopkins et al Crit Care Med; in press)

- http://www.versorgungsleitlinien.de/patienten/demenzinfo - http://leitlinien.degam.de/uploads/media/Patinfo_Demenz_002.pdf

3.6.1 Summary: Forgetfulness and confusion

- Reduced memory and concentration can appear after a sepsis.
- Memory training can improve attention, concentration and memory.
- Create memory aids in your daily routine.
- Choose only doable tasks and don't demand too much of yourself.
- Structure your days. Fixed rules and activities at certain days or times can help.
- A stable and caring environment is most important. Include your family and ask your friends for support.

3.7 Coping with bad memories, fright and fears (posttraumatic stress disorder)

Trauma is a physical or mental injury that causes helplessness, fright, and extreme fear, sometimes even mortal fear. This bad experience, like a situation where your life or someone else's was in danger, can shake to the core your faith in life, in yourself, or in other people. For many patients, being treated on ICU is just such a traumatic experience and is coupled with fear of dying; even more so because your relatives' fears and the doctors' concerns about your critical condition intensified the feelings.

It is possible that you are still haunted by memories of this time – memories of mechanical ventilation and suction of mucous from your lung, the noise level on ICU, and the beeping of monitors that displayed your heartbeat. For some people, these experiences are a horror scenario, a traumatic experience.
Each person has different strategies to come to terms with these experiences. The following section describes some of them.

Emotional distress (Acute stress disorder)

One reaction to this situation of emotional distress is insecurity in dealing with the experience. Patients who are weakened because of a severe illness, for example, are especially vulnerable to emotional distress. All people need their own time and pace to come to terms with their experiences. Reliable and confiding relationships with relatives, friends, and also the family doctor help a lot. But there are also patients who prefer to cope with their experiences alone. In most cases, these troubles fade after some weeks.

Adaptive disorder

An adaptive disorder develops more slowly, normally within one month after the traumatic experience took place. Feelings like sadness, anxiety, nightmares, and recurring memories last much longer than in acute stress disorders. Troubles can persist for weeks, if not months before they disappear gradually. Again, stable relationships with a partner, relatives, or friends are extremely helpful.

Posttraumatic stress disorder

If the symptoms mentioned above persist 6 months or longer, we call it posttraumatic stress disorder. The patient cannot get rid of the experience; the fear and anxiety is ever-present. Typical symptoms of a posttraumatic stress disorder are:

- Repeated affective memories of the experience (”flashbacks“ or ”intrusions“) or dreams (often nightmares) even in daytime. In German this is called “recurrent recollection.“ It can manifest in feelings and inner images, but also in physical reactions (such as pain or numbness).
- Memory gaps can occur, too. Often they are caused by the mechanical ventilation and the drugs given on ICU. In this case, coming to terms with the experience is even more difficult and the patient might fear that the traumatic experience is not over yet.
- Other symptoms include sleep disorders, jumpiness, increased irritability, or concentration disorders. Some patients experience a so-called “inner indifference.“ They no longer sense themselves and their feelings, and feel numb.

Symptoms of a posttraumatic stress disorder can show up immediately after the traumatic experience or they can be delayed. For example, the generation of wartime children managed alright for many years, and only in old age did many of them suffer from haunting memories and depressive feelings.

Treatment

First of all, close relatives or friends can help you by unobtrusive offers to talk. Their readiness to

listen can help you remove barriers to your recovery. But be careful! Don't let them push you if you are uncomfortable. We all need our own time. Some patients don't want to deal directly with the experience, others benefit from talking a lot about it. Both approaches are ok. Only you know how you want to live with the memories. You know best which approach suits you.

It is important that you talk about these troubles with your physician. If you don't, your treatment may address your physical symptoms only. You could say something like:

"Doctor _____, I also have some other troubles that are not directly related to my body but to my memories."

Then your physician will work to figure out what might help you best. Treatment with drugs may be a possibility. Another option might be professional psychotherapy. Ask your general physician about your time on ICU. As you will probably not remember many details, an objective explanation from an external perspective can help you to assess your experiences.
The aim of all efforts to come to terms with traumatic experiences is to integrate them into your life and to accept them as a part of yourself. We have all had many happy experiences, but we have to include the bad ones as well. They are also part of our life and determine who we are.
A psychotherapist can support you in this and can give you a lot of information about this disorder and concrete advice how to deal with it. Continuous psychotherapeutic care provides reliable support in critical situations. Please talk to your physician if you want to meet a psychotherapist.

Source: http://www.awmf.org/uploads/tx_szleitlinien/051-010p_S3_Posttraumatische_Belastungsstoerung_Patientenversion.pdf (last access 28.2.2011)

3.7.1 Summary: Memories and posttraumatic stress disorder

- Being treated on ICU can create unpleasant memories and feelings like fear of dying, frights, and helplessness.
- Insist on your individual way of coping with your experiences. Some people want to block out memories, others want to think about everything. Whatever option you choose, it is important that you stay in real life, and live in the here and now. Remember that you are no longer in danger.
- Look for activities that have a soothing effect and do you good – depending on what is the most appropriate approach for you.
- If sleep disorders and fears get too bad, psychotherapy might help you to come to terms with your experiences.
- In individual cases, drugs can help ease your troubles.

3.8 Impairment of swallowing, tasting, hearing, or smelling

Some patients suffer from hearing impairment after a sepsis. Some antibiotics affect the inner ear (ototoxicity), causing hearing loss.

Impairment of tasting and smelling can occur after sepsis too. The delicate taste buds and olfactory nerves are very sensitive to extraneous influences. Some patients report a metallic taste in the mouth and food can taste saltier or sweeter than usual. Long-term mechanical ventilation with a plastic tube in the throat can lead to permanent swallowing impairment. We still need more research to find the exact causes of all these impairments.

3.8.1 Smelling and tasting

This chapter will show you how to deal with smelling and tasting disorders. This difficulty is sometimes very burdensome because dysfunctional smelling or tasting is very annoying. The following tips have proven helpful to other patients:

- Cook meals you enjoyed before the sepsis.
- Take your time and enjoy your meals in a pleasant atmosphere.
- “You eat with your eyes first“ – prepare your meals in a ‘mouth-watering‘ way to stimulate your remaining senses.
- Cooking for others or eating together with others contributes to a successful meal.
- If you still have memories of smells and flavors. Maybe you can recall these memories while you are eating and enjoy them.

Impairment of smelling and tasting reduces appetite. But you need substantial food for your recovery. So eat even if you think the meal is flavorless! You need the energy for your recovery.

Talk to your family and – if possible – to other people who have the same troubles. You should also inform your physician about your impairment and about possible feelings and concerns caused by your smelling and tasting dysfunctions.

Pay special attention to what you eat and avoid bad food. Your impaired smelling and tasting might not warn you when you are at risk of eating rotten food.

Here is some practical advice:

Nutrition:

a. Food storage

- Store food in a cool and dry place.
- Note the purchase date on the package.
- Label plain packages.
- Store food and drink separately from toxic substances.

b. Food use

- Check purchase and expiry date before consumption.
- Check if the product looks “somehow strange.”
- In case of doubt, throw the food away before it can harm you.

c. Preparation

- Spice your food according to the recipe and by using scales.
- Try to rely on your sense of touch for checking temperature or consistency of food.
- Try to stimulate what is left of your capacity to taste sweet, sour, or salty food.
- It may be possible to cure tasting dysfunction for a short time by use of an anesthetic spray.
- Avoid spices that can cause unpleasant bad smells.
- Don’t leave the stove when you are cooking. You might burn your food.

d. Hygiene

- Perform personal hygiene and clothes changing according to a schedule.
- Ask your partner for help in choosing cosmetics or perfumes.
- Decide on the amount of cosmetics and perfume together with your partner.

Our sense of smell can protect us against dangers, in case of a fire or gas leak, for example. If your sense of smell is impaired, it is even more important to activate the other senses.

At home

- Be careful with open fire (candles, gas, heating).
- Label inflammable and toxic substances clearly; don’t pour them in other bottles, and remember to store them separately from food.
- Install smoke detectors in your house.

Profession and hobby

- If you need your sense of smell or taste for your job, avoid situations that might jeopardize yourself or others.
- Wear a respirator mask if necessary.
- Use smoke detectors.
- "Borrow" your friends' or colleagues' noses by asking them for help.

Compiled by Prof. Dr. med. Hilmar Gudziol, Universitäts-HNO Klinik Jena

3.8.2 Hearing

Some of the drugs you got on ICU, such as antibiotics or diuretics, might have affected your inner ear. This can cause inner ear hearing loss. Your family doctor will debrief you in detail, give you more information, and examine your ears to exclude possible other causes. After that, an ENT-physician can examine your hearing loss with special hearing tests.

3.8.3 Impaired ability to swallow (dysphagy)

Swallowing is vital. If we couldn't swallow, we would probably die of thirst or starve. Losing this important function not only majorly affects the patient's quality of life, but can also be dangerous.

For a start, difficulty swallowing can lead to malnutrition because it impairs eating and drinking. Because, after sepsis, patients are often in jeopardy from having lost weight on ICU already, this is particularly important.

Food or liquids can also accidentally get into the airways by "wrong swallowing" (the medical term for this is "aspiration"). This can lead to pneumonia.

In addition, impaired ability to swallow can isolate patients socially because it often causes unpleasant noises.

The following symptoms are possible:

- Feeling a lump in the throat, or pressure behind the breast bone or in the upper abdomen after swallowing (the "globus sensation")
- Gulping while swallowing
- Coughing during meals
- Disgorging undigested food
- Loss of weight

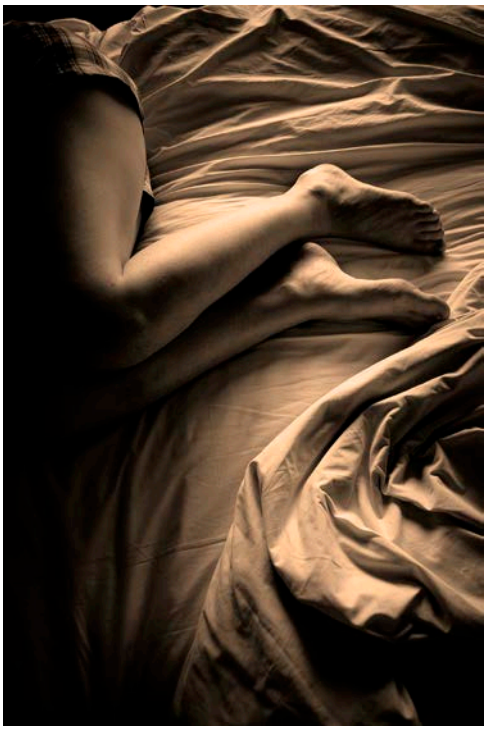
Therapy

It is important that you discuss your troubles with your family doctor who will recommend further tests, such as endoscopic examination of the esophagus or a video recording of swallowing using a contrast agent. Depending on the result of these examinations, an operation might be useful in some cases. If direct treatment of the cause is not possible, you can start logopedic training to

improve your swallowing.

The solution may be much easier. Start experimenting with your food temperature and consistency. It is possible that mashing up your food or thickening liquids may help ease difficulty swallowing.

3.9 Sleep disorders



After a sepsis, many patients complain about sleep disorders. This is often caused either by depression or a posttraumatic stress disorder, or merely by the disturbance to the circadian rhythm on ICU. In general we speak about a sleep disorder if a patient has difficulty in falling asleep or sleeping all through the night at least 3 times a week over a period of one month or longer. There are a variety of potential causes and degrees of severity. You should always discuss these issues with your family doctor.

There is some general advice on sleep hygiene you should bear in mind and stick to:

- Go to bed at the same time each day and get up on time in the morning if possible. Don't change this rhythm on weekends or vacations. Celebrate a "going-to-bed-ritual" with encouragements such as relaxing music or soothing scents (lavender, …)
- Stick to your individual time for sleep and don't stay in bed when you are awake. If you sleep too long, your sleep gets superficial. You should avoid sleeping in the daytime.
- Your bedroom should be as comfortable and cozy as possible, without anything that reminds you of your job or emotional distress. You should not work, watch TV, or eat in bed. Otherwise your body forgets that your bed should be linked with sleep. Make sure your mattress fits your body.
- Avoid activities that cause inner unrest or anger in the evening. Working; watching exciting movies; or having intensive discussions, such as about problems with your partner; until shortly before you go to bed leads to inner tension that impedes falling asleep. Don't eat late at night and especially avoid heavy or spicy food.
- Nocturnal thinking and musing that keep us awake is often extremely burdensome. Our "inner clock" makes us slide into an energy slump combined with emotional instability. For this reason, bedtime is not the moment for solving problems. Try to call pleasant memories to your mind.

- If you lie in bed sleeplessly, get up and do something (like cleaning up or reading). Small snacks or drinking something might be useful too. Do not go back to bed until you are tired.

Relaxation techniques or keeping a sleep record can also help. Due to their dependence potential, drugs should be taken only for a short time, and only after consulting with your family doctor.

Source: http://arbeitsblaetter.stangl-taller.at/SCHLAF/Schlaf-Stoerung.shtml

4 Coping with the disease

Coping with a severe disease is very individual. Personal history and experiences play a major role in how we cope with a crisis. There is no universally valid method, and a variety of possible strategies can help you accept your disease. Coping with a disease is a prolonged process. It doesn't happen in a consistent manner, but with permanent ups and downs that bring advances and setbacks.

Social support is an important factor; it can influence your recovery crucially. Therefore, if you feel like it, talk to friends and relatives about your concerns and emotions.
It might happen that you have strong feelings that result in mood swings. It can often be a relief to know that these feelings are absolutely normal, appropriate, and allowable while you are trying to cope with a disease.
Thoughts about your disease should not govern your life. Distraction can be very helpful too. You shouldn't brood about your troubles or worry about your health all day. You should do whatever you see fit and what does you good instead!

These strategies might be helpful:

- Concentrate on yourself and keep your mind on your own needs.
- Take yourself and your needs seriously.
- Try to find out what kind of support you need and accept help!
- Accept your feelings – even if they are strong. They will pass by!
- Try to find out what is important in your life and what resources you have available.

Source: www.krebsinformationsdienst.de (letzter Zugriff 28.02.2011)

4.1 Support for relatives

Unexpected severe disease also affects the partner, relatives, and friends of the patient. Quite often they need help in coping with this crisis. Frequently, they experience feelings like helplessness, fear, anger about what happened to their loved one, or even guilt.

Often relatives feel overwhelmed by these feelings and don't know how to cope with them. They don't want to stress the patient; they feel overwhelmed and are afraid of saying something wrong. They want to help, but sometimes have to realize that the patient doesn't want their help and needs time and space to come to terms with the disease. Maybe the patient needs another type of help than relatives and friends would choose for themselves.

There is no universally valid approach to healing. Once again you have to keep in mind that coping with a disease is very individual. In the end, you have to find your own way. However, there are some strategies that might make it easier.

Source: www.Krebsinformationsdienst.de

- Have the courage to show your sympathy. Offer affection. Don't withdraw for fear that you might do something wrong.
- Assure the patient that he or she is still an important member of your family or your circle of friends. Don't exclude the patient from your thoughts or decisions because you don't want to create a burden. Keep the patient involved, as usual.
- Respect and maintain the patient's autonomy as far as possible. Don`t be overprotective and don't take responsibility for tasks that the patient can manage. Don't decide anything over the patient's head

Often relatives think that they are all alone with their feelings. The focus of attention is the patient's treatment, recovery, and well-being. But this crisis situation impacts relatives too. A change of domestic roles may be necessary. Tasks the patient was responsible for before the disease may need to be managed by the relative now. If the patient had a job, the financial situation can change quickly. Future plans might get mixed up. The partner's expectations may have to be put aside.

Relatives play a major role in the patient's recovery. They can be very supportive. But they can only help the patient if they take care of themselves, observe their own limits, and pace themselves:

- Take care of yourself. Don't fall into the self-sacrifice trap. Take your own needs seriously.
- Set up times for "recharging your batteries."
- Accept help. Look for support to ease your burden.
- Accepting the patient's autonomy protects you from overload.

5 Practical advice

5.1 Applying for social security benefits

5.1.1 Disabled person's pass (degree of disability)

A recognized degree of disability (German: "anerkannter Grad der Behinderung" (GdB)) together with a disabled person's pass qualifies you for many benefits. The degree of disability is graded in percentage, in intervals of 10% - from 20% to 100%. The calculation does not add up the degree of disability for several individual diseases but assesses diseases in their entirety. So if Disease A would lead to a degree of disability of 30% and Disease B of 50%, this will not result in a degree of disability of 80%, but only perhaps 60%. It is important to know that any disability of 50% or higher is considered a severe disability.

In this case, you can apply for a disabled person's pass at your responsible local administration or at the "Versorgungsamt" (maintenance council). Your local administration decides your eligibility on the basis of the medical findings of your family doctor, specialists, or hospitals. For this reason, you should include all medical documentation in your application. The letter of recognition states your degree of disability and also serves as proof of certain medical conditions that qualify for claiming compensation.

Source: http://www.familienratgeber.de/schwerbehinderung/grad_der_behinderung.php

Contact details for your "Versorgungsämter" can be found at your local administration or here:
http://www.versorgungsaemter.de

This website also provides downloads of forms for first applicants or amendments according to severe disability law.

5.1.2 Pension

Application

According to the Pension Insurance, reduced earning capacity is present if performance capability is reduced for medical reasons.

In this case, there is a distinction between partly reduced earning capacity and completely reduced earning capacity. Pensions because of reduced earning capacity are granted on application (§ 99 SGB VI).

The application has to be submitted to the Pension Insurance agency in charge (§ 16 SGB I), but other funding agencies, municipalities and official representatives of the Federal Republic of Germany abroad also accept applications. The start of the pension depends on the date of the application.

5.1.3 Level of care

http://www.pflegestufe.info/stichworte/antrag.html

Application to the "Pflegekasse" (nursing care fund):

If you think that you need so much help that you meet the requirements to receive a certain level of care, you should apply for a level of care grading at the "Pflegekasse". This can be done informally in writing.

Evaluation of your application is free. You can normally contact the "Pflegekasse" via your health insurance. Even if you are not sure if you meet the criteria, you should apply for funding. Because of the "Pflegekasse's" complicated and bureaucratic system, it is very difficult to predict how they will assess an individual care situation.

In preparation for the medical service's (MDK) visit it makes sense to make some notes. In the framework of the assessment, MDK staff are supposed to advise people in need of care, as well as their relatives, individually. If you don't agree with the assessment result, you are entitled to look at the MDK assessment and enter an objection. The Care Reform of 2008 obligates the "Pflegekassen" to send a notification of their decisions within 5 weeks. (§ 18 (3) SGB XI).

deutsche SEPSIS HILFE e.V.

Source: http://www.krebsinformationsdienst.de/wegweiser/adressen/sozialrecht.php

5.1.4 Self-help groups

Many patients have formed self-help groups in order to support one another. In the end, no healthy person can understand the whole range of effects a disease has on those affected. For almost all of the diseases described in this manual, self-help groups exist in Germany. One example is the German Sepsis Help Group.

Contact:

www.sepsis-hilfe.org

or directly:

Deutsche Sepsishilfe e.V. Erlanger Allee 101, 07747 Jena, Tel: 0700-73774700

My personal Information

My family doctor (GP):	
Phone number of my family doctor:	
Emergency number KV-service:	
Emergency medical service	**112**

My diagnoses

Questions I want to ask my family doctor at the next appointment:

Date:	**Date:**	**Date:**

The three most important issues that bother me:

XVIII. On-line Only Supplemental Material

Effect of a primary care management intervention on mental-health-related quality of life among survivors of sepsis: a randomized clinical trial

Sepsis Monitoring Checklist

Sepsis survivors **M**onitoring and c**O**ordination in **O**utpatien**T** **H**ealth care

Monitoring Checklist:

☐ Monitoring 1 on ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋⌊_⌋⌊_⌋ (Name Case Manager)
day month year

☐ Monitoring 2 on ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋⌊_⌋⌊_⌋ (Name Case Manager)
day month year

☐ Monitoring 3 on ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋⌊_⌋⌊_⌋ (Name Case Manager)
day month year

☐ Monitoring 4 on ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋⌊_⌋⌊_⌋ (Name Case Manager)
day month year

☐ Monitoring 5 on ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋⌊_⌋⌊_⌋ (Name Case Manager)
day month year

☐ Monitoring 6 on ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋⌊_⌋⌊_⌋ (Name Case Manager)
day month year

☐ Monitoring 7 on ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋⌊_⌋⌊_⌋ (Name Case Manager)
day month year

☐ Monitoring 8 on ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋⌊_⌋⌊_⌋ (Name Case Manager)
day month year

Liaison physician in charge: (Name liaison physician)

Monitoring contact information:

Patient name	
Patient phone number	
General practitioner name	
General practitioner phone number	

Patient - ID: SM ⌊ ⊥ ⌋ - ⌊ ⊥ ⊥ ⊥ ⌋

Template for interview introduction

Hello Ms/Mr …..“,

This is …. from the Institute of General Practice at Jena University Hospital. I’m calling because I’d like to do the next interview for the SMOOTH study today. Is this okay for you?
(<u>if not,</u> schedule a new date)

Before we start the interview, I’d like to point out some details:

- *I will ask you some questions concerning your health today.*
- *Some of the questions have a similar wording or are about similar topics. This is necessary for our study, so please don’t be surprised. However, if you think that something is somehow strange, please don’t hesitate to tell me.*
- *Simply let me know if you don’t understand a question or if you want me to repeat a question.*
- *The interview will take around half an hour. You can have a break whenever you want to. Simply tell me.*
- *If you think that you need a break or if you want to stop the interview, please inform me. It’s no problem to continue the interview on another date.*
- *In the next few days, the results of this interview will be forwarded to your general practitioner, so you canask your GP about them!*

Do you have any questions about what we just discussed?

<u>If yes:</u> Write down the question, respond briefly to the question and either answer it sympathetically and as best you can or answer: *”This question is about treatment by your general practitioner; please discuss it with your GP.“; or ”Sorry, but I can’t answer this question right now/in the timeframe of this interview. May I write down the question and call you again some other time?”*

<u>If no,</u> please go on

“Okay, then let’s start with the interview!”

Patient - ID: SM ⌊ ⊥ ⌋ - ⌊ ⊥ ⊥ ⊥ ⌋

At first I'd like to know which three issues are most important in your life <u>right now</u>:

Moni-toring	1	2	3
1			
2			
3			
4			
5			
6			
7			
8			

Selection of training topics

Moni-toring	Training topic
1	
2	
3	
4	
5	
6	
7	
8	

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Patient - ID: SM ⌊ ⊥ ⌋ - ⌊ ⊥ ⊥ ⊥ ⌋

Nutrition

I'd like to ask you some questions about your weight and your diet. This helps us assess your nutritional condition. This information may be important for your further treatment.

How much did you weigh in kilograms **BEFORE** the sepsis? What is your height in meters?

Date	Weight	Height	BMI
⌊ ⊥ ⌋.⌊ ⊥ ⌋.⌊ ⊥ ⊥ ⊥ ⌋	⌊ ⊥ ⊥ ⌋, ⌊ ⌋ kg	⌊ ⌋, ⌊ ⊥ ⌋ m	⌊ ⊥ ⌋, ⌊ ⌋

How much do you weigh currently (in kilograms)?

Monitoring							
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**

	Monitoring							
→ (calculate) Body Mass Index	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
> 20	0	0	0	0	0	0	0	0
18.5 – 20	1	1	1	1	1	1	1	1
< 18.5	2	2	2	2	2	2	2	2
Have you lost weight unintentionally in the last 4 weeks?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Yes	0	0	0	0	0	0	0	0
No	0	0	0	0	0	0	0	0
If yes, how much?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
< 5%	0	0	0	0	0	0	0	0
5 – 10%	1	1	1	1	1	1	1	1
> 10%	2	2	2	2	2	2	2	2
In the last 5 days have you ever avoided eating due to an acute illness?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Yes	2	2	2	2	2	2	2	2
No	0	0	0	0	0	0	0	0

Patient - ID: SM ⌊ ⌋ ⌊ ⌋ - ⌊ ⌋ ⌊ ⌋ ⌊ ⌋ ⌊ ⌋

	Monitoring							
Do you eat fewer than 2 meals a day?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Yes								
No								
Do you eat only little fruit and vegetables?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Yes								
No								

If no: That's very important!

If yes: After a disease the body spends a lot of its reserves which need to be replenished with healthy and substantial food. Please talk to your physician about your dietary habits and discuss how you can improve them. Sometimes it is useful to keep a diet record.

Now I'd like to ask you about your alcohol and nicotine consumption:

	Monitoring							
Do you drink 3 or more glasses of beer, schnapps or wine on more than half of all days?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Yes								
No								
Do you smoke regularly (>1x/day, >5x/week)**?**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Yes								
No								

If no: Very good! Carry on like this!

If yes: Especially after a severe disease you should consider reducing alcohol and nicotine consumption. It is often difficult to give up settled habits. Some people even think *'I'm ill anyway. Why shouldn't I allow myself such small treats?'* I do understand this attitude. But maybe you can talk about it to your physician anyway. I'm sure he can help and support you.

Total evaluation nutrition

Monitoring							
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**

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Patient - ID: SM ⌊ ⊥ ⌋ - ⌊ ⊥ ⊥ ⊥ ⌋

ENT

Based on the following questions, I'd like to learn details about possible symptoms in the area of ears, nose, throat:

	Monitoring							
Have you had difficulties in swallowing since the last interview?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
On individual days	1	1	1	1	1	1	1	1
More than half of the days	2	2	2	2	2	2	2	2
Nearly every day	3	3	3	3	3	3	3	3
Have you had taste dysfunctions since the last interview?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
On individual days	1	1	1	1	1	1	1	1
More than half of the days	2	2	2	2	2	2	2	2
Nearly every day	3	3	3	3	3	3	3	3
Have you had hearing defects since the last interview?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
On individual days	1	1	1	1	1	1	1	1
More than half of the days	2	2	2	2	2	2	2	2
Nearly every day	3	3	3	3	3	3	3	3
Have you had olfactory dysfunction since the last interview?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
On individual days	1	1	1	1	1	1	1	1
More than half of the days	2	2	2	2	2	2	2	2
Nearly every day	3	3	3	3	3	3	3	3

Total evaluation ENT

Monitoring							
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**

Patient - ID: SM ⌊ ⊥ ⌋ - ⌊ ⊥ ⊥ ⊥ ⌋

Memory and feelings

7 Item-Scale

The next part has to do with troubling memories and feelings that may occur when you are treated as a patient in the ICU. Please indicate for every question how often you have experienced these troubles in the last month:

	Monitoring							
Have you tried to avoid activities, people, or places that remind you of the experience?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
Once a week or less frequently/sometimes	1	1	1	1	1	1	1	1
2-4 times a week/half of the time	2	2	2	2	2	2	2	2
5 times a week/almost always	3	3	3	3	3	3	3	3
Are you significantly less interested in activities that were important to you before the experience or have you reduced your activities significantly?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
Once a week or less frequently/ sometimes	1	1	1	1	1	1	1	1
2-4 times a week/half of the time	2	2	2	2	2	2	2	2
5 times a week/almost always	3	3	3	3	3	3	3	3
Did you feel alienated and different from other people in your social environment because of that?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
Once a week or less frequently/sometimes	1	1	1	1	1	1	1	1
2-4 times a week/half of the time	2	2	2	2	2	2	2	2
5 times a week/almost always	3	3	3	3	3	3	3	3
Did you feel apathetic or numb (such as not being able to cry or feeling unable to experience love and affection?)	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
Once a week or less frequently/sometimes	1	1	1	1	1	1	1	1
2-4 times a week/half of the time	2	2	2	2	2	2	2	2
5 times a week/almost always	3	3	3	3	3	3	3	3
Did you feel that, due to your experience, your future plans and hopes won't come true (e.g. that you won't have children or that you won't be successful in your job)?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
Once a week or less frequently/sometimes	1	1	1	1	1	1	1	1
2-4 times a week/half of the time	2	2	2	2	2	2	2	2
5 times a week/almost always	3	3	3	3	3	3	3	3

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Patient - ID: SM ⌊ ⌋ ⌊ ⌋ - ⌊ ⌋ ⌊ ⌋ ⌊ ⌋ ⌊ ⌋

	Monitoring							
Have you had difficulties in falling asleep or sleeping all through the night since the experience (i.e. in contrast to before)?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
Once a week or less frequently/sometimes	1	1	1	1	1	1	1	1
2-4 times a week/half of the time	2	2	2	2	2	2	2	2
5 times a week/almost always	3	3	3	3	3	3	3	3
Have you been nervous or easily scared (if someone behind you makes a sudden noise, for example)?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
Once a week or less frequently/sometimes	1	1	1	1	1	1	1	1
2-4 times a week/half of the time	2	2	2	2	2	2	2	2
5 times a week/almost always	3	3	3	3	3	3	3	3

Total assessment Memory and feelings *7 Item-Scale*

Monitoring							
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**

Nerves

Neurology – mod. ODSS

Below you find a list of difficulties due to nerve damage that can occur after a sepsis.

Please indicate how much these difficulties currently impair the following activities:

	Monitoring							
Putting on garments for the upper body (except buttons and zippers)	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not impaired	0	0	0	0	0	0	0	0
Impaired but still possible	1	1	1	1	1	1	1	1
Impossible	2	2	2	2	2	2	2	2
Washing and brushing your hair	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not impaired	0	0	0	0	0	0	0	0
Impaired but still possible	1	1	1	1	1	1	1	1
Impossible	2	2	2	2	2	2	2	2
Inserting a key into a lock	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not impaired	0	0	0	0	0	0	0	0
Impaired but still possible	1	1	1	1	1	1	1	1
Impossible	2	2	2	2	2	2	2	2

Patient - ID: SM ⌊ ⌋ - ⌊ ⌋ ⌋ ⌋ ⌋

	Monitoring							
Using a knife and fork (or a spoon, if a knife and fork were not used)	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not impaired	0	0	0	0	0	0	0	0
Impaired but still possible	1	1	1	1	1	1	1	1
Impossible	2	2	2	2	2	2	2	2
Opening and closing buttons and zippers	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not impaired	0	0	0	0	0	0	0	0
Impaired but still possible	1	1	1	1	1	1	1	1
Impossible	2	2	2	2	2	2	2	2
Do you have difficulty walking?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
No	0	0	0	0	0	0	0	0
Sometimes	1	1	1	1	1	1	1	1
Yes	2	2	2	2	2	2	2	2
Do you use a walking aid?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
No	0	0	0	0	0	0	0	0
Sometimes	1	1	1	1	1	1	1	1
Yes	2	2	2	2	2	2	2	2
Are you able to walk 10 m without help?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
No	2	2	2	2	2	2	2	2
Sometimes	1	1	1	1	1	1	1	1
Yes	0	0	0	0	0	0	0	0
If you use a wheelchair, can you stand up and walk a few steps with help?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
No	2	2	2	2	2	2	2	2
Sometimes	1	1	1	1	1	1	1	1
Yes	0	0	0	0	0	0	0	0
If you are bed-ridden most of the time, are you able to do some targeted movements?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
No	2	2	2	2	2	2	2	2
Sometimes	1	1	1	1	1	1	1	1
Yes	0	0	0	0	0	0	0	0

Total assessment neurology *Neurology – mod. ODSS*

Monitoring							
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**

Patient - ID: SM ⌊ ⊥ ⌋ - ⌊ ⊥ ⊥ ⊥ ⌋

Pain

painDetect Teil 1

Now please indicate how you would assess your pain. The following numbers can help you classify your pain: 0 means that you don't have pain at all, 10 means the worst pain imaginable. The numbers in between represent the level of pain intensity.

Please indicate the area of maximum pain (e.g. head, back, hip)

Monitoring							
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**

Monitoring 1											
Current pain intensity	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Maximum pain intensity in the last 4 weeks	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Average pain intensity in the last 4 weeks	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Monitoring 2											
Current pain intensity	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Maximum pain intensity in the last 4 weeks	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Average pain intensity in the last 4 weeks	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Monitoring 3											
Current pain intensity	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Maximum pain intensity in the last 4 weeks	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Average pain intensity in the last 4 weeks	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Monitoring 4											
Current pain intensity	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Maximum pain intensity in the last 4 weeks	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Average pain intensity in the last 4 weeks	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

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Patient - ID: SM ⌊ ⌋ - ⌊ ⌋ ⌋

Monitoring 5											
Current pain intensity	0	1	2	3	4	5	6	7	8	9	10
Maximum pain intensity in the last 4 weeks	0	1	2	3	4	5	6	7	8	9	10
Average pain intensity in the last 4 weeks	0	1	2	3	4	5	6	7	8	9	10
Monitoring 6											
Current pain intensity	0	1	2	3	4	5	6	7	8	9	10
Maximum pain intensity in the last 4 weeks	0	1	2	3	4	5	6	7	8	9	10
Average pain intensity in the last 4 weeks	0	1	2	3	4	5	6	7	8	9	10
Monitoring 7											
Current pain intensity	0	1	2	3	4	5	6	7	8	9	10
Maximum pain intensity in the last 4 weeks	0	1	2	3	4	5	6	7	8	9	10
Average pain intensity in the last 4 weeks	0	1	2	3	4	5	6	7	8	9	10
Monitoring 8											
Current pain intensity	0	1	2	3	4	5	6	7	8	9	10
Maximum pain intensity in the last 4 weeks	0	1	2	3	4	5	6	7	8	9	10
Average pain intensity in the last 4 weeks	0	1	2	3	4	5	6	7	8	9	10

Total assessment pain intensity *painDetect partl 1*

Monitoring							
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**

Patient - ID: SM ⌊ ⊥ ⌋ - ⌊ ⊥ ⊥ ⊥ ⌋

Neuropathic pain – *Paresthesia*

painDetect part 2

Please indicate any areas of possible paresthesia (sensations of burning, crawling ants, or electric shock; hypersensitivity to cold, heat or touching; numbness; or stabbing pain),

Monitoring							
1	2	3	4	5	6	7	8

	Monitoring							
Do you suffer from a burning sensation in the areas you indicated (e.g. stinging nettles)?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Never	0	0	0	0	0	0	0	0
Hardly	1	1	1	1	1	1	1	1
Slightly	2	2	2	2	2	2	2	2
Moderately	3	3	3	3	3	3	3	3
Strongly	4	4	4	4	4	4	4	4
Very strongly	5	5	5	5	5	5	5	5
Do you have a tingling or prickling sensation in the area of paresthesia (like crawling ants, electrical tingling)?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Never	0	0	0	0	0	0	0	0
Hardly	1	1	1	1	1	1	1	1
Slightly	2	2	2	2	2	2	2	2
Moderately	3	3	3	3	3	3	3	3
Strongly	4	4	4	4	4	4	4	4
Very strongly	5	5	5	5	5	5	5	5
Is light touching in this area painful (clothing, a blanket)?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Never	0	0	0	0	0	0	0	0
Hardly	1	1	1	1	1	1	1	1
Slightly	2	2	2	2	2	2	2	2
Moderately	3	3	3	3	3	3	3	3
Strongly	4	4	4	4	4	4	4	4
Very strongly	5	5	5	5	5	5	5	5

Patient - ID: SM ⌊ ⌋ - ⌊ ⌋ ⌋

	Monitoring							
Do you have sudden pain attacks in the area of your paresthesia?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Never	0	0	0	0	0	0	0	0
Hardly	1	1	1	1	1	1	1	1
Slightly	2	2	2	2	2	2	2	2
Moderately	3	3	3	3	3	3	3	3
Strongly	4	4	4	4	4	4	4	4
Very strongly	5	5	5	5	5	5	5	5
Is cold or heat (bath water) in this area occasionally painful?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Never	0	0	0	0	0	0	0	0
Hardly	1	1	1	1	1	1	1	1
Slightly	2	2	2	2	2	2	2	2
Moderately	3	3	3	3	3	3	3	3
Strongly	4	4	4	4	4	4	4	4
Very strongly	5	5	5	5	5	5	5	5
Do you suffer from a sensation of numbness in the area you indicated?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Never	0	0	0	0	0	0	0	0
Hardly	1	1	1	1	1	1	1	1
Slightly	2	2	2	2	2	2	2	2
Moderately	3	3	3	3	3	3	3	3
Strongly	4	4	4	4	4	4	4	4
Very strongly	5	5	5	5	5	5	5	5
Does slight pressure in this area, such as pressure with a finger, trigger pain?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Never	0	0	0	0	0	0	0	0
Hardly	1	1	1	1	1	1	1	1
Slightly	2	2	2	2	2	2	2	2
Moderately	3	3	3	3	3	3	3	3
Strongly	4	4	4	4	4	4	4	4
Very strongly	5	5	5	5	5	5	5	5

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Patient - ID: SM ⌊ ⌋ ⌊ ⌋ - ⌊ ⌋ ⌊ ⌋ ⌊ ⌋ ⌊ ⌋

Which statement best describes your course of pain?	Monitoring							
	1	2	3	4	5	6	7	8
Persistent pain with slight fluctuations	0	0	0	0	0	0	0	0
Persistent pain with pain attacks	-1	-1	-1	-1	-1	-1	-1	-1
Pain attacks without pain between them	+1	+1	+1	+1	+1	+1	+1	+1
Pain attacks with pain between them	+1	+1	+1	+1	+1	+1	+1	+1

Is your pain/your paresthesia radiating to other regions of your body?	Monitoring							
	1	2	3	4	5	6	7	8
Yes	+2	+2	+2	+2	+2	+2	+2	+2
No	0	0	0	0	0	0	0	0

Total assessment neuropathic pain *painDetect part 2*

Monitoring							
1	2	3	4	5	6	7	8

Patient - ID: SM ⌊ ⊥ ⌋ - ⌊ ⊥ ⊥ ⊥ ⌋

Mood

PHQ 9

This questionnaire is about your mood which might be affected by the disease. Your answers can help your physician to understand you better. Please answer all questions as best as you can, even if you think they are strange.

	Monitoring							
Over the last 2 weeks, have you had little interest or pleasure in doing things on more than half the days?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Yes	1	1	1	1	1	1	1	1
No	0	0	0	0	0	0	0	0
Over the last 2 weeks, have you felt down, depressed or hopeless on more than half the days?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Yes	1	1	1	1	1	1	1	1
No	0	0	0	0	0	0	0	0
Interim assessment								

Note:

→ ***If both questions are answered "No" continue the monitoring with the Objectives questions. Page 18.***

→ ***If one or both questions are answered "Yes" continue here!***

Over the last two weeks, how often have you been bothered by any of the following problems?

	Monitoring							
Trouble falling or staying asleep, or sleeping too much?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
Several days	1	1	1	1	1	1	1	1
More than half the days	2	2	2	2	2	2	2	2
Nearly every day	3	3	3	3	3	3	3	3
Feeling tired or having little energy?								
Not at all	0	0	0	0	0	0	0	0
Several days	1	1	1	1	1	1	1	1
More than half the days	2	2	2	2	2	2	2	2
Nearly every day	3	3	3	3	3	3	3	3
Poor appetite or overeating?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
Several days	1	1	1	1	1	1	1	1
More than half the days	2	2	2	2	2	2	2	2
Nearly every day	3	3	3	3	3	3	3	3

Patient - ID: SM ⌊ ⌋ - ⌊ ⌋ ⌋

	Monitoring							
Feeling bad about yourself - or that you are a failure or have let yourself or your family down?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
Several days	1	1	1	1	1	1	1	1
More than half the days	2	2	2	2	2	2	2	2
Nearly every day	3	3	3	3	3	3	3	3
Trouble concentrating on things, such as reading the newspaper or watching television?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
Several days	1	1	1	1	1	1	1	1
More than half the days	2	2	2	2	2	2	2	2
Nearly every day	3	3	3	3	3	3	3	3
Moving or speaking so slowly that other people might have noticed? **Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual?**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
Several days	1	1	1	1	1	1	1	1
More than half the days	2	2	2	2	2	2	2	2
Nearly every day	3	3	3	3	3	3	3	3
Thoughts that you would be better off dead, or of hurting yourself in some way?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
Several days	1	1	1	1	1	1	1	1
More than half the days	2	2	2	2	2	2	2	2
Nearly every day	3	3	3	3	3	3	3	3

Total assessment mood *PHQ 9*

Monitoring							
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**

Patient - ID: SM ⌊ ⊥ ⌋ - ⌊ ⊥ ⊥ ⊥ ⌋

Objectives

	Monitoring							
When you visited your physician last time, did you agree on some smaller objectives that can contribute to your recovery? *Smaller objectives could be: how often and how intensely you exercise, which exercises you will do, how much and what you eat, stopping smoking, or selecting which activities you decide to do (e.g. housework)*	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Yes	0	0	0	0	0	0	0	0
No	1	1	1	1	1	1	1	1

If no: This can be important. By formulating objectives you can actively influence your health in a positive way. Maybe you could think about some smaller objectives you want to achieve in order to make major advances in your health gradually. Talk about it with your physician! Agree on objectives and check at your next date if your plans worked out all right.

What objectives did you agree on?							
Monitoring							
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**

Has it worked?	Monitoring							
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Yes								
No								

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Patient - ID: SM ⌊ ⊥ ⌋ - ⌊ ⊥ ⊥ ⊥ ⌋

Exercise

Let me ask you some questions about your physical fitness. Regular exercise is an essential part of restoring good health.

Do you take physical exercise regularly?	Monitoring							
	1	2	3	4	5	6	7	8
Yes								
No								

If yes, what kind of exercise?							
1	2	3	4	5	6	7	8

If yes, how long per session?	Monitoring							
	1	2	3	4	5	6	7	8
< 10 min								
10 – 30 min								
31 – 60 min								
> 60 min								
Would you like to exercise more?								
	1	2	3	4	5	6	7	8
Yes								
No								

How could I support you in this goal?

Monitoring							
1	2	3	4	5	6	7	8

Patient - ID: SM ⌊ ⊥ ⌋ - ⌊ ⊥ ⊥ ⊥ ⌋

Self management

This part starts with a question about the medicines your physician prescribed for you. Please answer honestly, you have nothing to fear:

	Monitoring							
Have you taken your medicines as prescribed since the last interview?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Yes								
No								

If yes: That's very good!

If no: I appreciate your honesty! Does your physician know it? It is important for your health that you discuss with your physician which medicines you want to take or not. Please talk to him openly about it. It will certainly pay off!

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Patient - ID: SM ⌊ ⊥ ⌋ - ⌊ ⊥ ⊥ ⊥ ⌋

Memory and concentration

6-Item-Screener

Now I will ask you some questions where your memory is required. Some of the questions might seem very simple – please accept our apologies.

First, I will name three things. Please wait until I have said all three words; then repeat these words. Pay attention! Keep these things in mind. I will ask for them again in a few minutes.

The three things are:

Monitoring 1, 3, 5, and 7: **Apple – Table – Cent**

Monitoring 2, 4, 6, and 8: **Blue – Chair – Donkey**

	Monitoring							
Please repeat these 3 words!	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Correct	1	1	1	1	1	1	1	1
Incorrect	0	0	0	0	0	0	0	0
What year is it?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Correct	1	1	1	1	1	1	1	1
Incorrect	0	0	0	0	0	0	0	0
What month is it?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Correct	1	1	1	1	1	1	1	1
Incorrect	0	0	0	0	0	0	0	0
What day of the week is it?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Correct	1	1	1	1	1	1	1	1
Incorrect	0	0	0	0	0	0	0	0
What are the 3 things I asked you to remember?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
0/3 correct	0	0	0	0	0	0	0	0
1/3 correct	1	1	1	1	1	1	1	1
2/3 correct	2	2	2	2	2	2	2	2
3/3 correct	3	3	3	3	3	3	3	3

Total assessment memory and concentration *6-Item-Screener*

Monitoring							
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**

Patient - ID: SM ⌊ ⊥ ⌋ - ⌊ ⊥ ⊥ ⊥ ⌋

End/finalization of the monitoring interview:

We have reached the end of the interview. Lastly I'd like to know …

Is there anything your physician needs to know?							
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**

Scheduling the next appointment:

I'd like to schedule a date for the next interview in one month:

Our next interview takes place on …….. at ……. o'clock.

Monitoring							
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**
_____ **(Date)** _____ **(Time)**	_____ **(Date)** _____ **(Time)**	_____ **(Date)** _____ **(Time)**	_____ **(Date)** _____ **(Time)**	_____ **(Date)** _____ **(Time)**	_____ **(Date)** _____ **(Time)**	_____ **(Date)** _____ **(Time)**	_____ **(Date)** _____ **(Time)**

Many thanks for your cooperation! We wish you all the best for your recovery!

Kind regards,

Your Smooth study team

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XIX. On-line Only Supplemental Material

Effect of a primary care management intervention on mental-health-related quality of life among survivors of sepsis: a randomized clinical trial

Sepsis Case Manager

Training Manual

Sepsis survivors Monitoring and cOordination in OutpatienT Health care

Institute of General Practice and Family Medicine
Friedrich Schiller University

Contents

1.1 Introducing the study and the case management

"First, I'd like to explain what we plan to do today and what lies ahead for you in the course of this study.

- *Today we will have a training course for about 1 hour here at your general practitioner's practice.*
- *After that I will phone you once a month. At first I will ask you about current problems so that in future phone calls we can better accommodate your situation and needs. After that you will get tips for your everyday life and for your recovery. Your general practitioner is still the main person responsible for your therapy. Your GP knows your medical history best and will be the one who decides the best course together with you.*
- *If you want to have a break or stop the interview, simply let me know*
  (Do not emphasize the break too much; offer it once but don't repeat it)
- *Our study provides long-term aftercare for patients after acute sepsis for the first time. We want to support your recovery.*
- *I'm a trained study nurse and am your personal point-of-contact in this study. Our study team works hand in hand with your general practitioner.*

Explain that you want to ask some opening questions so that you can better assess the patient's conditions and better respond to the patient's needs.

"Before we start I'd like to point out some details:

- *All information we collect will be discussed with your general practitioner*
- *Your answers will be treated as confidential*
- *Some of the questions have a similar wording or are about similar topics. This is necessary for our study, so please don't be surprised. However, if you think that something is somehow strange, please don't hesitate to tell me.*
- *Simply let me know if you don't understand a question or if you want me to repeat it.*

1.2 Basic assessment

How much do you weigh currently (in kilograms)?	|__|__| kg
What is your height (in meters)?	|__|,|__|__| m

	Points
→ (Calculate) Body Mass Index	
> 20	0
18.5 – 20	1
< 18.5	2
Have you lost weight unintentionally in the last 4 weeks?	
Yes	0
No	0
If yes, how much? (convert kilograms into percentage for the patient, e.g. < 5% at 70 kg is < 3,5 kg)	
< 5%	1
5 – 10%	2
> 10%	
In the last 5 days (or longer), have you avoided eating anything due to an acute illness?	
Yes	2
No	0
Total points	**|__|__|__|**

Do you have difficulties…	
… in putting on garments for the upper body (except buttons and zippers)?	
Not impaired	0
Impaired but still possible	1
Impossible	2
… in opening and closing buttons and zippers?	
Not impaired	0
Impaired but still possible	1
Impossible	2
…in walking?	
No	0
Sometimes	1
Yes	2
Do you use a walking aid?	
No	0
Sometimes	1
Yes	2

If yes, which one?			
Rollator/walker	Crutches	Cane	Wheelchair

Please rate the pain intensity you are experiencing right now. Use a scale from 0-10.										
0	1	2	3	4	5	6	7	8	9	10
What was your average pain intensity in the last 4 weeks?										
0	1	2	3	4	5	6	7	8	9	10
Do you have a tingling or prickling sensation in the area of pain (like crawling ants, for example)?										
Never	Hardly	Slightly	Moderately	Strongly	Very strongly					
Do you suffer from a sensation of numbness in the area of pain?										
Never	Hardly	Slightly	Moderately	Strongly	Very strongly					

Did you have trouble falling or staying asleep on more than half the days in the last month? ,	Yes	No
Did you feel apathetic or numb (such as not being able to cry or feeling unable to experience love and affection) on more than half the days in the last month?	Yes	No

In the last month, have you had little interest or pleasure in doing things on more than half the days?	Yes	No
Over the last 2 weeks, have you felt down, depressed, or hopeless on more than half the days?	Yes	No

What do you think are the three most important issues/problems in your life right now?

Please decide based on the questionnaire results what kind of sepsis complications you will train the patient about today. If there are no obvious complications, train the patient on the topic “coping with the disease.” Then go on with the training module:

”Now we’ve finished the questionnaire. I’d like to give you an overview of your disease and how to cope with it.“

Ask patients if they want to go on with the training right now or if they need a break. If they need a break, schedule another time or date for training.

1.3 Basic training in the GP practice

You start with a short introduction about sepsis, preferably using the patient's individual medical history and therapy. Take into account the patient's educational level, keep your explanations simple if necessary, and don't use medical terms. Make sure the patient understands you, encourage asking questions. In case of more specific questions, tell the patient to ask his GP. Then go on to possible after-effects of sepsis.

1.3.1 Sepsis Six: Summary

After a sepsis, weight loss and muscle atrophy can happen over time.
Chronic pain can have many sepsis-related causes; there are a variety of treatment options.
Sepsis can damage nerve pathways which can cause sensations of numbness, tingling, and burning.
Severe diseases can affect the mood, but this is easy to treat nowadays.
Unpleasant feelings and memories from time spent in the ICU can take a heavy toll on some patients.
Concentration and memory can be reduced after a sepsis.

Then proceed with the topical training course.

"Now we will have a closer look at the sepsis after-effects you are experiencing." Or "Fortunately, you aren't showing any of these after-effects now. Therefore, I'd like to give you some general advice on how to cope with the disease."

Use the patient manual. It is part of the study and of your training course.
Show the manual to the patient and explain its different sections. Encourage the patient to read some of the chapters alone later on. It is not necessary to read the whole manual in one sitting. Invite the patient to dip into the manual every now and then.

"This manual is specially designed to help you to recover from your severe illness. It is based on scientific knowledge as well as on the long experience of physicians, specialists, and other patients who have overcome your illness."

When the training course is finished, explain the concept of individual follow-up training sessions by phone.

"Based on your answers in the questionnaires, we will deal with another topic in our next interview. It goes without saying that the main person in charge of your treatment is still your general

practitioner."

1.3.2 Ending the interview

- When the interview is done, please schedule a date for the next monitoring telephone-interview with the patient. The phone-interview should take place around 4 weeks after the first training course.
  Schedule a new date and time for the next monitoring interview at the end of each interview. Please make sure to follow the planned monthly intervals.
- If possible, choose **Monday, Tuesday, or Wednesday** for phoning the patient. Don't fix dates on Thursday or Friday because, due to the weekend, you might have problems in finding new dates to reschedule, if necessary.
- Try to schedule phone appointments at times when a liaison physician is on-call or on the premises.

Please write down the date of the next appointment at the bottom of the questionnaire (scheduling the next appointment).

Summarize all arrangements (dates, recall, etc.) and ask patients if they need details of the appointment or of other arrangements in writing. If yes, send the patient a note. Remind patients to weigh themselves on the day of the next monitoring interview because you will ask about current weight.

Thank patients for their cooperation and say goodbye in a friendly manner.

1.4 Monitoring

The course of action is as follows:

- You ask the patient a question.
- Depending on the answer several answer categories are possible, e.g. ”almost every day“, “in more than half the days“, ”on individual days“ or ”never.“

Mark the appropriate box according to the answer. At the bottom of each questionnaire section you will find a total assessment box. After the interview, please fill in the sum of all points here and mark – according to the result -- the red, the yellow, or the green box.
Inform the liaison physician about the result. If the result is “yellow” or “red”, the liaison physician will get in touch with the GP directly. Please fax “green” results to the GP by using the enclosed template.

Color	**Physician information**	**Priority**	**Consequence**
Green	Send results of analysis to liaison physician	Low	Send results to GP soon (normally by fax)
Yellow		Middle	**Liaison physician** calls GP and sends results soon
Red	Immediately notify the liaison physician	High	**Liaison physician** calls the patient‘s GP immediately!

- IMPORTANT: Complete the questionnaire **during** the monitoring – i.e. while you are interviewing the patient!
- Go over the questions one by one so that you don’t overlook any questions.

1.4.1 Framework conditions for the telephone interview

In order to support your telephone interview we have made up an interview-checklist:

- Choose a place where you can make the phone call without your colleagues disturbing you.
  Have the following documents at hand:
  - The relevant interview questionnaire
  - The file with all already existing monitoring questionnaires
  - The notes you made for preparing the interview

1.4.2 Phone interview introduction

The following examples are intended to provide assistance for starting the interview. Of course you can also use your own words or adapt the examples to the patient!

- Introduce yourself by saying the institute's name and your name. Address the patient by name.

  Example: "*Hello Mr Bestmann – this is the Institute of General Practice at Jena University Hospital. My name is Susanne Meier."*

  Tip: Address the patient by name. This makes him feel appreciated."
- Ask the patient if it is convenient to do the interview now (even if the date was scheduled beforehand!). Explain once again that you will conduct the interview now and that it will take around 30 minutes.

  Example: *"We have an appointment for a telephone interview today. I'd like to ask you some questions about your health and about how you are doing. The interview will take around 30 minutes. Is it ok if we start now?"*
- For building a relationship use a so-called "door-opener question" (e.g. How are you? How was your last week? Small-talk about the weather, etc.)

  Example: *"Well, that's quite an exciting story about your neighbor, but now I'd like to start (go on) with the interview. We can talk a bit longer about it when we are finished with the interview."*

  Tip: Don't allow the patient to talk endlessly. This is nothing more than a friendly warm-up. Lead the conversation to the interview as soon as possible. When the interview is finished, there is still time for such topics!

- Talk slowly, clearly and loudly enough –patients are often nervous and excited, especially at the first interview.

  Example: *"Mr Bestmann, I notice that you are a bit excited. Well, this is our first interview. Don't worry, I'm a bit excited, too. But I'm sure together we will succeed!"*

  Tip: You can help the patient overcome his nervousness by directly addressing it. This conveys a positive feeling and makes his reservations disappear!
- While doing the interview, please keep in mind that the patient is ill and that answers might be delayed and slurred. Remain patient and ask again if you don't understand at first.

  Example: *"Mr Bestmann, I didn't understand you just now. Would you please repeat your answer?"*
- Please document the results in the questionnaire **during** the interview and tell the patient that you are taking notes while you are interviewing.

  Example: *"Please don't be surprised if there are short breaks. I take down your answers immediately so that I won't miss anything."*
- Put this manual on the table in front of you while you are talking to the patient. If possible, use the pre-formulated – tested – wording. It will reassure you in the interview. It is important that you learn the sentences by heart and train them (by practicing them aloud) so that everybody knows what was said. Using the given wording also protects you against surprises.
- You are not responsible for the patient's answers or complaints. Whenever you feel insecure, you can say:

  "This is very important. Your general practitioner should know about these things. It is necessary that you bring up this subject next time you see your general practitioner. You can note these things/questions in your booklet to make sure you don't forget them at your next doctor's appointment."
- Always inform the liaison physician afterwards. He will assess everything else and take appropriate actions.
- Whatever you do, please keep in mind that the general practitioner is the responsible person. At the end of the day, it's the GP who must know what is happening. You are the GP's "extended arm". The liaison physician will forward everything to the GP. Make sure that you report as precisely as possible to the liaison physician. Stick to the monitoring list – otherwise we will have the "Chinese whispers" effect which could be really dangerous for the patient.

- Don't go into detail if patients want to discuss their issues more in-depth. Refuse politely: *"This is very important. Your general practitioner should know about these things. It is necessary that you bring up this subject next time you see your general practitioner. You can note these things/questions in your booklet to make sure you don't forget them at your next doctor's appointment."*
- Tell patients that you will start with some questions that will help you assess their condition and respond to their needs:

  "Before we start, I'd like to point out some details:
  - *All information will be directly discussed with your general practitioner*
  - *Your answers will be treated as confidential.*
  - *Some of the questions have a similar wording or are about similar topics. This is necessary for our study, so please don't be surprised. However, if you think that something is somehow strange, please don't hesitate to tell me.*
  - *Simply let me know if you don't understand a question or if you want me to repeat it."*

2 MONITORING

Structured long-term care of patients after sepsis

Sepsis survivors Monitoring and cOordination in OutpatienT Health care

2012-11-01_Monitoring_Fragebogen_final rev.

Study management:
Prof. Dr. Jochen Gensichen (PI)
Dr. Konrad Schmidt

Bundesministerium für Bildung und Forschung

Funded by the Federal Ministry of Education and Research
Grant ID: 01 E0 1002
Förderkennzeichen: 01 E0 1002

2.1 Monitoring Checklist:

☐ Monitoring 1 on ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋⌊_⌋⌊_⌋ (Name Case Manager)
day month year

☐ Monitoring 2 on ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋⌊_⌋⌊_⌋ (Name Case Manager)
day month year

☐ Monitoring 3 on ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋⌊_⌋⌊_⌋ (Name Case Manager)
day month year

☐ Monitoring 4 on ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋⌊_⌋⌊_⌋ (Name Case Manager)
day month year

☐ Monitoring 5 on ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋⌊_⌋⌊_⌋ (Name Case Manager)
day month year

☐ Monitoring 6 on ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋⌊_⌋⌊_⌋ (Name Case Manager)
day month year

☐ Monitoring 7 on ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋⌊_⌋⌊_⌋ (Name Case Manager)
day month year

☐ Monitoring 8 on ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋ ⌊_⌋⌊_⌋⌊_⌋⌊_⌋ (Name Case Manager)
day month year

Liaison physician in charge: (Name liaison physician)

Monitoring contact information:

Patient name	
Patient phone number	
General practitioner name	
General practitioner phone number	

2.2 Template for interview introduction

Hello Ms/Mr …..“,

This is …. from the Institute of General Practice at Jena University Hospital. I’m calling because I’d like to do the next interview for the SMOOTH study today. Is this okay for you?
(if not, schedule a new date)

Before we start the interview, I’d like to point out some details:

- *I will ask you some questions concerning your health today.*
- *Some of the questions have a similar wording or are about similar topics. This is necessary for our study, so please don’t be surprised. However, if you think that something is somehow strange, please don’t hesitate to tell me.*
- *Simply let me know if you don’t understand a question or if you want me to repeat a question.*
- *The interview will take around half an hour. You can have a break whenever you want to. Simply tell me.*
- *If you have the feeling that you need to have a break or stop the interview, please inform me. It’s no problem to continue the interview on another date.*
- *In the next few days, the results of this interview will be forwarded to your general practitioner, so you can ask your GP about them!*

Do you have any questions about what we just discussed?
If yes: Write down the question, respond briefly to the question and either answer sympathetically and as best you can or answer: ”This question is about treatment by your general practitioner; please discuss it with your GP“; or ”Sorry, but I can’t answer this question right now/in the timeframe of this interview. May I write down the question and call you again some other time?”

If no, please go on

“Okay, then let’s start with the interview!”

2.3 Current issues

At first I'd like to know which three issues are most important in your life <u>right now</u>:

Moni-toring	1	2	3
1			
2			
3			
4			
5			
6			
7			
8			

2.4 Nutrition

I'd like to ask you some questions about your weight and your diet. This helps us assess your nutritional condition. This information may be important for your further treatment.

How much did you weigh in kilograms **BEFORE** the sepsis? What is your height in meters?

Date	Weight	Height	BMI
⌊ ⌋⌋.⌊ ⌋⌋.⌊ ⌋⌋⌋⌋	⌊ ⌋⌋⌋, ⌊ ⌋ kg	⌊ ⌋, ⌊ ⌋⌋ m	⌊ ⌋⌋, ⌊ ⌋

How much do you weigh currently (in kilograms)?

Monitoring							
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**

	Monitoring							
→ (calculate) Body Mass Index	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
> 20	0	0	0	0	0	0	0	0
18.5 – 20	1	1	1	1	1	1	1	1
< 18.5	2	2	2	2	2	2	2	2
Have you lost weight unintentionally in the last 4 weeks?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Yes	0	0	0	0	0	0	0	0
No	0	0	0	0	0	0	0	0
If yes, how much?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
< 5%	0	0	0	0	0	0	0	0
5 – 10%	1	1	1	1	1	1	1	1
> 10%	2	2	2	2	2	2	2	2
In the last 5 days or longer, have you avoided eating anything due to an acute illness?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Yes	2	2	2	2	2	2	2	2
No	0	0	0	0	0	0	0	0

	Monitoring							
Do you eat fewer than 2 meals a day?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Yes								
No								
Do you eat only little fruit and vegetables?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Yes								
No								

If no: That's very important!

If yes: After a disease the body spends a lot of its reserves which need to be replenished with healthy and substantial food. Please talk to your physician about your dietary habits and discuss how you can improve them. Sometimes it is useful to keep a diet record.

Now I'd like to ask you about your alcohol and nicotine consumption:

	Monitoring							
Do you drink 3 or more glasses of beer, schnapps or wine on more than half of all days?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Yes								
No								
Do you smoke regularly (>1x/day, >5x/week)**?**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Yes								
No								

If no: Very good! Carry on like this!

If yes: Especially after a severe disease you should consider reducing alcohol and nicotine consumption. It is often difficult to give up settled habits. Some people even think 'I'm ill anyway. Why shouldn't I allow myself such small treats?' I do understand this attitude. But maybe you can talk to your physician about it anyway. I'm sure he can help and support you.

Total evaluation nutrition

Monitoring							
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**

2.5 ENT

Based on the following questions, I'd like to learn details about possible symptoms in the area of ears, nose, throat:

	Monitoring							
Have you had difficulties in swallowing since the last interview?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
On individual days	1	1	1	1	1	1	1	1
More than half of the days	2	2	2	2	2	2	2	2
Nearly every day	3	3	3	3	3	3	3	3
Have you had taste dysfunctions since the last interview?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
On individual days	1	1	1	1	1	1	1	1
More than half of the days	2	2	2	2	2	2	2	2
Nearly every day	3	3	3	3	3	3	3	3
Have you had hearing defects since the last interview?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
On individual days	1	1	1	1	1	1	1	1
More than half of the days	2	2	2	2	2	2	2	2
Nearly every day	3	3	3	3	3	3	3	3
Have you had olfactory dysfunction since the last interview?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
On individual days	1	1	1	1	1	1	1	1
More than half of the days	2	2	2	2	2	2	2	2
Nearly every day	3	3	3	3	3	3	3	3

Total evaluation ENT

Monitoring							
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**

2.6 Memory and feelings

7 Item-Scale

The next part has to do with troubling memories and feelings that may occur when you are treated as a patient in the ICU. Please indicate for every question how often you have experienced these troubles in the last month:

	Monitoring							
Have you tried to avoid activities, people, or places that remind you of the experience?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
Once a week or less frequently/sometimes	1	1	1	1	1	1	1	1
2-4 times a week/half of the time	2	2	2	2	2	2	2	2
5 times a week/almost always	3	3	3	3	3	3	3	3
Are you significantly less interested in activities that were important to you before the experience or have you reduced your activities significantly?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
Once a week or less frequently/sometimes	1	1	1	1	1	1	1	1
2-4 times a week/half of the time	2	2	2	2	2	2	2	2
5 times a week/almost always	3	3	3	3	3	3	3	3
Did you feel alienated and different from other people in your social environment because of that?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
Once a week or less frequently/sometimes	1	1	1	1	1	1	1	1
2-4 times a week/half of the time	2	2	2	2	2	2	2	2
5 times a week/almost always	3	3	3	3	3	3	3	3
Did you feel apathetic or numb (such as not being able to cry or feeling unable to experience love and affection?)	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
Once a week or less frequently/sometimes	1	1	1	1	1	1	1	1
2-4 times a week/half of the time	2	2	2	2	2	2	2	2
5 times a week/almost always	3	3	3	3	3	3	3	3
Did you feel that, due to your experience, your future plans and hopes won't come true (e.g. that you won't have children or that you won't be successful in your job)?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
Once a week or less frequently/sometimes	1	1	1	1	1	1	1	1
2-4 times a week/half of the time	2	2	2	2	2	2	2	2
5 times a week/almost always	3	3	3	3	3	3	3	3

	Monitoring

Have you had difficulties in falling asleep or sleeping all through the night since the experience (i.e. in contrast to before)?	1	2	3	4	5	6	7	8
Not at all	0	0	0	0	0	0	0	0
Once a week or less frequently/sometimes	1	1	1	1	1	1	1	1
2-4 times a week/half of the time	2	2	2	2	2	2	2	2
5 times a week/almost always	3	3	3	3	3	3	3	3
Have you been nervous or easily scared (if someone behind you makes a sudden noise, for example)?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
Once a week or less frequently/sometimes	1	1	1	1	1	1	1	1
2-4 times a week/half of the time	2	2	2	2	2	2	2	2
5 times a week/almost always	3	3	3	3	3	3	3	3

Total assessment Memory and feelings *7 Item-Scale*

Monitoring							
1	2	3	4	5	6	7	8

2.7 Nerves

Neurology – mod. ODSS

Below you find a list of difficulties due to nerve damage that can occur after a sepsis.

Please indicate how much your difficulties currently impair the following activities:

	Monitoring							
Putting on garments for the upper body (except buttons and zippers)	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not impaired	0	0	0	0	0	0	0	0
Impaired but still possible	1	1	1	1	1	1	1	1
Impossible	2	2	2	2	2	2	2	2
Washing and brushing your hair	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not impaired	0	0	0	0	0	0	0	0
Impaired but still possible	1	1	1	1	1	1	1	1
Impossible	2	2	2	2	2	2	2	2
Inserting a key into a lock	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not impaired	0	0	0	0	0	0	0	0
Impaired but still possible	1	1	1	1	1	1	1	1
Impossible	2	2	2	2	2	2	2	2

	Monitoring							
Using a knife and fork (or a spoon, if a knife and fork were not used)	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not impaired	0	0	0	0	0	0	0	0
Impaired but still possible	1	1	1	1	1	1	1	1
Impossible	2	2	2	2	2	2	2	2
Opening and closing buttons and zippers	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not impaired	0	0	0	0	0	0	0	0
Impaired but still possible	1	1	1	1	1	1	1	1
Impossible	2	2	2	2	2	2	2	2
Do you have difficulty walking?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
No	0	0	0	0	0	0	0	0
Sometimes	1	1	1	1	1	1	1	1
Yes	2	2	2	2	2	2	2	2
Do you use a walking aid?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
No	0	0	0	0	0	0	0	0
Sometimes	1	1	1	1	1	1	1	1
Yes	2	2	2	2	2	2	2	2
Are you able to walk 10 m without help?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
No	2	2	2	2	2	2	2	2
Sometimes	1	1	1	1	1	1	1	1
Yes	0	0	0	0	0	0	0	0
If you use a wheelchair, can you stand up and walk a few steps with help?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
No	2	2	2	2	2	2	2	2
Sometimes	1	1	1	1	1	1	1	1
Yes	0	0	0	0	0	0	0	0
If you are bed-ridden most of the time, are you able to do some targeted movements?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
No	2	2	2	2	2	2	2	2
Sometimes	1	1	1	1	1	1	1	1
Yes	0	0	0	0	0	0	0	0

Total assessment neurology *Neurology – mod. ODSS*

Monitoring							
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**

2.8 Pain

painDetect Teil 1

Now please indicate how you would assess your pain. The following numbers can help you classify your pain: 0 means that you don't have pain at all, 10 means the worst pain imaginable. The numbers in between represent the level of pain intensity.

Please indicate the area of maximum pain (e.g. head, back, hip)

Monitoring							
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**

Monitoring 1											
Current pain intensity	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Maximum pain intensity in the last 4 weeks	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Average pain intensity in the last 4 weeks	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Monitoring 2											
Current pain intensity	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Maximum pain intensity in the last 4 weeks	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Average pain intensity in the last 4 weeks	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Monitoring 3											
Current pain intensity	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Maximum pain intensity in the last 4 weeks	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Average pain intensity in the last 4 weeks	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Monitoring 4											
Current pain intensity	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Maximum pain intensity in the last 4 weeks	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Average pain intensity in the last 4 weeks	*0*	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*

Monitoring 5											
Current pain intensity	0	1	2	3	4	5	6	7	8	9	10
Maximum pain intensity in the last 4 weeks	0	1	2	3	4	5	6	7	8	9	10
Average pain intensity in the last 4 weeks	0	1	2	3	4	5	6	7	8	9	10
Monitoring 6											
Current pain intensity	0	1	2	3	4	5	6	7	8	9	10
Maximum pain intensity in the last 4 weeks	0	1	2	3	4	5	6	7	8	9	10
Average pain intensity in the last 4 weeks	0	1	2	3	4	5	6	7	8	9	10
Monitoring 7											
Current pain intensity	0	1	2	3	4	5	6	7	8	9	10
Maximum pain intensity in the last 4 weeks	0	1	2	3	4	5	6	7	8	9	10
Average pain intensity in the last 4 weeks	0	1	2	3	4	5	6	7	8	9	10
Monitoring 8											
Current pain intensity	0	1	2	3	4	5	6	7	8	9	10
Maximum pain intensity in the last 4 weeks	0	1	2	3	4	5	6	7	8	9	10
Average pain intensity in the last 4 weeks	0	1	2	3	4	5	6	7	8	9	10

Total assessment pain intensity *painDetect partI 1*

Monitoring							
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**

2.8.1 Neuropathic pain - Paresthesia

painDetect part 2

Please indicate any areas of possible paresthesia (sensations of burning, crawling ants, or electric shock; hypersensitivity to cold, heat, or touching; numbness; or stabbing pain)

Monitoring							
1	2	3	4	5	6	7	8

	Monitoring							
Do you suffer from a burning sensation in the areas you indicated (e.g. stinging nettles)?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Never	0	0	0	0	0	0	0	0
Hardly	1	1	1	1	1	1	1	1
Slightly	2	2	2	2	2	2	2	2
Moderately	3	3	3	3	3	3	3	3
Strongly	4	4	4	4	4	4	4	4
Very strongly	5	5	5	5	5	5	5	5
Do you have a tingling or prickling sensation in the area of paresthesia (like crawling ants, electrical tingling)?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Never	0	0	0	0	0	0	0	0
Hardly	1	1	1	1	1	1	1	1
Slightly	2	2	2	2	2	2	2	2
Moderately	3	3	3	3	3	3	3	3
Strongly	4	4	4	4	4	4	4	4
Very strongly	5	5	5	5	5	5	5	5
Is light touching in this area painful (clothing, a blanket)?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Never	0	0	0	0	0	0	0	0
Hardly	1	1	1	1	1	1	1	1
Slightly	2	2	2	2	2	2	2	2
Moderately	3	3	3	3	3	3	3	3
Strongly	4	4	4	4	4	4	4	4
Very strongly	5	5	5	5	5	5	5	5

	Monitoring							
Do you have sudden pain attacks in the area of your paresthesia?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Never	0	0	0	0	0	0	0	0
Hardly	1	1	1	1	1	1	1	1
Slightly	2	2	2	2	2	2	2	2
Moderately	3	3	3	3	3	3	3	3
Strongly	4	4	4	4	4	4	4	4
Very strongly	5	5	5	5	5	5	5	5
Is cold or heat (bath water) in this area occasionally painful?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Never	0	0	0	0	0	0	0	0
Hardly	1	1	1	1	1	1	1	1
Slightly	2	2	2	2	2	2	2	2
Moderately	3	3	3	3	3	3	3	3
Strongly	4	4	4	4	4	4	4	4
Very strongly	5	5	5	5	5	5	5	5
Do you suffer from a sensation of numbness in the area you indicated?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Never	0	0	0	0	0	0	0	0
Hardly	1	1	1	1	1	1	1	1
Slightly	2	2	2	2	2	2	2	2
Moderately	3	3	3	3	3	3	3	3
Strongly	4	4	4	4	4	4	4	4
Very strongly	5	5	5	5	5	5	5	5
Does slight pressure in this area, such as pressure with a finger, trigger pain?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Never	0	0	0	0	0	0	0	0
Hardly	1	1	1	1	1	1	1	1
Slightly	2	2	2	2	2	2	2	2
Moderately	3	3	3	3	3	3	3	3
Strongly	4	4	4	4	4	4	4	4
Very strongly	5	5	5	5	5	5	5	5

Which statement best describes your course of pain?	Monitoring							
	1	2	3	4	5	6	7	8
Persistent pain with slight fluctuations	0	0	0	0	0	0	0	0
Persistent pain with pain attacks	-1	-1	-1	-1	-1	-1	-1	-1
Pain attacks without pain between them	+1	+1	+1	+1	+1	+1	+1	+1
Pain attacks with pain between them	+1	+1	+1	+1	+1	+1	+1	+1

Is your pain/your paresthesia radiating to other regions of your body?	Monitoring							
	1	2	3	4	5	6	7	8
Yes	+2	+2	+2	+2	+2	+2	+2	+2
No	0	0	0	0	0	0	0	0

Total assessment neuropathic pain *painDetect part 2*

Monitoring							
1	2	3	4	5	6	7	8

2.9 Mood

This questionnaire is about your mood which might be affected by the disease. Your answers can help your physician to understand you better. Please answer all questions as best as you can, even if you think they are strange.

	Monitoring							
Over the last 2 weeks, have you had little interest or pleasure in doing things on more than half the days?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Yes	1	1	1	1	1	1	1	1
No	0	0	0	0	0	0	0	0
Over the last 2 weeks, have you felt down, depressed or hopeless on more than half the days?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Yes	1	1	1	1	1	1	1	1
No	0	0	0	0	0	0	0	0
Interim assessment								

Note:

→ ***If both questions are answered „No“ continue the monitoring with the Objectives questions. Page 18.***

→ ***If one or both questions are answered „Yes“ continue here!***

Over the last two weeks, how often have you been bothered by any of the following problems?

	Monitoring							
Trouble falling or staying asleep, or sleeping too much?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
Several days	1	1	1	1	1	1	1	1
More than half the days	2	2	2	2	2	2	2	2
Nearly every day	3	3	3	3	3	3	3	3
Feeling tired or having little energy?								
Not at all	0	0	0	0	0	0	0	0
Several days	1	1	1	1	1	1	1	1
More than half the days	2	2	2	2	2	2	2	2
Nearly every day	3	3	3	3	3	3	3	3
Poor appetite or overeating?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
Several days	1	1	1	1	1	1	1	1
More than half the days	2	2	2	2	2	2	2	2
Nearly every day	3	3	3	3	3	3	3	3

	Monitoring							
Feeling bad about yourself - or that you are a failure or have let yourself or your family down?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
Several days	1	1	1	1	1	1	1	1
More than half the days	2	2	2	2	2	2	2	2
Nearly every day	3	3	3	3	3	3	3	3
Trouble concentrating on things, such as reading the newspaper or watching television?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
Several days	1	1	1	1	1	1	1	1
More than half the days	2	2	2	2	2	2	2	2
Nearly every day	3	3	3	3	3	3	3	3
Moving or speaking so slowly that other people might have noticed? **Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual?**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
Several days	1	1	1	1	1	1	1	1
More than half the days	2	2	2	2	2	2	2	2
Nearly every day	3	3	3	3	3	3	3	3
Thoughts that you would be better off dead, or of hurting yourself in some way?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Not at all	0	0	0	0	0	0	0	0
Several days	1	1	1	1	1	1	1	1
More than half the days	2	2	2	2	2	2	2	2
Nearly every day	3	3	3	3	3	3	3	3

Total assessment mood *PHQ 9*

Monitoring							
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**

2.10 Objectives

	Monitoring							
When you visited your physician last time, did you agree on some smaller objectives that can contribute to your recovery? *Smaller objectives could be: how often and how intensely you exercise, which exercises you do, how much and what you eat, stopping smoking, or selecting which activities you decide to do (e.g. housework)*	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Yes	0	0	0	0	0	0	0	0
No	1	1	1	1	1	1	1	1

If no: This can be important. By formulating objectives you can actively influence your health in a positive way. Maybe you could think about some smaller objectives you want achieve in order to make major advances in your health gradually. Talk about it with your physician! Agree on objectives and check at your next date if your plans worked out all right.

What objectives did you agree on?							
Monitoring							
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**

Has it worked?	Monitoring							
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Yes								
No								

2.11 Excercise

Let me ask you some questions about your physical fitness. Regular exercise is an essential part of restoring good health!

Do you take some physical exercise regularly?	Monitoring							
	1	2	3	4	5	6	7	8
Yes								
No								

If yes, what kind of exercise?							
1	2	3	4	5	6	7	8

If yes, how long per session?	Monitoring							
	1	2	3	4	5	6	7	8
< 10 min								
10 – 30 min								
31 – 60 min								
> 60 min								
Would you like to exercise more?								
	1	2	3	4	5	6	7	8
Yes								
No								

How could I support you in that goal?

Monitoring							
1	2	3	4	5	6	7	8

2.12 Self management

This part starts with a question about the medicines your physician prescribed for you. Please answer honestly, you have nothing to fear

	Monitoring							
Have you taken your medicines as prescribed since the last interview?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Yes								
No								

If yes: That's very good!

If no: I appreciate your honesty! Does your physician know it? For your health it is important that you discuss with your physician which medicines you want to take or not. Please talk to him openly about it. It will certainly pay off!

2.13 Memory and concentration

Now I will ask you some questions where your memory is required. Some of the questions might seem very simple – please accept our apologies.

First, I will name three things. Please wait until I have said all three words; then repeat these words. Pay attention! Keep these things in mind. I will ask for them again in a few minutes.

The three things are:

Monitoring 1, 3, 5, and 7: **Apple – Table - Cent**

Monitoring 2, 4, 6, and 8: **Blue – Chair - Donkey**

	Monitoring							
Please repeat these 3 words!	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Correct	1	1	1	1	1	1	1	1
Incorrect	0	0	0	0	0	0	0	0
What year is it?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Correct	1	1	1	1	1	1	1	1
Incorrect	0	0	0	0	0	0	0	0
What month is it?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Correct	1	1	1	1	1	1	1	1
Incorrect	0	0	0	0	0	0	0	0
What day of the week is it?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
Correct	1	1	1	1	1	1	1	1
Incorrect	0	0	0	0	0	0	0	0
What are the 3 things I asked you to remember?	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**
0/3 correct	0	0	0	0	0	0	0	0
1/3 correct	1	1	1	1	1	1	1	1
2/3 correct	2	2	2	2	2	2	2	2
3/3 correct	3	3	3	3	3	3	3	3

Total assessment memory and concentration *6-Item-Screener*

Monitoring							
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**

2.14 End/finalization of the monitoring interview:

We have reached the end of the interview. Lastly, I'd like to know …

Is there anything your physician needs to know?							
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**

Scheduling the next appointment:

I'd like to schedule a date for the next interview in one month:

Our next interview takes place on …….. at ……. o'clock.

Monitoring							
1	**2**	**3**	**4**	**5**	**6**	**7**	**8**
_____ **(Date)** _____ **(Time)**	_____ **(Date)** _____ **(Time)**	_____ **(Date)** _____ **(Time)**	_____ **(Date)** _____ **(Time)**	_____ **(Date)** _____ **(Time)**	_____ **(Date)** _____ **(Time)**	_____ **(Date)** _____ **(Time)**	_____ **(Date)** _____ **(Time)**

Many thanks for your cooperation! We wish you all the best for your recovery!

Kind regards, Your Smooth study team

At the end of the monitoring, transition the patient into the training unit:

"At our last telephone interview we noticed that …. might be an important issue for you. I will give you some useful information about this now. Please tell me in case there is something you don't understand – I'm happy to explain it to you. You will also find everything we are talking about now in your manual."

3 Training modules

3.1 Impairments due to neurological or muscular disorders (polyneuropathy/myopathy)

3.1.1 Nerve damage - Polyneuropathy (summary)

- Because of the inflammation, a sepsis can lead to damage of nerves and muscles.
- Symptoms of this so-called neuropathy can be pain, muscle weakness, or unpleasant sensations like tingling.
- Physical therapy is important to maintain and improve mobility and functionality.
- Pain and impairment of mobility can always also impact the mind and social relationships. Psychological therapy can help you get back to feeling better.
- TENS-devices and alternative methods can helpfully complement basic therapy.
- Don't be afraid to request help for your everyday life (like nursing services or medical aids)

3.1.2 Nerve damage - Polyneuropathy (detailed version)

- Explain how the disease comes into existence.
  - *"Because of the inflammation that has affected the whole body, nerve pathways have been damaged. If nerves no longer work as they should, the brain receives the wrong signals like numbness, pain, or tingling. Also, as the nerves no longer move the muscles, these start to decline."*
- Ask the patient about possible symptoms of a polyneuropathy. Make the patient describe these symptoms.
- Explain the variety of possible symptoms like
  - Reduced mobility
  - Loss of strength and muscle atrophy
  - Pain attacks or persistent pain during soft touch, heat or cold exposure, or even without any noticeable external stimulus
  - Tingling or numbness
- Explain possible benefits of physical therapy/physiotherapy. Similar to ergotherapy/occupational therapy, its objectives are:
  - to ease pain
  - to re-learn inappropriate sequences of movement
  - to maintain functionality
  - to counteract muscle atrophy
- Then tell the patient that good medicines are available for treatment of neurological pain.
  - *"Most medicines need 2 – 4 weeks to take their full effect. You should discuss with your*

general practitioner which medicine is best for you. Based on your medical history and the other medicines you are taking, your general practitioner will find out which medicine works best for you.“

- *”In most cases, these medicines provide relief and help you sleep better at night and stay active during the day.”*

- Inform the patient that non-medical treatments might help, too, but that not all of them are covered by medical insurance.
- Explain that pain always affects mental health, too:
  - *”Pain perception takes place in the brain and not in the hand or the foot. That’s why two different people experience the same pain trigger completely differently.”*
  - The individual attitude to life, as well as social activities and relationships, can influence pain perception significantly.
  - For this reason, pain often gets worse if patients stay at home all the time and shut themselves away.
- Talking to the general practitioner or to a psychologist can help to...
  - detect pain intensifying behavior
  - reduce avoidance behavior and anxieties
  - learn pain coping strategies
  - inform about new approaches like hypnosis.
- For example, it might make sense to use relaxation techniques like autogenic training, progressive muscle relaxation following Jacobson’s techniques or yoga in addition to the basic therapy. However, you should check if the patient is physically able to do this. Please mention that not all these therapies are covered by medical insurance.

3.2 Chronic pain

3.2.1 Pain (summary)

- Chronic pain can have many causes. It is defined as pain that goes on for more than 3 – 6 months.
- Pain can be treated with drugs. Don't be afraid of asking your physician. Pain is recorded in the pain memory and intensifies pain. For this reason, an early and effective pain treatment is very important.
- Physical therapy and additional therapies (heat, cold, etc.) can be helpful in order to reduce pain, promoting movement patterns.
- Additionally, pain always carries emotional burdens and affects social relationships. Pain perception and processing is very different between individuals. Conversations and training can help to reduce pain promoting behavior and thought patterns.
- If it helps, give alternative methods like acupuncture or relaxation techniques a try.

3.2.2 Pain (detailed version)

- Explain to the patient that chronic pain can occur after a sepsis. Chronic pain is pain that persists for more than 3 – 6 months, but it can be treated effectively so that quality of life is not too much affected
- Pain can be recorded in the brain's pain memory and thus lead to an increase of pain. That's why effective pain treatment is very important.
- Pain has negative effects on many things – on the mood, on functionality, and even on social relationships. Tell the patient that for this reason, pain therapy needs to be multi-faceted.
- Pain is easy to treat. It is not necessary to endure pain!
- Tell the patient that lots of different analgesics are available. If the patient raises concerns, try to find out the reasons.
    - If the patient is afraid of addiction, explain that pain therapy with mild analgesics does not bear any risks of addictiveness (e.g. Ibuprofen, Diclofenac, etc). The same is true for retarded drugs that release their active agent over the day.
    - If the patient is afraid that of not having "reserves" after taking drugs even for light pain, you should point out that pain treatment over time can reduce pain in the long run (pain memory) and that more potent analgesics are at hand for severe pain. The GP can inform the patient about this.
- If the patient has concerns because of negative side effects, please encourage discussing this with the GP. In principle, many side effects can be treated, and some of them become weaker in the course of therapy.

- Tell the patient that physical methods like physiotherapy, movement therapy, massages, cold or heat therapy might be beneficial.
- As a general rule, physical activity is one of the best pain therapies.
    - If the patient doesn't want to move because of fear of pain, ask the patient to discuss with the GP which kind of physical activity would help to change relieving postures and incorrect movement patterns as these often make the pain even worse instead of easing it.
  - If possible, patients should find a physical activity they are good at and like doing. They should start moderately and slowly increase efforts bit by bit. It is important to set realistic goals without demanding too much of oneself.
  - Regularity is more important than intensity.
  - Distribute exercises over the day. 2 x 15 minutes or 3 x 10 minutes can easily be integrated into daily routine
  - Set up an individual program with a lot of variety.
- Inform the patient about relaxation techniques that might be beneficial in addition to the basic therapy (such as progressive muscle relaxation using Jacobson's techniques or autogenic training). Relaxation techniques can improve stress management and muscle tenseness – which both increase pain.
- Alternative methods like acupuncture can help as well if they are feasible for the patient (please find out in advance). Mention that not all of these methods are covered by medical insurance.
- Pain perception takes place in the brain and not in the hand or the foot. For this reason, people react completely differently to the same pain trigger! The general attitude towards life as well as social activities and relationships can influence perception of pain significantly.
- Ultimately, there is the possibility of psychotherapy
  - Psychotherapy can improve patients' understanding of their own pain perception and can help reduce concerns and anxieties.
  - Psychotherapy can identify and gradually improve behavior patterns caused by pain. (for example, avoiding social contacts or physical activities automatically reinforces pain).

3.3 Loss of weight

3.3.1 Nutrition (summary)

- In the course of a critical illness, the body uses its own reserves – resulting in loss of weight and muscular atrophy.
- It is important that you weigh yourself regularly.
- If you suffer from a lack of appetite, take your time for your meals and make them as

enjoyable as possible. Cook your favorite meals frequently.

- Try to have additional little meals and snacks every 2 – 3 hours. Always have something to eat at hand.
- High-protein food (dairy products, meat, etc.) can work against muscular atrophy. If it doesn't work, dietary supplements can be tried (such as the "astronaut's diet")

3.3.2 Nutrition (detailed version)

Tell the patient why sepsis can lead to a loss of weight and to a bad nutritional condition.

- *"Sepsis causes a lot of stress for the body which requires a lot of energy. This need of energy can no longer be covered by normal food intake. That's why the body has to use its own reserves which leads to muscle atrophy and loss of weight."*

Explain to the patient that it is very important to stop this process of losing weight and that gaining weight is important for his recovery:

- *"If your body is malnourished, you…*
  - *will be vulnerable to infections because your immune system is weak.*
  - *will feel tired and exhausted and your physical working capacity will be poor.*
  - *will suffer from bad wound healing and maybe even from bedsores because you don't have "padding."*
- *"It is important that you weigh yourself regularly and notice changes in weight. Please bring up the subject with your general practitioner if you notice changes in your weight."*
- High protein food is important for building muscles and helps improve wound healing. Particularly suitable are foods such as meat, fish, eggs, and dairy products.
- *"If you suffer from lack of appetite, these tips might be useful:*
  - *Have small but frequent meals.*
  - *Have nourishing snacks and high-protein drinks at hand between meals.*
  - *Eat your favorite dishes as often as possible.*
  - *Avoid heavy and greasy dishes if they cause digestive problems.*
  - *Take your time! Eat slowly and relax for a while after your meals.*
  - *If you feel full early in the meal, avoid juices and bouillons during the meal. You should drink after you've finished your meal."*
- Invite patients to discuss with their GPs which nutrition objectives are sensible and feasible (x kg in x weeks). It can make sense to keep a dietary record for some days.
- *"Nutrition counseling can help you in planning a balanced diet."*

In case of significant weight loss, the so-called "astronaut's diet" can be helpful. This is a high-caloric nutritional supplement, normally available in small bottles. Make sure the patient has a

weighing scale that works correctly.

3.4 Coping with deep sadness (depression)

3.4.1 Depression (summary)

- A depressive mood is common after severe illnesses. You are not alone! One in five persons suffers from long-lasting depression at least once in life.
- Sadness, lack of motivation, or sleeplessness can be symptoms of depression.
- Get active! By asking for help you have already taken the first step to face your disease. Do sports, cultivate contacts, ask family and friends for support, do whatever is good for you.
- Psychotherapy can help break up old thought patterns and develop helpful techniques. Medicines can be supportive too. They can help you to get going.
- Depression is easy to treat. It's not destiny. Play your part in fighting it!

3.4.2 Depression (detailed version)

The following section covers eight major aspects that are important for dealing with depressive patients. As always, ask patients to contact their GP if something is unclear.

- Episodes of sadness and despondency are frequent after severe diseases. However, a permanent gloomy mood, untypical cheerlessness and lack of motivation, exhaustion, listlessness, and hopelessness, as well as physical troubles like pain and sleeplessness, can be symptoms of depression.
- Sometimes patients talk about death and their wish to die. This is something the GP should absolutely know. Only he can judge how serious it is. He will decide – together with the patient – what to do about it. Often for the patient it's not that dramatic to talk about death, and many patients think about it frequently. No patient will commit suicide just because you talked about death or suicide together. In contrast, for many patients it is much more difficult to talk about their guilt or about their fear of being a burden for others. This is down to the fact that most people live in a social network of family and friends they don't want to bother.
- Depression is not destiny. It's easy to treat these days.
- Even if active cooperation is currently difficult – the patient will benefit from it in the long run. Regular communication between patient and GP is crucial for this active cooperation. They should agree upon small, easy-to-reach goals for the patient's everyday life. After all, patients know best what works for them. It is important to listen closely to the patient. The GP and patient could, for example, make a deal that the patient calls a friend or takes a walk or cooks a favorite dish once a week. Next time they meet, the GP asks if the patient managed to reach these small goals. The more goals the patient reached, the better for recovery!
- Another important point is physical activity. Of course no top performances should be

expected. The patients benefits most from manageable and regular activities. Tell the patient that you know how difficult it is to brace oneself up for this.

"It will be helpful if you make up a small plan for activities each week – not as a duty but as an encouragement".

Another important factor is encouragement by partner and family. The patient should be urged to accept help and support.

- For treating depression, a variety of drugs are available. They need to be prescribed by a physician.
  a. The patient might ask if the drugs are really necessary. Your answer is "YES, because your mind needs a period of support, and your body needs to re-adjust itself."
  b. Patients might ask you for how long they have to take the drugs. Your answer is: *"It can take longer than you think is necessary, because many drugs need some time to take full effect. The actual period of time has to be decided by your physician who knows your medical history best!"*
  c. The patient might ask you if you can recommend something that relieves feelings of depression. Your answer is: *"Your physician knows your medical history best! Please ask your GP directly what you can do."*
  d. The patient might ask you if the following symptoms are normal after taking the medication: unusual tiredness, increase of weight, dry mouth, sexual dysfunction, or mild irritations. Your answer is: *"These side effects are quite frequent at the beginning of taking medication. Normally they wear off after a while. But your physician needs to know about them to be able help you and prescribe the right medicines!"*
  e. The patient might ask whether to buy additional natural medicines in order to promote recovery. Your answer is: *"Your physician knows your medical history and your treatment best! Please ask your GP directly what you can do".*
  f. For treating depression psychotherapeutic approaches are available too. Normally they are offered by psychologists or psychiatrists and are covered by medical insurance. The GP can refer patients to psychotherapists. The most important methods start by addressing the patient's current situation. They identify possible stress factors, unproductive behaviors and the habit of brooding again and again about certain issues. The patients and their therapists together develop strategies for changing these unfavorable habits. Please encourage patients to discuss these things with their GP.

source: (last access 28.2.2011)

http://www.versorgungsleitlinien.de/patienten/pdf/NVL-Depression-Patienten-Konsultation-1.0.pdf

http://www.degam.de/leitlinien/pat_info_muede.pdf

3.5 Memory and concentration

3.5.1 Memory and concentration (summary)

- Reduced memory and ability to concentrate can appear after a sepsis.
- You are able to do something against it. Improve attention, concentration, and memory using memory training. Create memory aids in your daily routine.
- Choose only feasible tasks and don't demand too much of yourself. Get active. Go for a walk, dance, go hiking, paint – do whatever you like!
- Include your family, ask your friends for support.
- Structure your days. Hard rules and fixed activities at certain days or times can be helpful.

3.5.2 Cognition (detailed version)

The following section covers six major aspects that are important for dealing with patients who experience forgetfulness and absent-mindedness (memory and concentration). Please go about it carefully – many patients are very embarrassed!

- Many patients with memory disorders and reduced concentration ability feel at a loss. They have the feeling that they can no longer "rely on themselves." In addition, they feel embarrassed because you, the case manager, notice their difficulties and might think that they are "stupid." Therefore, don't judge anything and beware of casual comments like *"yes, of course"* or *"that's easy"* or *"anybody can do that."* A thoughtless chuckle might easily destroy hard-won trust!
- Tell the patient that these memory disorders and absent-mindedness resulting from a sepsis often vanish spontaneously after a while. Point out that the physician can explain the causes for these problems in detail. This is NOT YOUR JOB! Inform the patient that the GP will not only do physical examinations but also ask about memory.
- Ask the patient to actively train doing something simple (e.g. sudokus, riddles, music, crafting). Exercises to boost attention and concentration – brain jogging – can be helpful, too.
- Encourage the patient to make everyday life easier by introducing fixed regularities. The patient should do certain tasks always at the same time or on the same day (like phoning a friend each Wednesday afternoon at 3 pm). Point out that fixed structures will help. Tell the patient to *"put everyday objects (like keys) always in the same place. Check more than once if you switched off the stove."*
- Encourage the patient again and again to meet people. "Listening and answering" is a good exercise and helps a lot. Babysitting is one of the best exercises.
- Reassure the patient that asking for help does not show any weakness. Patients should neither ask too much of themselves nor let problems get them down. Recovery is a question of patience. It takes some time.

Sources: (last access 28.Feb 2011)

- Hopkins et al. Crit Care Med; 2011 (in press)
- http://www.versorgungsleitlinien.de/patienten/demenzinfo
- http://leitlinien.degam.de/uploads/media/Patinfo_Demenz_002.pdf

3.6 Coping with bad memories, fright and fears

3.6.1 Posttraumatic stress disorder – memories you can't shake off (summary)

- Being treated in the ICU can entail unpleasant memories and feelings like fear of dying, frights, and helplessness.
- Insist on your individual way of coping with your experiences. Some people want to block out memories, others want to think about everything. Whatever option you choose, it is important that you stay in real life, and live in the here and now. Bring to your mind that you are no longer in danger.
- Look for activities that have a soothing effect and do you good – depending on what is the most appropriate approach for you.
- If sleep disorders and fear get too bad, psychotherapy might help you to come to terms with your experiences.
- In individual cases, drugs can help ease your troubles.

3.6.2 PTSD (detailed version)

The following section covers seven important aspects for dealing with patients who suffer from bad memories, fright, or fears.

- If the patient talks about fears, helplessness, fright, depression or everyday troubles, please explain that:

  "Many people who were treated in the ICU often experience such feelings and memories afterwards. I can understand your troubles. You are not alone in these feelings. In most people, these feelings settle down after a while. This condition will most certainly change over the next few weeks.
- Many people have very bad memories of mechanical ventilation and suction. The noise level in the ICU and the beeping of monitors that display your heartbeat can be quite worrying, too:

  "These experiences and memories are very frightening and depressing. But please keep in mind that these measures have kept you alive. That time is over now. You don't need to be afraid any longer. It's nothing more than memories. It is no longer real; it's over."
- Coping strategies for unpleasant experiences differ significantly. Different people have their own ways of coming to terms with it: blocking out, brooding or talking to other people. Never force the patient into a certain coping strategy. Only the patient knows what is best in this situation:

  "Time and quiet are necessary to come to terms with these experiences and to be able to carry on. Reliable and confiding relationships help a lot: talking to your partner, to your grown-up children, to your friends, and to your GP will help you. "

- Explain to the patient that experiences might come back as persisting memories or nightmares – even at daytime. Sometimes memory gaps occur so that patients cannot remember traumatic experiences:
  "Sometimes these memories come back to you as nightmares or frights – even at daytime. Some will be very detailed, others rather fragmented. With these repetitions, your mind tries to learn how to 'live with the experience', or 'get over it.' These bad dreams will disappear eventually. Every patient needs his own period of time for it."
- Invite the patient to ask the GP or relatives who visited the ICU to share their experiences of what happened in the ICU:
  "Perhaps your relatives visited you. Ask them about their impressions – What did the ward look like? What happened there? Your GP can explain what kind of treatment you received in the ICU. More information will help you reduce your fear."
- There are different therapeutic methods for supporting patients to cope with bad experiences.
  "Many patients who saw a psychotherapist in your situation were able to cope better with their problems. Please discuss with your GP if this could be an option for you".
- Treatment with drugs might also be an option. However, this has to be decided by the GP.
  "For many patients in your situation, treatment with drugs was helpful. Please discuss with your GP if this could be an option for you."

Source (last access 28.2.2011)
http://www.awmf.org/uploads/tx_szleitlinien/051-010p_S3_Posttraumatische_Belastungsstoerung_Patientenversion.pdf

3.7 Coping with the disease

Tell the patient that disease management is very individual. Personal history and experiences play a major role in how to cope with a crisis.

"Coping with a disease is a prolonged process. It doesn't happen in a consistent manner but in a series of ups and downs, with progress and setbacks, for example if additional complications occur."

Encourage the patient to ask family and friends for support -- talking can help a lot!

"It might happen that you have feelings that result in mood swings. Many of these feelings are absolutely appropriate and are 'correct' and normal while you are trying to cope with a disease."

Explain that the attempt to come to terms with the disease can vary from day to day. Sometimes

patients are gathering information and want to share experiences with friends and family members, and on other days patients don't want to think about the disease at all and prefer to "bury their heads in the sand." Both approaches are correct and sensible in different phases of the disease.

"Thoughts about your disease should not govern your life. Distraction can be very helpful, too. You shouldn't brood about your troubles or worry about your health all day."

"These strategies might be helpful:

- *Concentrate on yourself and keep your mind on your own needs.*
- *Take yourself and your needs seriously.*
- *Try to find out what kind of support you need and accept help!*
- *Accept your feelings – even if they are strong. They will pass by!*
- *Try to find out what is important in your life and what are your resources!"*

Source (Last access: 28.02.2011)
www.krebsinformationsdienst.de

3.8 Closing

3.8.1 Ending the conversation

"You are very welcome to look up everything we talked about in the patient manual. Please use it as a source of information."

Before ending the conversation, ask patients if you are done or if they want you to pass on any additional information to the GP:
"Before we end our conversation/call I'd like to ask a final question: Is there anything your GP should know?"

- After the interview, please schedule a date for the next monitoring telephone-interview with the patient. The phone-interview should take place around 4 weeks after the first training course. Schedule a new date, including a time, at the end of each monitoring interview for the next one. Please make sure to follow the planned monthly intervals.
- If possible, choose **Monday, Tuesday or Wednesday** for phoning the patient. Don't fix dates on Thursday or Friday, because due to the weekend, you might have problems in finding new dates if the patient needs to reschedule.
- Try to schedule phone appointments at times when a liaison physician is on call or on the premises.

Please write down the date of the next appointment at the bottom of the questionnaire (scheduling the next appointment).

Summarize all arrangements (dates, recall, etc.) and ask patients if they need details of the appointment or of other arrangements in writing. If yes, send the patient a note. Remind patients to weigh themselves on the day of the next monitoring because you will ask about their current weight.

Thank patients for their cooperation and say goodbye in a friendly manner.

Example: *"Mr. Bestmann, we are almost done now. Many thanks for your great cooperation. Do you have any more questions?"*
"We will call you again in one month in order to assess your state of health again!"
"Many thanks! We wish you all the best! You can call your general practitioner anytime if something doesn't work well. We will talk again on … DATE …. Goodbye!"

Tip: A positive, appreciatory end of the phone call motivates the patient for future interviews and training and makes your work easier!

XX. On-line Only Supplemental Material

Effect of a primary care management intervention on mental-health-related quality of life among survivors of sepsis: a randomized clinical trial

Sepsis PCP Manual

Sepsis survivors Monitoring and cOordination in OutpatienT Health care

Smooth
Sicher leben nach Sepsis.

Center for Sepsis Control & Care

Institute of General Practice and Family Medicine
Friedrich Schiller University

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Sepsis: ”Red Flags“ in family practice

- Fever **or** hypothermia
- Hypotonia
- Tachycardia
- Shivering
- Cardiac murmur
- Acute deteriorating conditon
- Circulatory centralization
- Disturbance of consciousness
- Petechiae and hematoma

Laboratory:

- Leukocytosis
- Neutropenia
- Thrombocytopenia
- Increase of CRP/PCT/sed rate

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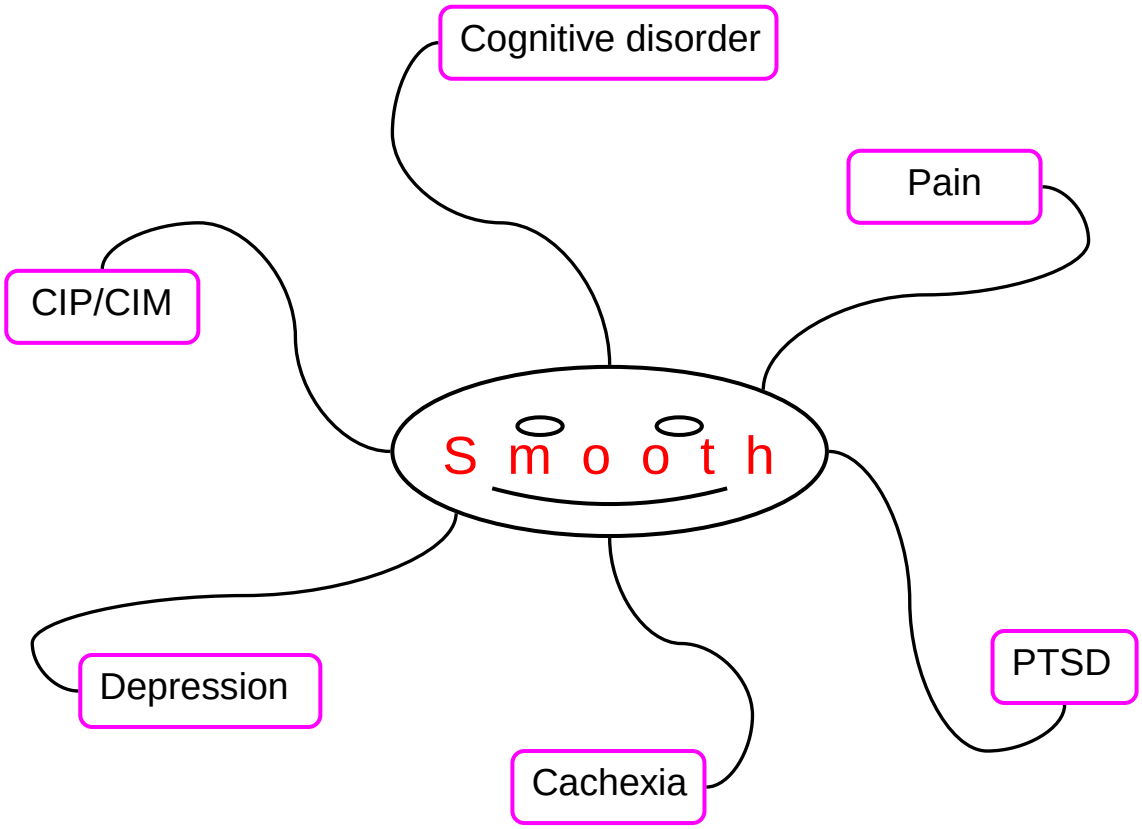
Doc's Sepsis Six



1. Introduction

Dear Colleague,

Many thanks for participating in the SMOOTH study, for your support, and your cooperation with the Institute of General Practice at Jena University Hospital. SMOOTH (Sepsis survivors Monitoring and cOordination of OutpatienT Healthcare) represents a concept of structured long-term care for patients after sepsis. This includes three primary elements: management of hospital discharge, training for doctors and patients, and monitoring.

This Manual for General Practitioners aims to give you the best possible help for supporting your post-sepsis patient. You will get an overview of frequent sepsis complications, their symptoms, and guideline-based treatment. The manual consists of two main parts:

In the first part, you will get a brief overview of the long-term complications of sepsis and their treatment. We cover six main topics here, called the “Sepsis Six.” For each main topic, we identify five issues of particular relevance. This process was coordinated with renowned experts. We summarize these key issues separately for you in order to provide a useful tool for your everyday practice. The tool is enclosed as a pocket card.

In the second part you will find additional information and literature references about all other sepsis complications.

The contents of this Manual for General Practitioners are based on the latest scientific publications and on current guidelines.

Guidelines of the different professional societies can be found on the CD-ROM enclosed.

We are looking forward to a lively exchange and good cooperation!

Your Smooth study team

1.1 The SMOOTH study

Only a few experts know that sepsis is the third most common cause of death in Germany (1). Long-term consequences of the disease, like polyneuropathy or chronic pain, are often overlooked as well. With SMOOTH, the Institute of General Practice at Jena University Hospital is running the world's first interventional study on structured aftercare of sepsis patients.

SMOOTH aims at studying the effects of a post-hospital aftercare program for sepsis patients focusing on general practitioner care. This program includes coordinated management of hospital discharge, morbidity-specific training for patients and general practitioners, and continuous patient monitoring. We hope that, in time, this will help identify and treat sepsis sequelae.

We will record the effects of this intervention using specifically designed questionnaires at 6, 12, and 24 months after discharge from ICU. Our primary intervention objective is to achieve an improvement in health-related quality of life for these patients after 6 months.

You can find a detailed description of the study in the study protocol that you received.

1.2 Monitoring

Monitoring involves interviewing patients on the phone on a regular basis. As a part of the intervention, the monitoring takes place over 12 months. Immediately after the patient's discharge from the hospital or rehab center into general practitioner care, we conduct a "basic interview" in order to get early hints of possible sepsis complications. After that, monitoring proceeds once a month during the first six months and every three months during the second six months.

We base the monitoring on validated assessment tools (such as the PHQ-9 questionnaire for depression) that can provide early indications of sepsis complications. In addition, it includes questions about the patient's self-management like "Have you taken your medicines as prescribed since the last interview?"

We will inform you about the outcomes of the monitoring by fax and/or telephone. A "traffic lights" scheme shows the necessary course of actions resulting from the assessment. Green means "nothing unusual", yellow means "suspicious signs – control needed," and red means "immediate treatment indicated."

1.3 Case Management (2)

Case management means "a situation-related and continuous offer of support for patients in order to prevent a deterioration of the disease" (3). This concept was developed for individualized care in social welfare at the beginning of the last century, such as for at-risk teens (4). In medical care, case management has been provided for psychiatric patients since the 1960s – especially for patients with schizophrenia (5). Currently case management is given in outpatient long-term care, as for geriatric patients (6), or in integrated care, as in coordinated hospital discharge (7).

There are five elements that are crucial for case management (8):

- Identification: active recording and selection of patients in need
- Assessment: regular, comprehensive assessment of individual patient needs
- Planning: therapeutic goals set up together with the patient
- Coordination: interdisciplinary implementation of treatment
- Monitoring: continuous monitoring of outcomes and timely initiation of indicated actions

Within the SMOOTH study, two people coordinate case management: the case manager and the liaison physician who will "manage" the patient's long-term care together with the general practitioner's practice.

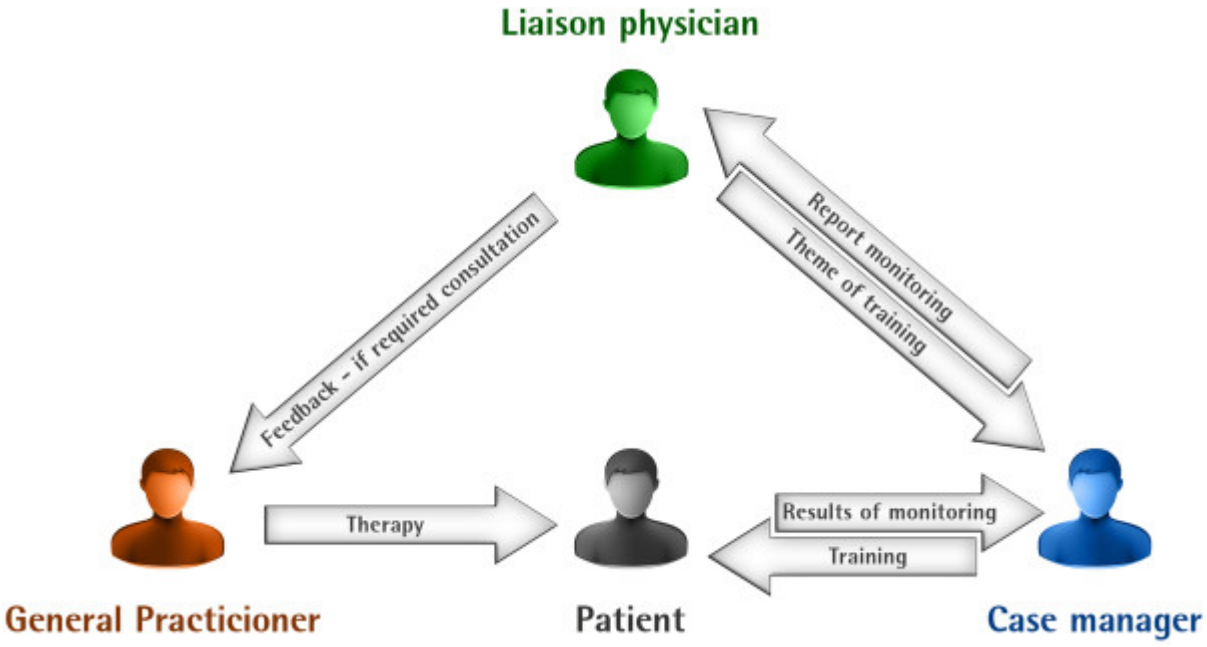
Study nurses who are involved in the study and have professional training as a nurse or physician's assistant are called *case managers*. They have many years of experience in patient care, sometimes even in intensive care, and maintain close contact and communication with the patient. They perform the patient training, as well as the monitoring, which is followed by problem-specific additional training. As far as possible, each patient gets only one case manager who will provide training and monitoring for the whole duration of the study.

The Sepsis Six are the focus of the patient training. In addition, the training teaches self-management and practical everyday techniques. We include a copy of the patient manual in this file in order to give you, the general practitioner, an overview of its contents.

All physicians involved in the study are at your disposal as liaison physicians. They work hand-in-hand with the case managers. The liaison physician informs the general practitioners about monitoring results, keeping them updated on trainings and providing advice and support to the general practitioners concerning treatment of the post-sepsis patient. To provide this support, the

liaison physician can ask the experts at Jena University Hospital for information.

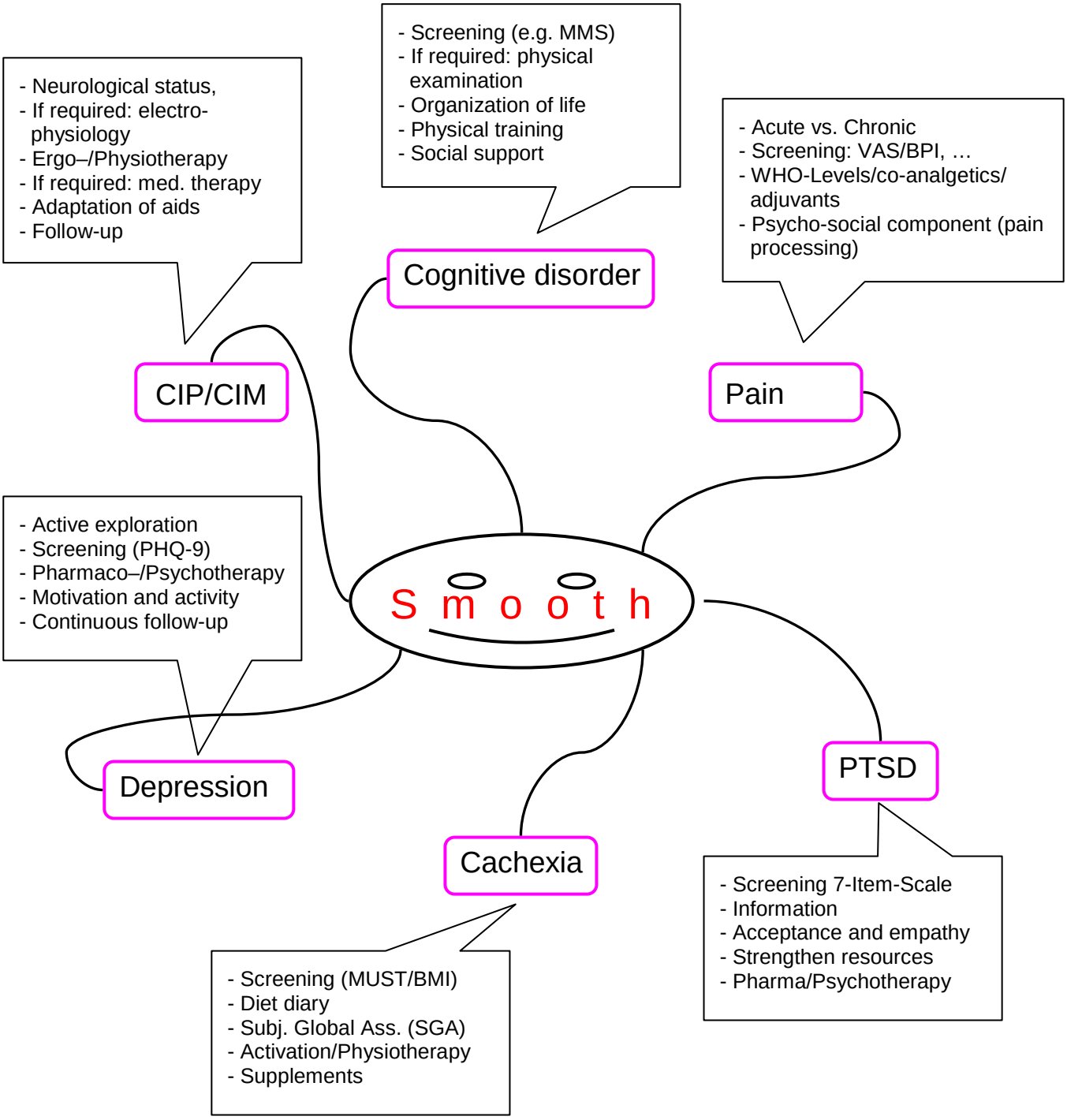
The following illustration shows the relationships and cooperation between everyone involved in the intervention: general practitioner, patient, liaison physician, and case manager.



The SMOOTH study implements the five classic case management elements as follows:

- Identification: Identification of patients with ”severe sepsis/septic shock“ while they are still on ICU
- Monitoring and assessment: Screening tools regularly assess the patient’s needs and monitor the course of diseases and complications
- Planning and coordination: The liaison physician provides feedback from the results of monitoring to the general practitioner. If necessary, based on recommendations and interdisciplinary consultations, the general practitioner and patient together plan therapeutic goals with due regard to the specific recommendations and results of the monitoring.

Doc's Sepsis Six – at a glance



2 Doc's Sepsis Six – the essentials in brief

2.1 Cachexia

- In their acute phase, certain severe diseases, including sepsis, lead to clinically relevant increases (ca. 40%-80%) in the resting metabolic rate.
- Due to a persisting catabolic metabolism, further weight loss can occur during ambulant follow-up treatment.
- Checking the patient's nutritional condition is strongly recommended. For this, tools like the "Malnutrition Universal Screening Tool" (MUST) and the "Subjective Global Assessment" (SGA) are available. The body mass index can give the first hints that nutrition is poor, but it is often insufficient.
- Elements of dietetic treatment include: nutrition counseling, keeping a weight and diet protocol, strengthening the musculoskeletal system by pursuits such as physical activity, sports, or physiotherapy and
- if necessary – supporting treatment with the use of supplements, such as high-caloric drinks.

2.2 Critical Illness Polyneuropathy – and myopathy

- Polyneuropathy is a critical illness that often occurs as a complication after sepsis. It is verified in 60 – 70% of patients with severe sepsis. Polyneuropathy is diagnosed electro-physiologically (EMG).
- Polyneuropathy appears in the context of multi-organ failure during intensive care therapy. Due to a septic inflammation reaction, an axonal degeneration of mainly motoric nerve fibers with consecutive muscle atrophy takes place.
- Muscle weakness and atrophy are the main symptoms; sensibility disorders and neuropathic pain also appear.
- For further ambulatory treatment, assessing the course of the disease by considering the patient's neurological status is recommended. A specialist should perform an electro-physiological examination and, if necessary, initiate treatment with drugs.
- Intensive ergo– and physiotherapy is the primary therapeutic approach. Apply adjuvant medical aids when necessary according to the degree of severity.

2.3 Pain

- Pathophysiologically, chronic pain distinguishes between nociceptively induced pain and neuropathic pain. If nociceptive as well as neuropathic pain is present, this is called ”mixed pain.“
- Apart from a thorough anamnesis and physical examination, numeric rating scales (NRS) are excellent diagnostic tools, proven in everyday practice. For detailed assessment, the Graded Chronic Pain Scale (GCPS) helps assess chronic pain, while painDetect measures neuropathic pain.
- The WHO pain treatment ladder provides an orientation for medical treatment of nociceptive chronic pain. For neuropathic pain, consider so-called co-analgesics (anticonvulsives, such as Gabapentin, Pregabalin, Carbamazepin; and antidepressants like Amitryptilin). “Mixed pain” requires an early combination therapy of antiepileptics, antidepressants, NSAIDs and opioids.
- When treating pain it is important to consider the psycho-social component of pain. Take into account the patient’s everyday life and social environment. Pain is centrally processed and is subject to multiple cognitive modulations.
- Adjuvant therapies like acupuncture, TENS, physical methods, and psychological support help effectively for nearly all sorts of pain.

2.4 Cognitive disorder

- Ongoing neuro-cognitive disorders can occur due to septic encephalopathy arising from, for example, a hypotonia-caused cerebral underperfusion.
- Elements of dementia diagnostics like Mini-mental State help in diagnosis. Septic encephalopathy is a diagnosis of exclusion. Consider detailed organic diagnosis (Imaging: CAT; Laboratory: hemogram, glucose, TSH, B12, electrolytes, creatinine, folic acid, liver function reading) if not already performed in hospital.
- After severe courses of sepsis, expect persistent cognitive impairment in the form of attention, concentration, and memory deficits.
- Currently, there are no medicinal therapies for septic encephalopathy.
- Primary therapy approaches consist of non-medical treatments like attention and concentration training, physio– and ergotherapy, and exercises relating to practical management of life and involvement of the patient’s psycho-social environment.

2.5 Posttraumatic stress disorder (PTSD)

- Many studies have shown a direct connection between intensive care therapy and symptoms of a resulting PTSD. This is caused by massive exposure to stress, due to both the disease itself and the intensive care interventions (repeated intubation, weaning, loss of communication and of autonomy, noise level, and circadian dysrhythmia). The main symptoms can be divided into four categories: hyper-arousal (sleeplessness and jumpiness), intrusion (nightmares and musing behavioral loops), trauma-related avoidance, and a negative attitude towards oneself and the world in general.
- The most important diagnostic tool in PTSD is talking to the patient. Only listening, empathy, trust building, and offering security can make patients talk to you about their traumatization. If this dialogue indicates that a PTSD is present, standardized tools like the 7-Item-Scale can provide diagnostic verification.
- If a PTSD is present, it is important that the patient feels safe and comfortable in the physician-patient relationship. Inform the patient about the cause and symptoms of this disease and its association with the traumatization the patient experienced (psycho-education). In repeated resource-oriented dialogues, ask patients about their strengths, convictions and strategies for coping with fear of death and with the memories of traumatic experiences. Encourage patients to use their resources and to accept help.

  Spontaneous remission in patients who survived a severe illness is significantly higher than in victims of direct violence.

  In the first six months, an open and unbiased “wait-and-see” approach is possible. The first choice for therapy is psychotherapeutic or psychiatric treatment.

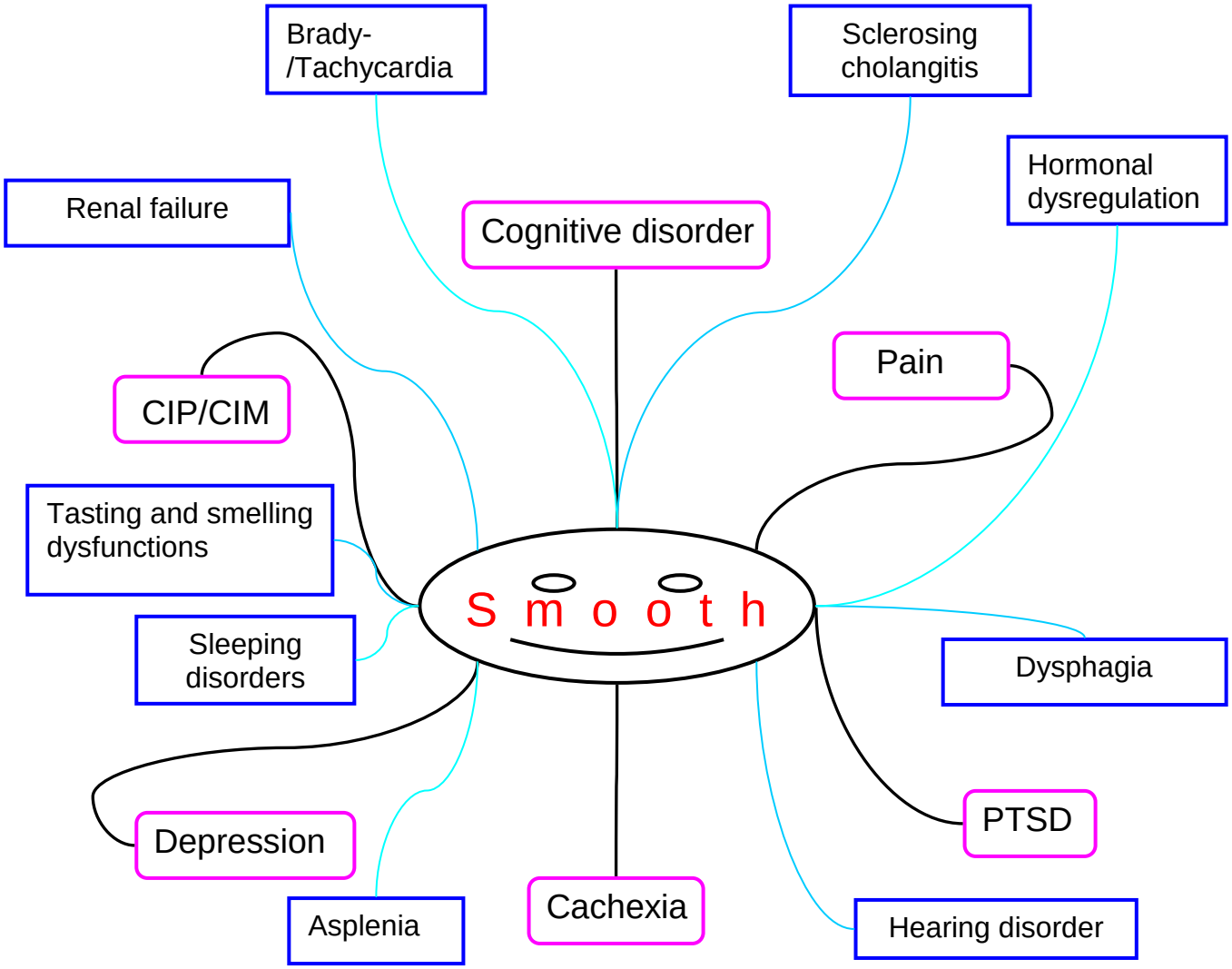
  Depending on the degree of severity of PTSD symptoms, consider an adjuvant medical therapy. For treating PTSD, selective serotonin re-uptake inhibitors are especially recommended (SRI: such as Paroxetin, Sertralin, Fluoxetin). These drugs reduce fear and psycho-motoric restlessness (hyper-arousal), memories and nightmares (intrusions), and trauma-related avoidance. Retarded-release Venlafaxin is an alternative drug. Temporary use of benzodiazepine is possible, but should be controlled and limited.
- Patients without a stable and supporting social environment have a poor prognosis. Address this! Offer help for organizing support and arrange psychotherapeutic or trauma-centered co-treatment.

2.6 Depression

- Depressive symptoms after intensive care treatment are frequent and affect the patient’s quality of life considerably. They often manifest as diffuse somatic troubles.

- In cases of frequent suppression and shame, it is necessary to actively explore the depressive symptoms. The health questionnaire for patients (PHQ-D) has proven successful as a diagnostic tool in general practice. Asking about thoughts of suicide is obligatory in depressive patients. In case of acute suicidality and inability of the patient to make and stick to an agreement, consider immediate referral to a psychiatric ward.
- Psycho-/pharmacotherapy: For mild to moderate symptoms psychotherapeutic treatment is indicated. If a “bridging” is needed, this can be done by cognition-oriented one-on-one conversations in the framework of psychosomatic primary care. Moderately severe to severe depressive disorders should be treated with an adjuvant pharmacotherapy. In addition to primary care by the Family Physician, application of selective serotonin re-uptake inhibitors (SRI) and tricyclic anti-depressants (TCA) is recommended here.
- Sports and physical activity can contribute considerably to therapy success. For this reason, repeatedly encourage depressive patients to try some sort of exercise. It can be very helpful to give them an activity-log (to record, for example, the number and duration of walks) that includes agreements on certain objectives. In the next appointment, directly address and comment on objectives relating to practical everyday living, like household chores or shopping, in order to develop strategies or look for possible improvement.
- The course of the depression should be controlled continuously. See your patient frequently in the first weeks (at least once a week). If there is no success at all after several weeks (3-4) or symptoms get even worse, reconsider the choice of therapeutic approach and/or prescribed medication.

Doc's *Sepsis all* – Rare complications



3 Doc's Sepsis all – rare complications

In addition to the six main complications after sepsis, there are less frequent sequelae as well which you should keep in mind when treating post-sepsis patients.

3.1 Secondary sclerosing cholangitis

- After intensive care therapy, an increase in sclerosing cholangitis can appear. This is probably due to an initial ischemic damage of the biliary system. By destruction of intra-hepatic bile ducts with strictures and fibrotization, biliary cirrhosis develops over time.
- Unfortunately, therapeutic possibilities are currently limited (73).
- Relevant interventions for primary care include controlling cholestasis parameters (AP, gamma GT, bilirubin) regularly.

3.2 Chronic renal insufficiency

- In 23% of patients with a severe sepsis, an acute renal insufficiency occurs while they are on ICU. In most cases this sudden, and in principle reversible, deterioration of glomerular-tubular function is probably due to hemodynamic-ischemic and/or septic/toxic reasons.
- A single dialysis treatment during intensive care treatment is enough to elevate the risk of a chronic renal insufficiency.
- Relevant interventions for primary care are: control of retention parameters, checking medications for possible nephrotoxicity, and urging the patient to drink enough.

3.3 Tasting, swallowing, smelling, and hearing dysfunction

- There is not yet any proven evidence for these symptoms in relation to sepsis. Etiology is also unclear with multifactorial origin a possibility.
- Practicable diagnostic tests in primary care include so-called "taste-strips" and "sniffing sticks," a swallowing test with 1 teaspoon of water, and the "whisper-test" from a distance of 4 m. Consider further diagnostics with interdisciplinary specialists (ENT, neurology, radiology). Referral to a specialist center (such as for dysphagy) might be helpful, too.
- Explore the increasing ambulatory treatment possibilities (such as logopedical swallowing therapy).

3.4 Asplenia, heart rate variability (HRV), hormonal situation, and sleep disorder

- Around 10,000 people die of pneumococcal infection each year in Germany, more than 8,000 patients are splenectomized, and one in 1,000 German citizens doesn't have a

functioning spleen (9). The most frequent pathogens in post-asplenic sepsis are pneumococci. Less frequent are haemophilus influenzae and meningococci. Check the vaccination status of these patients carefully.

- Heart rate is regulated by the autonomic nervous system. Several scientific publications point to reduced heart rate variability after sepsis (10) (11). This might result from direct damage to the autonomic nervous system in the context of the septic inflammatory reaction. Even if you find no clinical abnormality, check heart rate variability for possible bradycardia or tachycardia with a 24-h-ECG in ambulatory care.
- During a critical illness, changes of the hormonal situation occur in the context of a so-called neuroendocrine stress syndrome (12). It is crucial to consider critical-illness-associated adrenal insufficiency and blood sugar volatility in follow-up treatment of sepsis patients. At least at intervals, assess fasting blood sugar in ambulatory care.
- Occurrence of sleep disorders in ICU patients has been known for 30 years. (12). Reasons for this include: the ICU itself, with its high noise level; light and sleep interruptions because of treatment; the acute illness of the patient; medication; and mechanical ventilation (13) (14). Sleep disorders can have multifactorial consequences and results, such as increased catabolism, dysfunctional cellular or hormonal immunity, respiratory dysfunction, or sympathetic activation (15). Long-term effects have barely been examined, however, disturbed or insufficient sleep is a frequent problem for patients who have survived a critical illness (16).

4 Background

With its 60,000 deaths per year, sepsis is the third most common cause of death in Germany. An additional 85,000 patients per year survive severe sepsis or septic shock (1). Long-term courses and sequelae have not been studied sufficiently. Yet 20 – 30% of sepsis survivors receive treatment in rehab centers that barely meet appropriate standards (1). After discharge, the major part of these patients is treated in general practices, where sequelae of sepsis are not widely known, and so they do not receive the attention they need. The following text provides a short overview of possible long-term sepsis complications:

We must emphasize Critical Illness Polyneuropathy (CIP) or Critical Illness Myopathy (CIM) here. Both have been known for more than two decades already (17). More than 70% of patients experiencing septic shock and 60% of patients experiencing severe sepsis show significant electrophysiological changes after three days (18). In the course of the disease, many of these patients suffer from severe functional impairment of health-related quality of life (19). Due to delirium caused by intensive care therapy and functional impairment while being in hospital, many patients experience extreme stress. The median point prevalence for posttraumatic stress disorder is 22% for patients who survived a critical disease requiring intensive care treatment (20). Relatives frequently show similar burden-induced symptoms. A recent review indicates a median point prevalence of 28% for significantly depressive symptoms after ICU therapy (21). Recently, ongoing neurocognitive impairments are of increasing interest too. A new prospective cohort study observed a significant occurrence of neurocognitive impairments after severe sepsis which might be caused by low cerebral perfusion (22). The authors assume 20,000 new sepsis-caused cases in the U.S., with all the entailing dramatic consequences for patients, relatives, and the health system.

Another sequela of sepsis is rapid weight loss. Studies with patients suffering from chronic heart failure and tumor diseases show a clear association between cachexia and increased mortality (23) (24). Chronic pain is another long-term sequela of severe sepsis (25). Two years after surviving a severe sepsis, patients report a significantly higher pain-associated reduction in quality of life than the general population.

In summary, most patients who survived sepsis in Germany will suffer many years of significant functional impairment – physically, socially and emotionally – accompanied by severe neurocognitive and mental impairment. Several studies have shown that the global parameter ”health-related quality of life;” a multi-dimensional construction of physical, mental, social, and behavioral components of well-being and functionality; was significantly reduced in sepsis survivors (26). For this reason, we chose it as the primary endpoint in this study.

So far, the literature has rarely described specific after-care treatment programs for sepsis associated diseases. Hacking et al. achieved a significant improvement of function by means of intensified rehabilitation in patients with sepsis-caused amputations (27). Thus the authors made a case for early sepsis-specific aftercare in order to minimize sequelae. Jones et al. observed a significant improvement in function-depending quality of life (SF-36) and a tendency toward reduced depression merely by providing a self-help manual to 126 critical illness patients.(28). Based on their cohort study, Iwashyna et al. explicitly argued in favor of intervention programs in sepsis rehabilitation (22).

The SMOOTH study wants to investigate effects of a post-hospital aftercare program for sepsis patients focusing on general practice care. This includes coordinated discharge-management, intensive training of patients and general practitioners, as well as close follow-up monitoring. Case managers who train and monitor the patient (in this case provided by staff from the study center) support the FAMILY PHYSICIAN and reduce the primary care workload (29). As individual motivation has proven to be the crucial predictor for health-related quality of life of discharged ICU patients, the study places special focus on the patient's self-management (30).

In summary, this study aims to improve our understanding of long-lasting neurocognitive, motoric-functional, and psycho-social impairments of this patient group; to show possible preventive and therapeutic approaches (30); and to implement these into general practitioner care.

5 Definition and diagnosis of sepsis

Severe sepsis, septic shock, and consecutive multi-organ failure are life-threatening complications of systemic infections and represent the most frequent cause of death for patients in non-cardiologic ICUs, with an incidence of around 116 per 100,000 inhabitants (31).

Sepsis is a complex systemic inflammatory host reaction to an infection. Sepsis, severe sepsis, and septic shock represent a disease continuum that is defined by a combination of vital parameters, laboratory findings, hemodynamic data, and organ function. Depending on antibiotic pre-treatment, bacteremia occurs in only 30% of patients with severe sepsis or septic shock. For diagnosing sepsis, apply the following criteria (32):

I. Evidence of an infectious source of inflammation

(at least one of the following criteria):

- infection is microbiologically confirmed
- infection is clinically confirmed
- infection is suspected

II. Evidence of systemic inflammatory response syndrome (SIRS)

(at least two of the following criteria):

- hypothermia (<36°C / 96.8 °F) or hyperthermia (>38°C / 100.4 °F)
- tachycardia (>90/min)
- tachypnea (>20/min), and/or arterial PaCO2 <4.3 kPa (33 mm Hg), and/or mechanical respiration
- leukocytosis >12,000/µl or leucopenia <4,000/µl, and/or left shift >10% in differential blood count

III. Infection-related organ dysfunction

(at least one of the following criteria):

- acute encephalopathy (reduced alertness, restlessness, disorientation, delirium not influenced by psychotropics)
- thrombocytopenia (platelets <100,000/µl or a drop in platelet count >30% in 24h not caused by blood loss)
- arterial hypoxemia (paO2 <10kPa (75 mmHg) in room air, paO2/FiO2 <33kPa (250 mmHg) not caused by evident pulmonary or cardial disease
- arterial hypotension (systolic arterial blood pressure <90mmHg or mean arterial pressure <70mmHg for at least 1h despite adequate blood volume supply; absence of other reasons for hypotension)

- renal dysfunction (urine excretion <0.5 ml/kg/h for at least 1h despite adequate volume substitution and/or serum creatinine increase >2 times above the local lab's reference range)
- metabolic acidosis (base deficit >5.0mEq/l or plasma lactate concentration >1.5 times above the local lab's reference range)

Septic shock is diagnosed when all of the following three criteria are met:

I. Evidence of an infectious source of inflammation (see above)
II. Evidence of systemic inflammatory response syndrome (SIRS)
III. Evidence of arterial hypotension despite adequate volume therapy:

- Either systolic blood pressure <90mmHg or mean arterial pressure <70mmHg for at least 2h. Use vasopressors if necessary (dopamine >5µg/kg/min, or norepinephrine, epinephrine, phenylephrine or vasopressin at any dose) in order to stabilize the systolic blood pressure to >90mmHg or the mean arterial pressure to >70mmHg

Measuring procalcitonine (PCT) for early verification of diagnosis is recommended. Drawing blood cultures allows for successful pathogen identification and should be done even before giving antibiotics.

6 Frequent complications of sepsis

6.1 Cachexia

Nutritional status is the basis of health and an expression of it. Nutritional condition reflects the balance of diet (the amount and type of food or nutrients consumed) and personal requirements of nutrients and energy. Energy deficits evolve if the uptake of energy persistently falls below the required level. (33)

1. The subordinate term malnutrition involves all clinically relevant nutrition deficits, hence deficiency states. This must be differentiated from under-nutrition (meaning only reduced energy stores)

a) Disease associated decrease of weight: Decrease of weight in correlation with pathological activities - involuntary decrease of weight >10%/6 months
b) Protein deficiency: Decrease of endogenous protein stock →Serum albumin, protein electrophoresis, total protein content in 24h urine
c) Specific nutrition deficiency: deficit of essential nutrients (vitamins, minerals, essential fatty acids) → bone density, vitamin level

According to the German Association for Nutritional Medicine's (Deutsche Gesellschaft für Ernährungsmedizin) guideline for enteral nutrition, the quiescent energy requirement of a healthy human between 30 and 70 years of age is about 22.5 kcal/kg/day and 0 – 7% above that value for an ill person.
A prevalence study detected malnutrition in 24.2% of patients on internist acute wards (34).
Certain diseases, including sepsis, lead to clinically relevant increases (ca. 40 – 80%) of the quiescent energy requirement (35). These values vary and depend on the degree of severity of the disease. For this reason, nutrition therapy is already significantly important during intensive care.
It can also be assumed that, in the long-term course of patients after sepsis, weight might decrease due to a possible persistent catabolic metabolism. Therefore regular assessment of the nutritional condition of these patients is necessary.

6.1.1 Monitoring nutritional condition

As a screening instrument established in ambulatory treatment, we provide the MUST (Malnutrition Universal Screening Tool, see appendix) (36) (37) for case management (in the German version by Tatjana Schütz (Charité Berlin)).

This procedure considers the BMI, unplanned loss of weight, and abrosia due to acute diseases.

If the sum equals 1, the risk of malnutrition is average. Even in this case, nutrition counseling should be considered. If necessary you can assess the nutritional condition in a differentiated way (including the involvement of muscle mass) based on the Subjective Global Assessment (36) (38).

6.1.2 Therapy of malnutrition

If there are indications of malnutrition, supportive dietetic treatment is recommended.

This may involve nutrition counseling, use of high caloric supplements, and tube feeding.

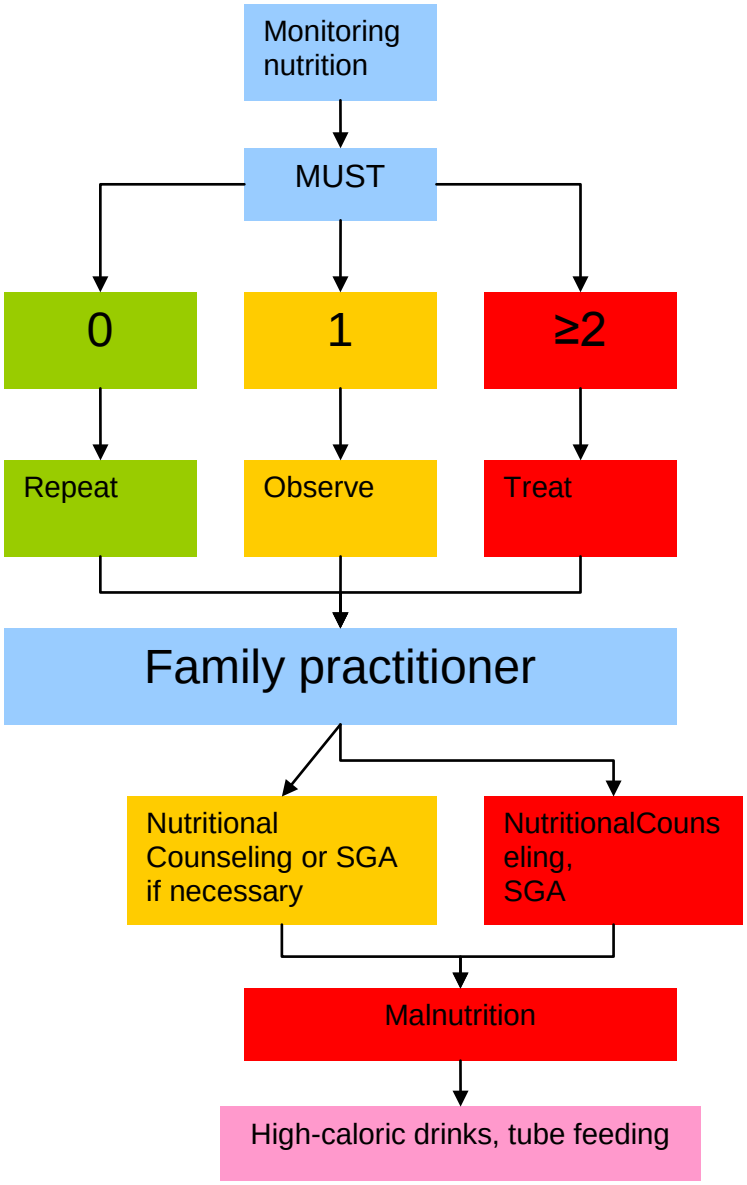
As long as oral nutrition is possible, seek a combination of normal diet and supplements. Qualified nutrition counseling is part of every dietetic treatment.

The patient should complete a nutrition log which could help reveal possible deficits in the diet.

Patients suffering from manifested or imminent malnutrition should be nourished directly via tube or high-caloric drinks in order to maintain or improve their nutritional condition.

6.1.3 Traffic lights scheme: nutrition module

0 points	Screening negative. Repeat! No indication of cachexia. Wait for the next screening
1 point	Screening uncertain. Observe! If necessary: perform additional Subjective Global Assessment; provide nutrition advice.
≥2 points	Screening positive. Give therapy! Perform Subjective Global Assessment; provide nutrition advice, physical activation, and supplements; consider in-patient therapy.



6.2 Critical Illness Polyneuropathy and Myopathy

The functional impairments critical illness polyneuropathy (CIP) and myopathy (CIM) have been recognized for more than two decades (17). Neuronal injury due to septic inflammatory reaction can cause these impairments. For this reason, CIP is considered a multi-organ failure caused by sepsis.

More than 70% of patients show indications of significant electrophysiological diversifications only three days after a septic shock, as do about 60% of patients after severe sepsis (18). Clinically important risk factors include increased duration of mechanical ventilation and weaning, as well as the resulting delays in mobilization and rehabilitation. Many patients suffer from long-term effects such as myasthenia, amyotrophia, sensory disorders, and neuropathic pain, which significantly affect quality of life.

Diagnosis of CIP is based on an electrophysiological detection (EMG) of axonal injury which is characterized by an axonal degeneration, primarily of motoric neurons (39).

Whereas benign CIP regresses relatively rapidly, expect only an incomplete regression in patients who suffered a severe sepsis.

A few years after CIP, electrophysiological correlates can still be detected, possibly causing persisting myasthenia and fatigue resulting in lasting reduction of quality of life.

The primary treatment approach for CIP in ambulant therapy involves intensified measures of rehabilitation such as physio– and ergotherapy and, if necessary, logopedic and respiratory therapy.

Consider the level of neuropathic pain in your treatment concept. Assess and document the neurological status regularly in order to register impairments of the functional level over time. A neurological assessment including electrophysiological measurements is recommended every 3-6 months.

To classify a neuropathy's level of severity and follow-up, we provide the neuropathy deficiency score (see appendix). We recommend a 64/128 Hz tuning fork for measuring the perception of vibration. The perception of pain can be determined with a *Neurotip* or a tooth pick. The perception of temperature can be determined with a *TipTherm* or with a cooled tuning fork. A 10 g-monofilament or a cotton ball is usually used to determine the perception of tangency or pressure. The patella or Achilles tendon reflex is recommended for neuropathic assessment of proprioceptive reflexes of the inferior limb.

According to the current guideline for diagnostics and therapy of diabetic polyneuropathy (40), the following scheme offers a good overview for neurologic assessment.

If necessary, we'd like to provide you with a combined instrument for measuring both temperature and tangency perception.

Test	Instrument/ Assessment	Question		Answer	
				normal	not normal
Perception of pain	*e.g. tooth pick* A missing perception of pain counts as "not normal".	Is this painful?	Distal (Dig I/V, metatarsus)	☐	☐
			Proximal (pretibial)	☐	☐
Superficial sensibility/ Perception of touch	*e.g. cotton ball* A missing superficial sensibility counts as "not normal".	Do you feel this?	Distal (Dig I/V, metatarsus)	☐	☐
			Proximal (pretibial)	☐	☐
Perception of vibration/ proprioception	*128-Hz tuning fork (according to Rydel-Seiffer, 8/8 means full perception, shown by fork deflection)* Initially: metatarsophalangeal joint of the hallux, if the perception is missing: examination of a proximal spot, e.g. malleolus medialis **lower standard limits :** **< 30 years: 6/8** **> 30 years: 5/8** *(Hilz et al., 1998)*	I'm going to apply a tuning fork. Please tell me, when you're not feeling any vibration anymore.	metatarso-phalangeal joint of the hallux	☐ R: __/8 L: __/8	☐ R: __/8 L: __/8
			Malleolus medialis	☐ R: __/8 L: __/8	☐ R: __/8 L: __/8
			Tuberositas tibiae	☐ R: __/8 L: __/8	☐ R: __/8 L: __/8
Perception of temperature	*e.g. cooled tuning fork, TipTherm* A missing perception of temperature counts as "not normal"	Do you feel cold or warm at this spot?	Distal (Dig I/V, metatarsus)	☐	☐
			Proximal (pretibial)	☐	☐
Perception of pressure/ perception of touch	*10g-monofilament:* A missing perception of touch counts as "not normal".	Do you feel this?	Plantar side of os metatarsal II in the area of the ball of the toe	☐	☐

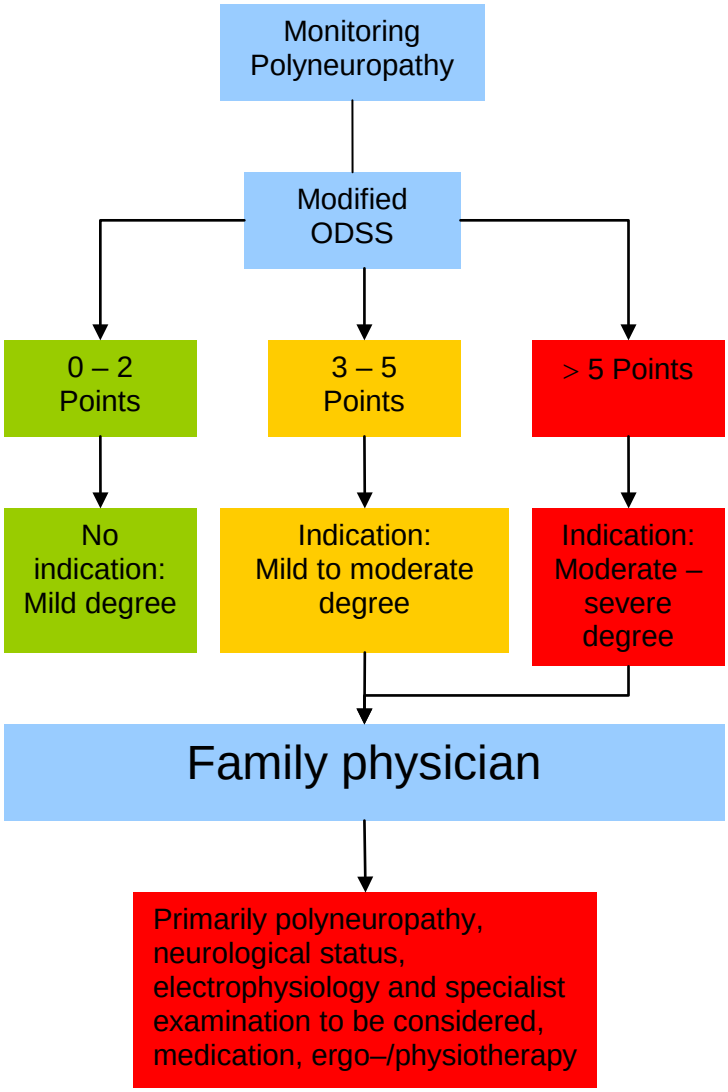
Proprioceptive reflexes:

	Right	Left
Patellar reflex	☐ normal ☐ reduced ☐ missing	☐ normal ☐ reduced ☐ missing
Achilles tendon reflex	☐ normal ☐ reduced ☐ missing	☐ normal ☐ reduced ☐ missing

To monitor critical illness polyneuropathy, we provide a set of items according to the ODSS (overall disability sum score) (41) for case management to check functionality of the superior and inferior limbs, for example “opening zippers and buttons” or “climbing stairs”.

Polyneuropathy module according to ODSS (41)

	Not affected	**Affected but not impossible**	**Impossible**
	0	**1**	**2**
Dressing of the torso (except zippers and buttons)	☐	☐	☐
Washing and brushing of hair	☐	☐	☐
Inserting a key into a lock	☐	☐	☐
Using a knife and fork (or spoon, if knife and fork could not be used)	☐	☐	☐
Opening and closing buttons and zippers	☐	☐	☐
	No	**Sometimes**	**Yes**
Do you have problems while walking?	☐	☐	☐
Do you use a walking aid? (If so, what kind: wheeled walker, crutches, cane, wheel chair)	☐	☐	☐
	Yes	**Sometimes**	**No**
Can you walk 10m (33feet) on your own?	☐	☐	☐
If you're using a wheelchair, could you stand and walk a few steps with help?	☐	☐	☐
If you're bed-ridden most of the time, can you make a few targeted motions?	☐	☐	☐



5.1.1 Traffic lights scheme polyneuropathy module

0-2 Points	Screening negative. No or only slight indications of polyneuropathy
3-5 Points	Screening positive. Indication of *moderately severe polyneuropathy*, neurological status, NDS, electrophysiology, consider physiotherapy
>5 Points	Screening positive. Indication of *severe polyneuropathy*, neurological status, NDS, if necessary neurological assessment, electrophysiology, medication, physio–, and ergotherapy

6.3 Pain

”Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.“ (*International Association for the Study of Pain*)

Pain itself is not an illness, but an important symptom that is subject to multiple physiological, psychological, and social influences. Pain is an elementary sense perception that is specifically triggered by tissue damaging (noxious) stimuli (42). Each pain perception leads to an assessment of pain, the cognitive component, and to an expression of pain, the psycho-motoric component.

Pain is labeled either acute or chronic, depending on its duration. Acute pain is a time-limited reaction of pain incurrence and pain forwarding. The international cut-off point for chronic pain is set at 6 months.

Chronic pain consists of either nociceptor-mediated pain or neuropathic pain. Recent considerations also suggest a “mixed pain” model (43) that includes both components. Pain develops dynamically (44) and cannot be regarded from a biological point of view only. Therefore, do not classify dichotomously into acute and chronic pain, but on a continuum that takes into account a bio-psycho-social model to explain chronification of pain. On this basis, the Mainz Stadium Model of Pain Chronification (45) was developed which can also be applied without knowing about psycho-social stress factors.

Consideration of the bio-psycho-social model is integrated into the general practice guideline “pain” (46). According to this guideline, you should observe the following approaches:

- Sensitization to the bio-psycho-social interrelationship in pain development
- Making your teaching disease-specific and symptom-related
- Avoiding polypharmacy and misuse of drugs
- Sensitization to the dangers of use of painkillers (ulcer, cardiovascular risks, addiction, etc.)
- Awareness of side effects and interactions
- Use of opioids strictly according to given indications
- Consequent application of the WHO scheme for acute and chronic pain
- Avoiding over-, under-, and mistreatment

Chronic pain is a long-term complication of severe sepsis (25). Two years after having survived a severe sepsis, patients report a significantly higher pain-associated impairment of quality of life

than the general population. The SMOOTH study records chronic pain by use of the "Graded Chronic Pain Scale" (GCPS) (47). Your patient's monitoring uses painDETECT to screen for pain (48). This questionnaire was primarily developed for diagnostic classification of neuropathic pain, but it also includes items that refer to intensity, localization, and course of pain (see appendix), so it is well-suited for our pain monitoring. The core questions about pain intensity are:

- How would you assess your pain now, at this moment?
- How strong was the strongest pain during the last 4 weeks?
- How strong was the pain during the past 4 weeks on average?

6.3.1 Traffic lights scheme: pain module – acute and chronic pain

	0-2 Points	Screening negative. No indication or only mild pain: follow up
	3-5 Points	Screening positive. Moderate pain: physical examination, maybe further diagnostics, check medication/therapeutic approach
	>5 Points	Screening positive. Severe pain: physical examination, diagnostics, adapt therapeutic approach, WHO scheme, adjuvants, physio– and psychotherapy if necessary

6.3.2 Traffic lights scheme: pain module – neuropathic pain - painDETECT

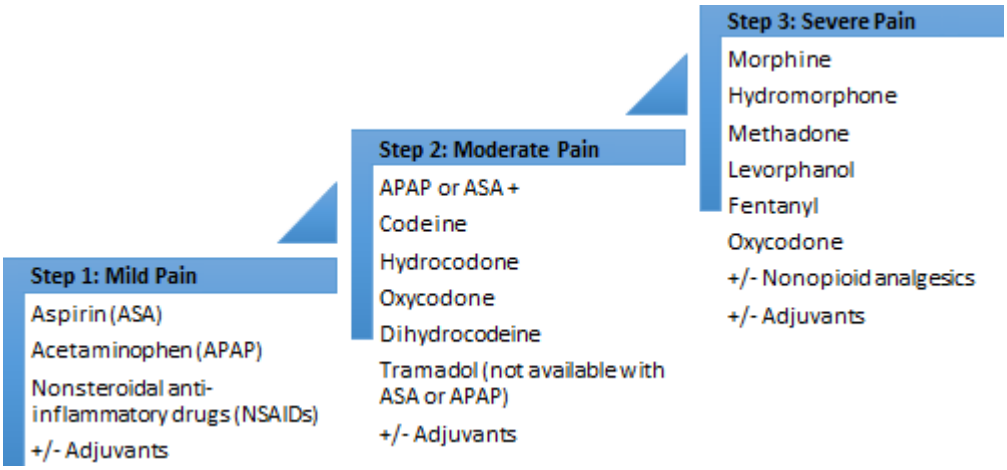
	0-12 Points	Screening negative. No indication of neuropathic pain
	13-18 Points	Screening unclear. Possible indications: physical examination, diagnostics/medication if necessary
	19-38 Points	Screening positive. Physical examination, diagnostics and specialist consultation, medication/therapeutic approach, physiotherapy

6.3.3 Pain treatment in general practice (46)

Therapeutic goals (46) of general practice pain treatment are:

- Rational and efficient treatment with few side effects, including non-medical treatments and patient activation.
- Fostering cooperation based on partnership by informing the patient about the illness in order to remove fears
- In case of acute pain: stop the pain.
- Prevent chronification of pain.
- In case of chronic pain: develop and observe a patient-adapted medication-regime and adequate pain control.

For medical treatment of nociceptive chronic pain, the WHO pain treatment ladder can provide orientation. In case of neuropathic pain, consider so-called co-analgesics (anticonvulsives, such as Gabapentin, Pregabalin, Carbamazepin and anti-depressants, such as Amitryptilin). Treatment of “mixed pain” requires an early combination therapy (43) with antiepileptics, anti-depressants, NSAIDs, and opioids. Additionally, antiemetics, laxatives, neuroleptics, cortisone and local anesthetics can be used. Adjuvant forms of pain treatment include Acupuncture, TENS, other forms of physical therapy, and psychotherapy.



WHO-pain treatment ladder (46)

A practical solution for pain assessment in general practice is the 11-grade (0-10) numeric rating scale (NRS). The patient is asked: *How bad is your pain on a scale from 0 to 10, 0 meaning no pain at all and 10 meaning the worst pain imaginable.*

Neuropathic pain after sepsis can be classified into the group of peripheral generalized painful neuropathies (infectious or post-infectious, immunological). The following measurements are important for diagnosing neuropathic pain:

- Clinical-neurological examination for assessment of neuronal malfunction patterns and degree of sensory deficiencies
- Assessment of pain intensity on the numeric rating scale 0 – 10
- Assessment of localization of pain and sensitivity disorders: body outlining of pain spreading, punctum maximum, pain spreading superficially or deep
  → *A symmetric distribution pattern in the lower extremities indicates polyneuropathy.*
- Assessment of sensory symptoms: numbness, burning, tingling, dysesthesia
- Questionnaires for assessing the neuropathic pain component: painDETECT

6.4 Neurocognitive disorder and septic encephalopathy

In discussions about septic encephalopathy (SE), persistent neurocognitive impairment as a sequela of sepsis becomes more and more the focus of attention in intensive care medicine.

A recently conducted cohort-study identified neurocognitive disorders after severe sepsis as significant (22).

Septic encephalopathy is an acute diffuse cerebral dysfunction that manifests especially in change of vigilance. (49).

Of all septic patients, 23% develop septic encephalopathy, which is associated with increased lethality (50).

Stage	Symptoms
I	Decreasing memory capacity, disturbances of concentration, perception and writing
II	Confusion, spatial and temporal disorientation
III	Muscular rigidity or stupor, seizures, gaze palsy, hemiparesis
IV	coma

Stages of septic encephalopathy (49), (51)

Symptoms include agitation, confusion, disorientation, and stupor up to coma. They can occur early in the course of sepsis. Cerebral hypotension is a predictor for septic encephalopathy. Effects of inflammatory mediators on the brain, inadequate cerebral perfusion pressure, changes of the blood-brain-barrier, cerebral microcirculation disorders, cerebral ischemia, metabolic dysfunctions and infections of the central nervous system are assumed to be further factors. (51).

Septic encephalopathy manifests clinically in qualitative (mostly in the form of delirium) or quantitative (somnolence, sopor, coma) consciousness disorders (52). Septic encephalopathy is a diagnosis of exclusion, a careful differential diagnosis is always necessary.

The clinical course of SE is variable-fluctuating and reflects the level of severity of the sepsis. It is likely that short-term, mild encephalopathy will heal completely, whereas permanent cognitive impairment in the form of attention, concentration, and memory deficits, and reduced resilience will remain in severe cases.

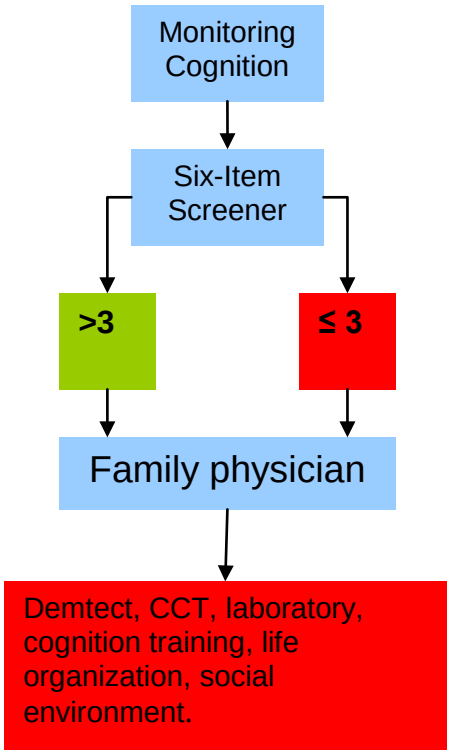
For assessing the grade of severity, elements from dementia diagnostics, such as Mini-mental State, can be helpful.

Septic encephalopathy is a matter of diagnosis of exclusion. It is important to consider detailed organic diagnostics to exclude treatable causes like hypothyroidism or normal pressure

hydrocephalus if not performed in hospital (e.g. CCT, blood count, glucoses, TSH, vitamin B12, electrolytes, creatinine, folic acid, liver function reading).

Medical treatment of septic encephalopathy is not available yet. Primary therapeutic approaches are non-medical treatments like attention- and concentration training, physio- and ergotherapy, practical help for everyday life, and especially including the psycho-social environment.

Cognition is monitored by use of the six-item-screener (53) .



6.4.1 Traffic lights scheme: cognition module

	>3 Points	Screening negative: No action necessary
	≤3 Points	Screening positive: further diagnostics like psychometric tests (e.g. Mini-mental State), consider CCT or laboratory, non-medical treatment

6.5 Posttraumatic stress disorder (PTSD)

The DSM-IV offers a good psycho-traumatological definition of "trauma:" "Direct personal experience of an event that involves actual or threatened death or serious injury, or other threat to one's physical integrity; or witnessing an event that involves death, injury, or a threat to the physical integrity of another person; or learning about unexpected or violent death, serious harm, or threat of death or injury experienced by a family member or other close associate. The person's response to the event must involve intense fear, helplessness, or horror." Posttraumatic stress disorder is a reaction to one or more traumatic experiences, such as violence, abuse, terrorist attacks, natural disasters, or diagnosis of a life-threatening disease.

Many scientific publications have shown a direct correlation between the presence of PTSD and a prior intensive care treatment (54).

Lifetime prevalence of PTSD is 8% (55). A newer population sample from Germany (56) assesses full PTSD at a lower rate, with a one-month-prevalence of 2.3%. Median point prevalence for PTSD is at 22% for survivors of critical diseases requiring intensive care (20).

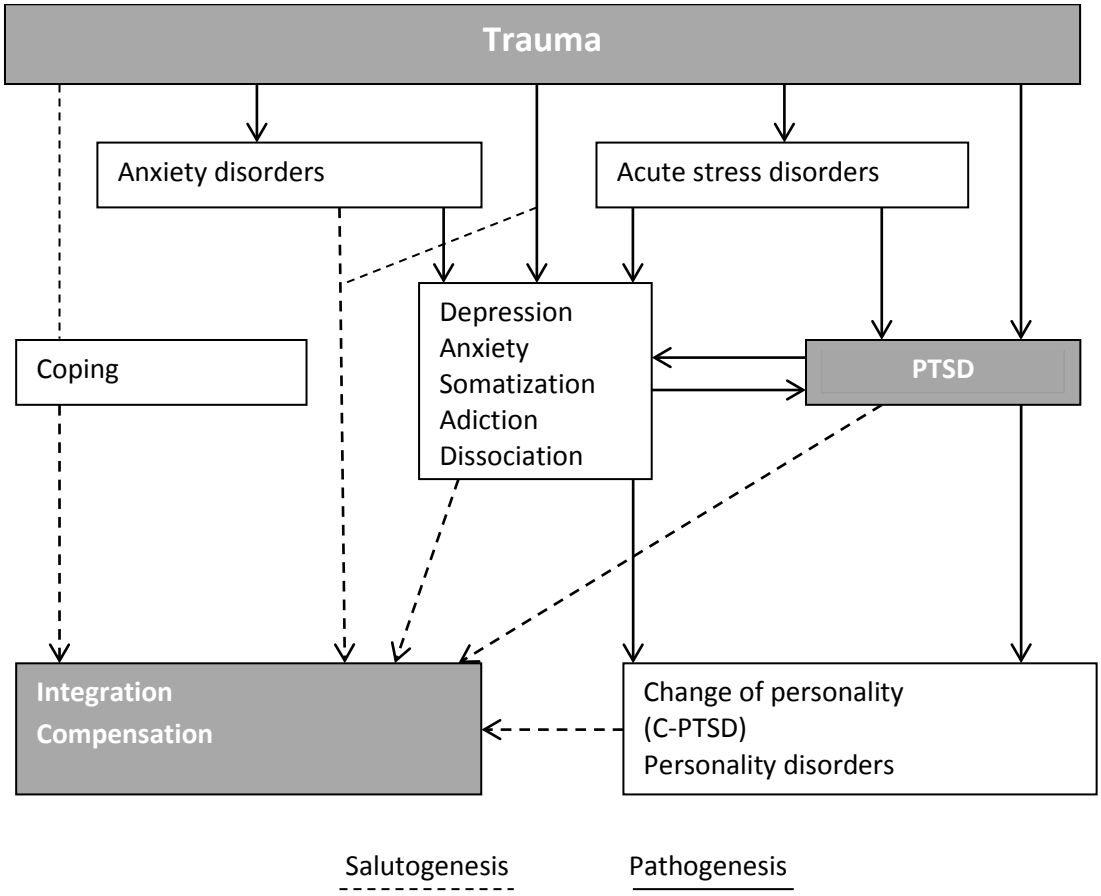
Because of their illness and necessary intensive care treatment, patients undergo extreme stress. Major factors for this include respiratory insufficiency, intubation, ventilation, delirium, the feeling of being at the mercy of others, high noise levels, and loss of autonomy and communication.

A missing or delayed diagnosis prevents adequate therapeutic intervention which can lead to chronification. As a result of the trauma-associated stress activation mechanism, chronic posttraumatic stress disorder can determine and influence the course of physical diseases.

Presence of PTSD becomes apparent in a period of up to 6 months after the initial trauma. As most of all post-sepsis patients are already in general practitioners' care at this time, screening and identification of traumatization must take place in primary care (57). For this reason, the FAMILY PHYSICIAN holds the key to early identification and treatment of the trauma aftermath (58).

Frequency of PTSD is trauma-specific:

- ca. 50% after rape
- ca. 25% after other crimes of violence
- ca. 50% in victims of war, displacement, or torture
- ca. 10% in victims of traffic accidents
- ca. 10% after severe organ diseases (heart attack, malignoma)
- **ca. 22% after intensive care treatment of critical illness**
- ca. 12% after prolonged weaning from mechanical ventilation



Overview trauma-reactive development (59)

6.5.1 PTSD in general practice

Knowing that a PTSD might occur, the FAMILY PHYSICIAN needs to subtly observe the patient to make sure to detect the often rather undisclosed symptoms. There are four cluster-like groups of symptoms (60) that should be present for at least one month before it can be declared a PTSD. Symptoms lasting less than a month are, rather, adjustment disorders/acute stress reactions.

- Intrusion: repeated memories, nightmares, flashbacks, feelings of intense distress, and physical reactions to reminders of the event/at confrontation.
- Avoidance: Avoiding thoughts and feelings that recall the trauma, attempting to forget the event, sometimes partial amnesia of the event.
- "Numbing:" emotional isolation, social withdrawal, isolation, loss of relationships and interests.
- "Hyper-arousal:" Difficulties in falling asleep and sleeping all night, emotional lability, irritability, flashes of anger, concentration disorders, jumpiness.

Until treatment can be taken over by a psychotherapist experienced in trauma, the following aspects should be taken into account for primary psycho-somatic care of PTSD (58):

- Provide a secure environment including a stable physician-patient-relationship.
- Organize help ("Who could help you?", Is there a trauma-experienced psychotherapist nearby?, "To bridge the time, short-term appointments with me might be possible.", …) Even if options are limited, it is important to clearly formulate the offer.
- Encourage patients to accept help.
- Listen empathetically, maybe touch the patient carefully; during physical examinations talks are often more relaxed.
- Resource-oriented counseling techniques; ask patients about their strengths and convictions and encourage them to include them in their recovery.
- Initiate psycho-education and information about the correlation between trauma and the patient's symptoms

There are also pharmacological options:

- First choice medications are serotonin re-uptake inhibitors (SRI: such as Paroxetin, Sertralin, Fluoxetin, Citalopram) or serotonin and noradrenalin re-uptake inhibitors (Venlafaxin retard.). These drugs reduce fear and flashbacks, and also feelings of numbness and loss of interests.
- Benzodiazepines should only be given in case of hyper-arousal for more than 5 days, because they present an increased dependence potential in PTSD patients.
- In case of sleep disorders, sedative tricyclic anti-depressants or Mirtazapin can be given.

6.5.2 PTSD monitoring

For PTSD screening within the study monitoring, the case manager uses the 7-Item-Scale by

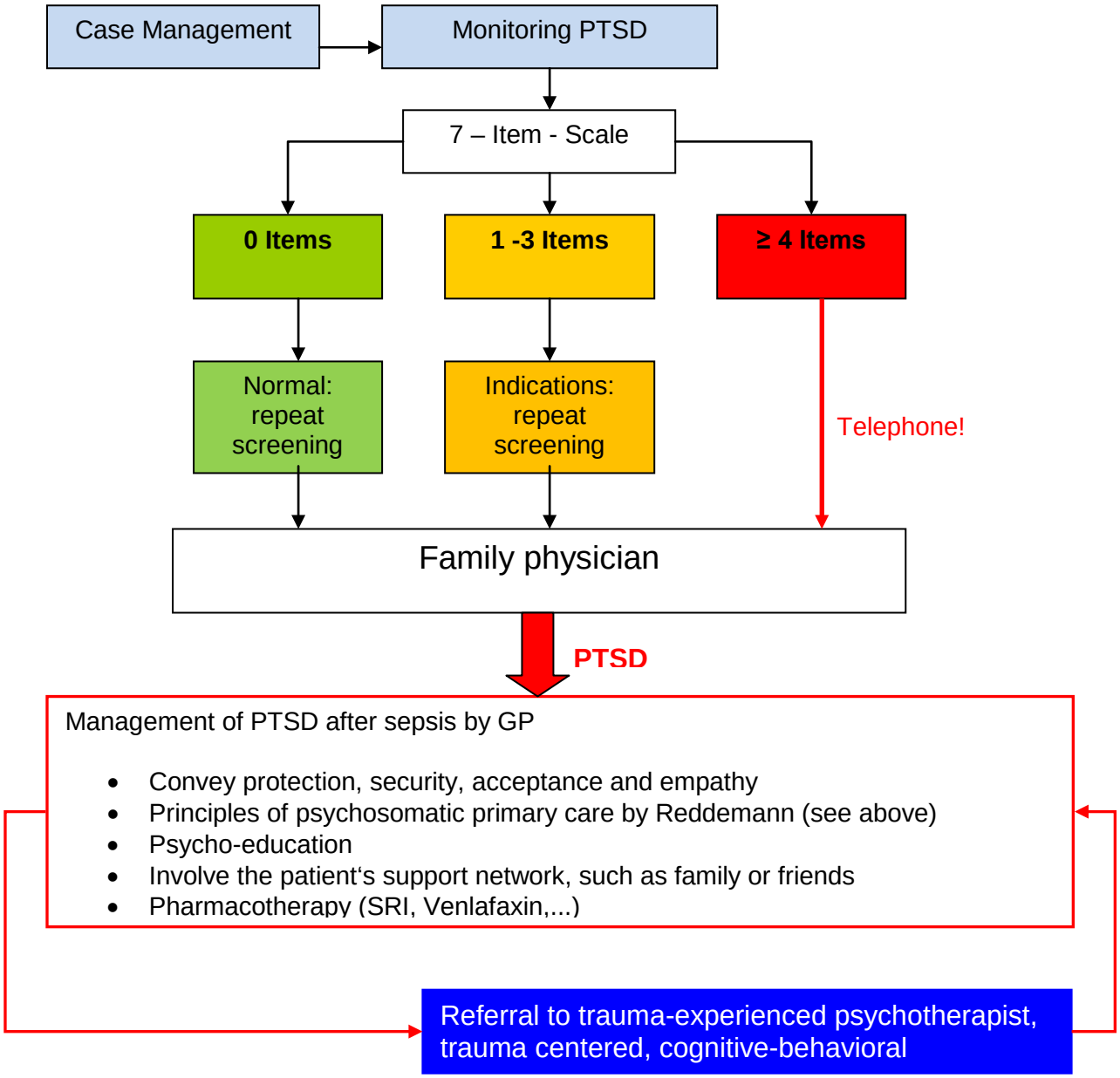
Breslau in its 7-item-version by Maercker et al. You can find it in the appendix.

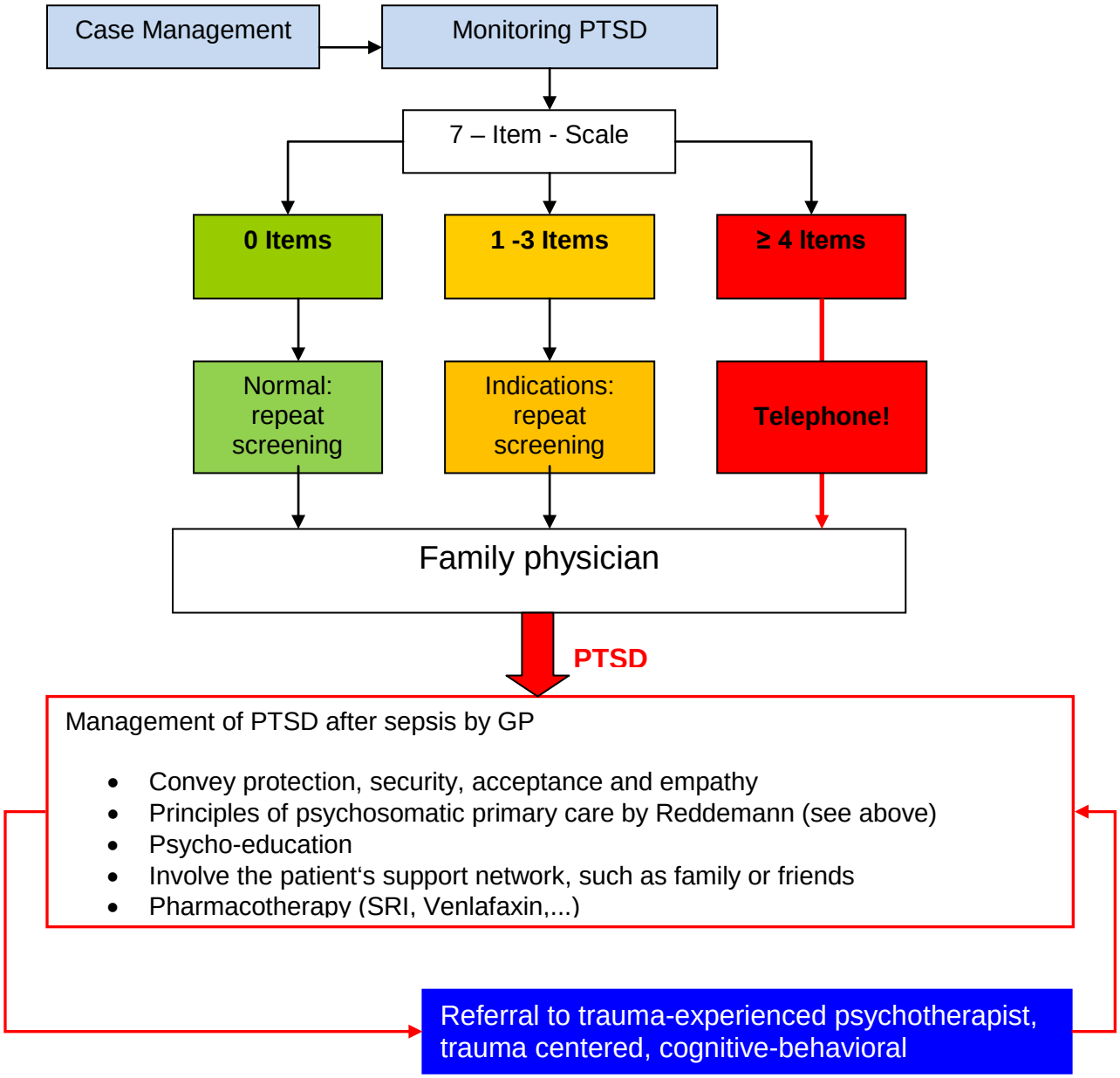
A question is assessed positive if the symptom appears at least 2 – 4 times a week. A PTSD diagnosis can be made if four or more answers are positive. Here, too, the monitoring employs the so-called traffic lights scheme that highlights the necessity of specific therapeutic consequences.

In the framework of the monitoring, the study nurse will interview the patient on the basis of the 7-Item-Scale once a month in the first six months after discharge from hospital or rehab center and once every three months during the second six months. If monitoring results suggest the presence of PTSD, you will be informed immediately.

6.5.3 Traffic lights scheme PTBS-Module:

	0 Points	Screening negative: no indication
	1-3 Points	Screening unclear: indications present → Follow-up
	≥4 Points	Screening positive: PTSD likely – Establish trust and security, ask about symptom cluster, strengthen resources, organize help, trauma-centered psychotherapy, medication if necessary





6.6 Depression

Depression is a mood disorder that causes a persistent feeling of sadness, loss of interest and lack of motivation. It is often accompanied by physical troubles. Depression affects the whole life. Patients have trouble doing normal day-to-day activities; they suffer from self-doubt and concentration disorders and tend to muse a lot.

Interactions between physical and mental illness are various and well-documented, especially for depressive symptoms after intensive care treatment. A recently published Review (21) indicates a point prevalence of 28%.
Identifying depressive disorders is often difficult because patients rarely spontaneously report typical symptoms of depressive disorders. As such, you cannot assign symptoms and rather suspect organic causes for their troubles.
The following troubles indicate depression:

- General exhaustion, lassitude
- Sleep disorders
- Lack of appetite, stomachache, loss of weight, obstipation, diarrhea
- Diffuse headache
- Feeling of pressure in throat and breast, globus sensation
- Functional disorders of the cardiovascular system (e.g tachycardia, syncope)
- Dizziness, flicker in front of the eyes, visual disorders
- Muscle tension, diffuse neuralgiform pain
- Loss of libido, absence of menstruation, sexual disorders
- Memory disorders

6.6.1 Depression monitoring

For depression screening within the monitoring, the case management uses the PHQ-9 questionnaire (61) which is a well-established tool in primary care of depression. The screening starts with two questions from the PHQ-2 (62). If the patient answers one of the questions with ”on more than half of the days“ or “nearly every day,” then administer the whole PHQ-9.
If five or more answers in the PHQ-9 are positive (1 – 9 “Nearly every day,” “on more than half of the days,” or “on single days”) this indicates a major depression. If only 2 – 4 answers are positive, another depressive syndrome is probable.

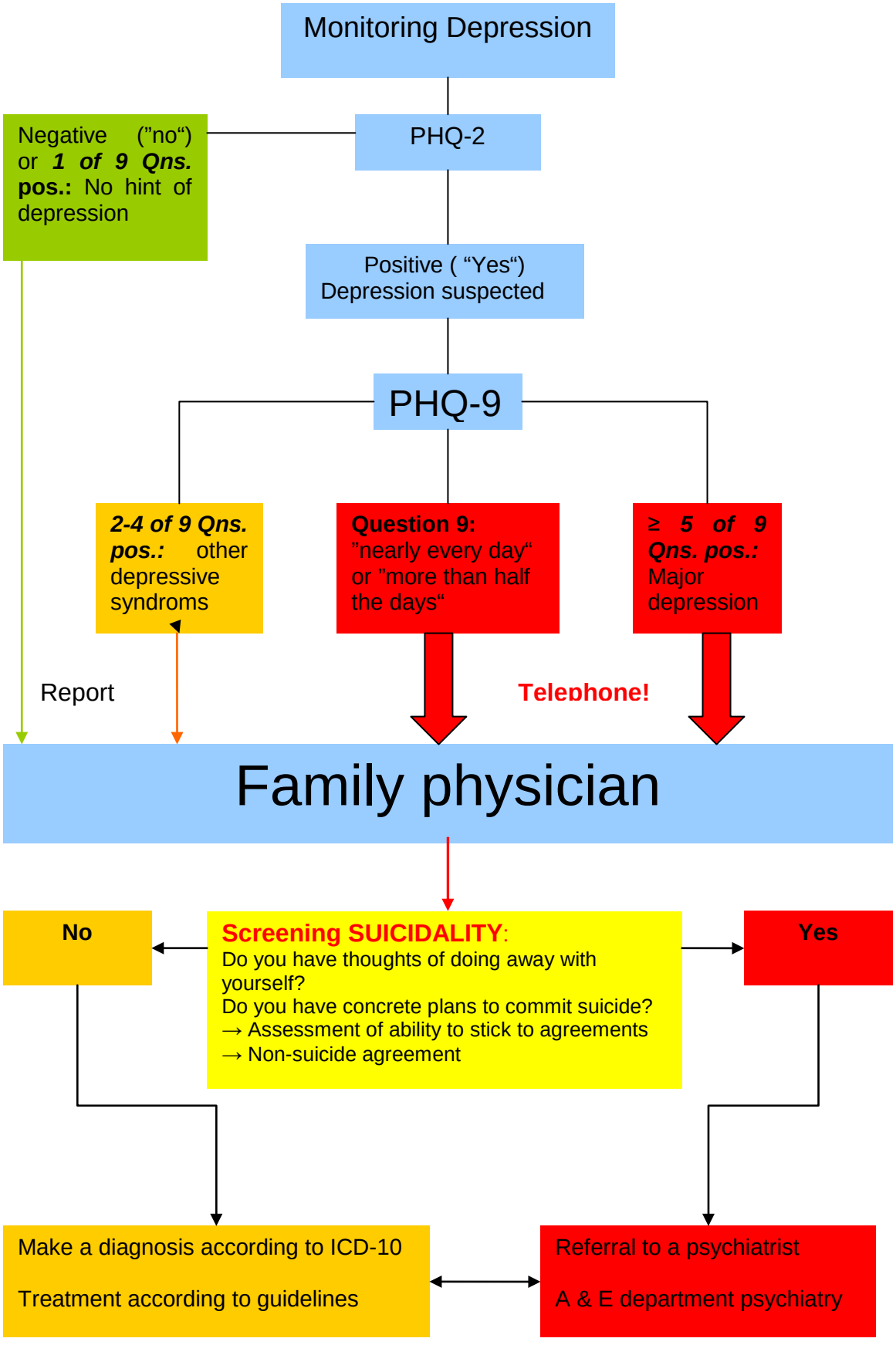
Over the last 2 weeks, how often have you been bothered by any of the following problems?	Not at all	Several Days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself – or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead, or of hurting yourself in some way	0	1	2	3

PHQ-2

PHQ-9

PHQ-2/PHQ-9 (61) (62)

If the monitoring suggests a major depression, or if the patient answers question 9 – suicidality – “nearly every day”, we will contact you immediately. The following figure shows you how to integrate the monitoring result into your treatment concept:



6.6.2 Traffic lights scheme: depression module

	0-1 of 1 – 9	Screening negative: no hints
	2-4 of 1 – 9	Screening unclear, hints, follow-up control
	≥ 5 of 1 – 9	Severe depressive episode, suicidality screening. If positive: emergency referral to psychiatric hospital. If negative, medication and psychotherapy Establish trust and security, symptom cluster, strengthen resources, organize help, trauma-centered psychotherapy, maybe medication, ICD-10 diagnostic.
	Question 9 ≥ on more than half of days	Suicidality suspected. Suicidality screening. If confirmed, immediate referral to psychiatric A & E.

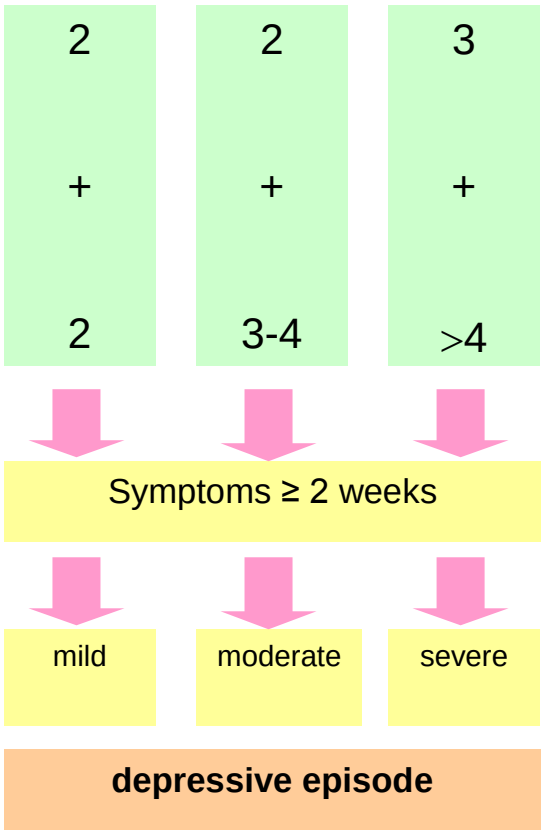
6.6.3 Diagnostics of depressive disorders according to ICD-10 (63)

Primary symptoms:

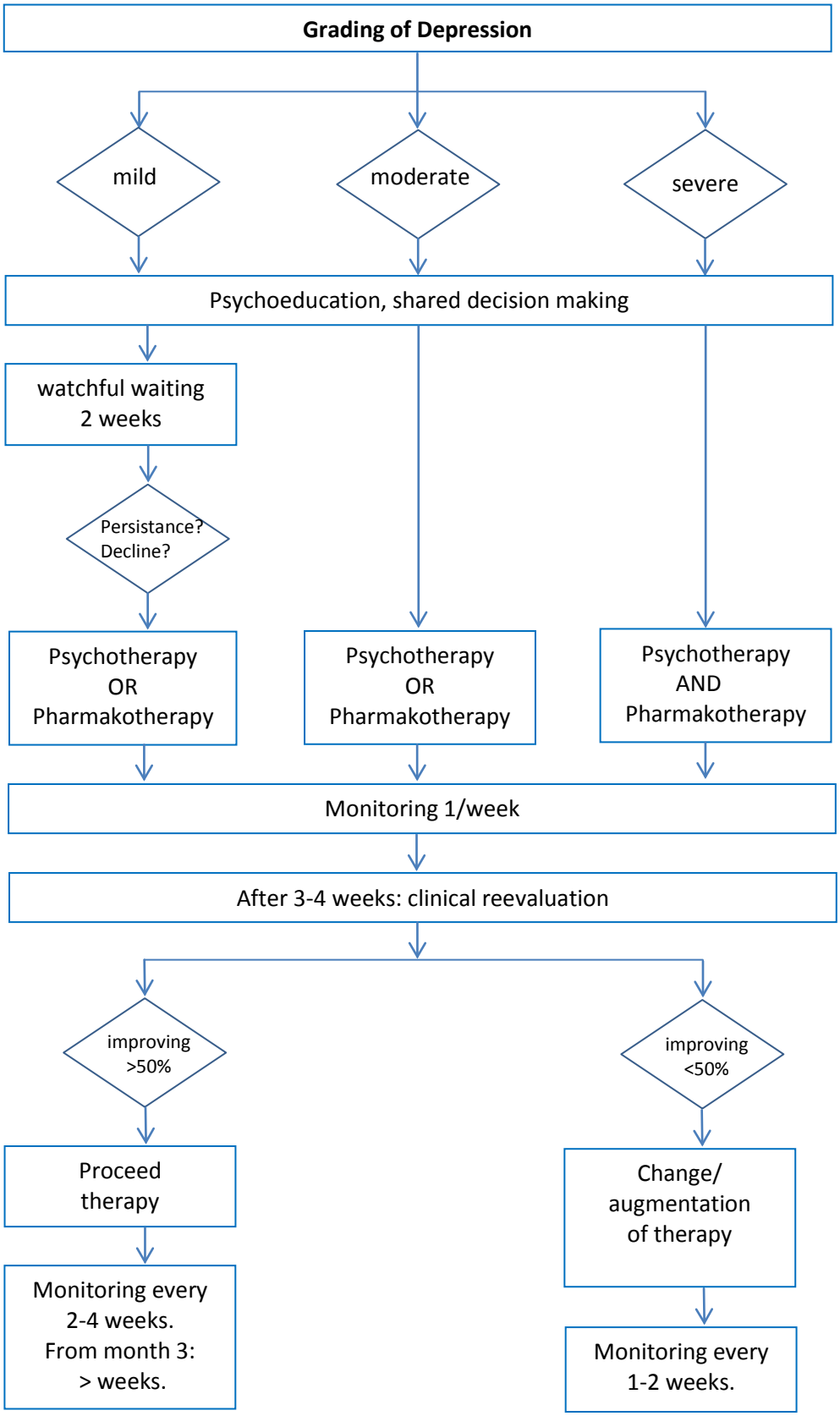
- ►gloomy, depressive mood
- ►loss of interests, cheerlessness
- ►lack of motivation, increased fatigue

Additional symptoms:

- ►reduced concentration and attention
- ►reduced self-esteem
- ►feelings of guilt and worthlessness
- ►negative and pessimistic future perspectives
- ►thoughts/acts of suicide
- ►sleep disorders
- ►lack of appetite



6.6.4 Basic principles of therapeutic procedure (64)



6.6.5 ”Active-observant company”

In case of a mild depressive episode you can refrain from a specific therapy if you provide ”active-observant company,“ because these patients often recover spontaneously. If symptoms persist for 14 days or longer, therapy introduction is indicated. To avoid pharmacological side effects, give preference to psychotherapeutic approaches for mild and also moderate episodes. Pharmacotherapy is not recommended for initial treatment of mild episodes except in some exceptional cases.

6.6.6 Admission to hospital and referral to a specialist – at what time?

If symptoms persist for more than three months, regardless of severity, consultation with a specialist in psychiatry, psychosomatics, or psychotherapy is recommended. In addition to resistance to therapy, the following criteria should lead to interdisciplinary cooperation:

- Unclear psychiatric differential diagnosis
- Pharmacotherapy and/or psychotherapy problems
- Interaction problems within the combination therapy of anti-depressants with other drugs

In case of acute self-endangerment or endangerment of others or of severe psycho-social factors that impede therapy success, the patient must receive stationary treatment.

6.6.7 Psychotherapy

Sufficient motivation and understanding of the disease are necessary for starting psychotherapy. For treatment of mild to moderate depressive episodes, psychotherapy is as effective as medication. In moderately severe and severe episodes, psychotherapy should be applied in combination with pharmacotherapy. In severe depression, pharmacotherapy is often needed as a prerequisite for starting psychotherapy. Scientifically recognized approaches for treating depression include cognitive behavioral therapy and interpersonal psychotherapy. Both should be conducted by medical or psychological psychotherapists. Onset of effect cannot be expected earlier than three months after starting treatment.

6.6.8 Pharmacotherapy

Pharmacotherapy of depression is recommended for moderately severe to severe depression. In mild depressive episodes evidence remains unclear. Onset of effect can be expected after around three weeks. If this is not the case, employ a dosage increase, a change of medication, or an augmentation therapy with another drug. Expect frequent side effects; however, often improvement is visible after only a few days. You will find the most important substance-related information listed below:

SRI (Serotonin re-uptake inhibitor)	Indication: moderately severe to severe depression Side Effects: - bleeding tendency with NSAIDs Physical unrest/agitation, suicidal thoughts - Serotonin syndrome: confusion, delirium, sweating, mydriasis, myoclonus, RR
TCA (Tricyclic anti-depressants)**:**	Indication: moderately severe to severe depression Side effects - anticholinergic (CAVE in pat. with cardiovascular diseases, glaucoma, prostatic hypertrophy, intestinal stenoses, obstipation, cognitive disorders, seizures) ➢ Regular ECG-controls: dysrhythmia? ➢ Small packaging units as taking a week's ration might be lethal!
Others:	➢ Mirtazapin (tetracyclic, a2-antagonist) ➢ Venlafaxin/Duloxetin (SSNRI)
General remarks: → **before treatment:** ECG, laboratory (blood count, electrolytes, transaminases, creatinine, TSH) → **"Initial dose"** → low, gradual dose escalation → **Maintenance dose** until 4 – 9 months after remission; 2 years after recurrence	

7 Rare or underestimated sepsis complications

7.1 Sclerosing cholangitis

The term secondary sclerosing cholangitis (SSC) summarizes a whole spectrum of chronic cholestatic diseases of the intra- and/or extra-hepatic bile system. SSC is characterized by erratic inflammation exacerbations with consecutive fibrotizations and strictures of bile ducts in a rapidly progressive course. Several cases of progressive sclerosing cholangitis after septic shock were observed in the last years. The disease started with an increase of cholestasis parameters (bilirubin, alkaline phosphatases, gamma-glutamyltranspeptidases). If a septic shock patient develops cholestasis while treated on ICU, SSC is always a possibility.(65). In endoscopy, several stenoses, pre-stenotic dilatations, and a rarefication in part of the small intra-hepatic bile ducts normally show up. Liver biopsy shows fibrotizating cholangitis.

Because of the fast progression of sclerosing cholangitis, liver cirrhosis can develop quickly, leading to liver failure. Early diagnostics is therefore very important. Consider orthotropic liver transplantation at an early stage. In general practice, regular control of liver function and consideration of sclerosing cholangitis by differential diagnosis is very important after any sepsis.

7.2 Chronic kidney insufficiency

Acute kidney injury (AKI) is frequent in septic patients and represents a fundamental and independent risk factor for lethality. Sepsis is the most frequent cause of AKI on ICU. AKI occurs in 23% of patients with severe sepsis and in around 50% of patients with septic shock. (66). According to a prevalence study in Germany, more than 40% of septic patients suffer from AKI (67).

AKI is a sudden, principally reversible deterioration of glomerular and tubular function. Pathophysiologically, we must differentiate between hemodynamic-ischemic and septic-toxic geneses. Later restitution of renal function is often incomplete. Patients who needed dialysis because of acute kidney injury bear a significantly higher risk of developing a progressing chronic kidney insufficiency. General practice consequences are control of retention parameters, nephrotoxicity check of medications, and urging the patient to drink enough.

7.3 Swallowing, tasting, smelling and hearing disorders

The monitoring assesses these rather rare complications using a specifically designed ENT-module. The module consists of four questions to be answered by choosing one of four levels.

Based on the answers of these questions, an ENT score can be calculated.

Since the last interview, did you have …	**Not at all**	**On single days**	**On more than half of the days**	**Nearly every day**
	0	**1**	**2**	**3**
…difficulties in swallowing?	☐	☐	☐	☐
… taste dysfunctions?	☐	☐	☐	☐
…olfactory dysfunction?	☐	☐	☐	☐
…hearing defects?	☐	☐	☐	☐

7.3.1 Traffic lights scheme: ENT-module:

	0 Points	Screening negative: no hints
	1-2 Points	Screening unclear: possible hints, follow-up
	≥3 Points	Screening positive: ENT-disorders present. A detailed examination and diagnostic assessment is necessary, including use of taste strips, sniffing sticks, swallowing test, whisper test, and specialist consultation if needed.

7.3.2 Dysphagia

This description of dysphagia is based on the guideline ”Neurogene Dysphagie“ (68) of the German Society of Neurology.

Dysphagia is a well-known, but underestimated complication in patients after long-term ventilation. It occurs in around 80% of patients after long-term ventilation.

Dysphagia can be of mechanical, psychogenic or neurogenic origin. Within the condition of critical illness neuropathy, usually it is neurogenic dysphagia that occurs after sepsis. However, also consider mechanical causes due to repeated intubation, ventilation and tracheostoma.

Dysphagia bears an increased risk for aspiration and pneumonia, as well as for reduced quality of life.

The 50-ml-water test can assess the danger of aspiration; with swallowing observed by a physician.

If dysphagia is suspected in post-sepsis treatment (without confirmed diagnosis), the FAMILY PHYSICIAN can make a first assessment.

For this, you should watch out for the following symptoms:

- frequent swallowing
- chewing weakness
- reduced food or drink intake
- changed position when swallowing (e.g. anteflexion of the head)
- saliva/drinks/food get struck in the throat
- choking fits or coughing after meals/drinks
- unclear fever attacks and/or pneumonia (may be silent aspirations!)
- unintended loss of weight

In addition, anamnesis of medication is important, because drug-induced myopathies (corticoids, statins, fibrates, etc.) can come along with dysphagia.

For enhanced diagnostics, aim for close interdisciplinary cooperation. A confirmed diagnosis needs extensive ENT, neurological, and radiological examinations like laryngoscopy, electro-myography (EMG), manometry, or video-cinematography of a gastrografin swallow. By now, many places have specialist centers for dysphagia.
For treating dysphagia, ambulant care is more and more available, such as swallowing training in logopedic practices.

7.3.3 Dysgeusia

Dysgeusia can be caused epithelial, neural or central.
Due to the infection in patho-physiologically complex sepsis, epithelial damage of taste buds is possible, as well as lesions of gustatory afferences. Distinct etiology and epidemiology of this complication are not yet clear.

Because of this inadequate body of evidence, monitoring for dysgeusia occurrence is only done by asking about tasting impairment (”Have you had taste dysfunctions since the last interview?“) – possible answers are ”not at all,“ ”on single days,“ ”on more than half of days,” or “nearly every day.” In practice, it is recommended to test the overall tasting ability by oral applications of the different gustatory substances; sweet, sour, salty, and bitter; in above-threshold concentrations (taste strips, or drops).

Therapeutically, there are few options for treating dysgeusia. After sepsis, drug side effects should be examined by differential diagnosis. Dysgeusia can also be caused by tumors in the throat or head region, so careful and thorough diagnostics are necessary.

The following practical advice might be helpful for dysgeusia patients: (69):

- Perform olfactory compensation by carefully spicing your food (aromas).
- Stimulate the tactile senses (through consistency, temperature, spiciness).
- Stimulate remaining taste (sweet, sour, salty, bitter).
- Temporarily remove dysgeusia by use of a lidocaine spray.
- “You eat with your eyes first.” (color, garnish)

For physicians, the following practical recommendations for treating patients with smell or taste disorders might be relevant:

- Empathy
- Develop individual coping strategies.
- ”You are not alone with your problem“
- Psychological strain is normal.
- Patients should try to enjoy their memories of meals and drinks.
- “Take your time with meals!”, nice atmosphere
- “You shouldn’t become an unsuccessful eater or a “food refuse-nik.”
- Healthy diet (beware of everything “white”)
- Talk about problems with your partner, FAMILY PHYSICIAN, or self-help group.
- Get something positive out of this impairment.
- The sooner patients accept this impairment, the better they can cope with it.
- Correct unscientific attempted explanations by the patient.

7.3.4 Dysosmia

A correlation between dysosmia and sepsis has not yet been proven either. For diagnostics, so-called sniffing sticks can help assess the olfactory dysfunction.

Dysosmia too, can be multifactorially caused. It is often related to sinu-nasal causes. The

monitoring includes a question on dysosmia. If the patient answers this with “on more than half the days” or more frequently, further diagnostics and a thorough anamnesis are indicated.
If there is no obvious sinu-nasal correlation, consider an ENT diagnosis of exclusion.
As a basis for further information, you can find two S2-guidelines of the German Society of Oto-Rhino-Laryngology on the CD enclosed [“Dysosmia” (70) and ”Dysgeusia“ (71)]

7.3.5 Hearing disorders

Hearing disorders are divided up into sound conduction disorders, sensorineural hearing loss, and combined hearing disorders. Hearing disorders in sepsis patients are mostly sound conduction disorders due to ototoxicity of drugs, especially antibiotics (aminoglycosides), diuretics (Furosemid) and proton pump inhibitors (Omeprazol). In case of a suspected hearing disorder, the FAMILY PHYSICIAN should do a thorough anamnesis and physical examination including examination of the ears with otoscopy. The whistle test from a distance of 4 m or a (high frequency) finger rubbing in front of the ear as well as a Rinne and Weber test (tuning fork test) allow for a first assessment of the level of severity, as well as confirming diagnosis of a sound conduction disorder.

Consider an ENT specialist treatment with a tone audiogram.

7.4 Asplenia – anatomical or functional (9)

Sepsis patients are often asplenic, mostly after traumatic spleen rupture or through miscellaneous hematological diseases. Any infection, especially those caused by encapsulated bacteria like pneumococci, can be life-threatening for these patients. This complication is called “post-splenectomy sepsis (PSS)” or “overwhelming post-splenectomy infection (OPSI)”. In addition to pneumococci (which are often the pathogen in PSS), there may be other pathogens, such as hemophilus influenzae, meningococci, or others.

There are several strategies for prevention of severe infections after splenectomy or other kinds of spleen function loss: vaccinations, prophylactic application of antibiotics, immediate antibiosis if an infection is suspected, detailed patient information about risks after splenectomy, and a document for patients that informs them about splenectomy. If these precautions are implemented, PSS risk is considerably reduced.
Antibiotic prophylaxis in asplenia/splenectomy:

- In children always for at least 3 years after splenectomy (depending on the disease, with lifelong application in thalassemia for example)
- In adults no general recommendation (only at high PSS risk)

- After a bout of PSS for 1 -2 years
- With an expected poor success of pneumococci vaccination (such as during chemotherapy)
- Amoxicillin 2x20mg/kg p.o. is suitable. In case of allergy alternatively Erythromycin 1x10 mg/kg

Impfplan bei Asplenie

Bitte Aktualisierungen unter www.asplenie-net.org beachten! (Stand: 09 / 2010)

Alter	Grundimmunisierung	1. Auffrischimpfung	2. Auffrischimpfung
Pneumokokken			
2-11 Mo.	3 x PCV-13 (Abstand 4 Wo.)	PCV-13 (mit 12 Mo.)	PSV-23*% (mit 24 Monaten)
12-23 Mo.	1 x PCV-13	PCV-13 (nach 2-6 Mo.)	PSV-23*% (nach 2-6 Mo.)
2-5 J.	1 x PCV-13		PSV-23% (nach 2-6 Mo.)
≥ 6 J.	1 x PCV-13# oder 1 x PSV-23		PSV-23% (nach 5 J.)
* frühestens ab 24 Monaten % spätere Auffrischungen alle 5 Jahre # Empfehlung auf Basis von Expertenmeinung; PCV-13 noch ohne Zulassung für Kinder ≥ 6 J. u. Erwachsene. Details unter www.asplenie-net.org.			
Meningokokken			
2-12 Mo.	2 x MCV-C (Abstand 8 Wo.)	MCV-C (mit 12 Mo.)	MPV-ACWY+ (nach 6-12 Mo.)
1-10 J.	1 x MCV-C		MPV-ACWY (nach 6 Mo.)
≥ 11 J.	1 x MCV-ACWY		
+ frühestens ab 24 Monaten			
Haemophilus			
2 Mo.-5 J.	Grundimmunisierung laut Impfplan der STIKO		
> 5 Jahre	einmalige Impfung mit HiB-Konjugatimpfstoff		
Influenza (Grippe)			
> 5 Jahre	jährliche Grippeschutzimpfung		

Abkürzungen		
PCV-13	13-valenter Pneumokokken-Konjugatimpfstoff	Prevenar-13®
PSV-23	23-valenter Pneumokokken-Polysaccharidimpfstoff	Pneumovax®
MCV-C	Meningokokken-Konjugatimpfstoff Serotyp C	Meningitec®, NeisVac-C®, Menjugate®
MCV-ACWY	Meningokokken-Konjugatimstoff Serotyp A, C, W, Y	Menveo®
MPV-ACWY	Meningokokken-Polysaccharidimpfstoff A, C, W, Y	Mencevax ACWY®
HiB	*Haemophilus influenzae* Typ B-Konjugatimpfstoff	ACT-HiB® (nur über Import)

nach (9)

Stand-by therapy in case of asplenia/splenectomy (German)

- In case of indications of a bacterial infection (fever, shivering, exhaustion, malaise), immediate medical supervision is indicated.

- Antibiotic therapy within hours; diagnostic steps like drawing of blood cultures should not delay antibiotic therapy.
- Calculated parenteral initial therapy by FAMILY PHYSICIAN or as part of initial hospital treatment: Ceftriaxon i.v.

Alternatively, give Amoxicillin/Clavulan acid, in case of an allergy to penicillin, Cefaclor/Cefuroxim or Macrolides (Azithromycin, Clarithromicin).

7.5 Heart rate variability (HRV) (72) and hormones (73)

Several publications indicate sepsis-caused genesis of disorders on heart rate variability (10) (11) as well as hormonal balance (73). Reduced heart rate variability can possibly result from a direct damage of the autonomic nervous system as part of the septic inflammatory reaction. Changes in hormonal regulation have been observed in critical illnesses in the context of a so-called neuro-endocrine stress syndrome. Due to the initial extreme activation of the hypothalamic-hypophyseal-adrenal axis, complications like critical illness adrenal insufficiency or recurrent hyper/hypoglycemia can occur.

For following-up with sepsis patients, take into account the long period of regeneration. An ongoing catabolic metabolism can especially have an impact on the hormonal situation and on the glucose metabolism. The FAMILY PHYSICIAN should undertake regular controls of fasting blood sugar and, if applicable, of the cortisol levels.

Reduction of heart rate variability is often observed together with the first sepsis symptoms and disappears if the clinical condition improves. Check the HRV of post-sepsis-patients at least once with a 24-h-ECG.

7.6 Sleep disorders

”Sleep disorder“ includes a large variety of symptoms that can be classified according to different systems (e.g. ICD-10, DSM-IV, ICSD-2). Nearly all classification systems differentiate between insomnia and hypersomnia because both are taken into account in the definition criteria of many sleep disorders (74). According to the current guideline for “insomnia,” ICSD-2 and DSM-IV use the term “non-restorative sleep” to record entities that cannot be clearly differentiated by using the classification scheme insomnia versus hypersomnia, because insomnia as well as hypersomnia can be present (68).

The following explanations about occurrence of sleep disorders in intensive care patients focus on sleep disorders in the sense of insomnia. According to WHO diagnosis criteria, insomnia is present in cases where problems falling asleep or sleeping all through the night occur at least three times a week over a period of one month. (75). The international classification of sleep disorders defines insomnia as ”trouble due to insufficient sleep or not feeling well rested after a usual period of sleep time.” (68).

Sleep disorders have been well known in intensive care patients for more than 30 years (12). Reasons for the disturbed circadian rhythm include ICU caused stressors like high noise level, light at night, interruptions due to care activities, drugs, and mechanical ventilation (13) (14). Impaired sleep can have many consequences, such as increased catabolism, dysfunctional cellular and

humoral immunity, respiratory dysfunction, activation of the sympathetic nervous system, or delirium (15). Long-term effects have received little study. A direct correlation between sepsis and sleep disorder has only been observed experimentally so far (76). However, being a common problem of patients who have survived a critical illness, follow-up care should take disturbed or insufficient sleep into account. (16).

From an etiological point of view, primary insomnia is mostly a psycho-physiological disorder with increased physical tension and habitual sleep-preventing associations (68).

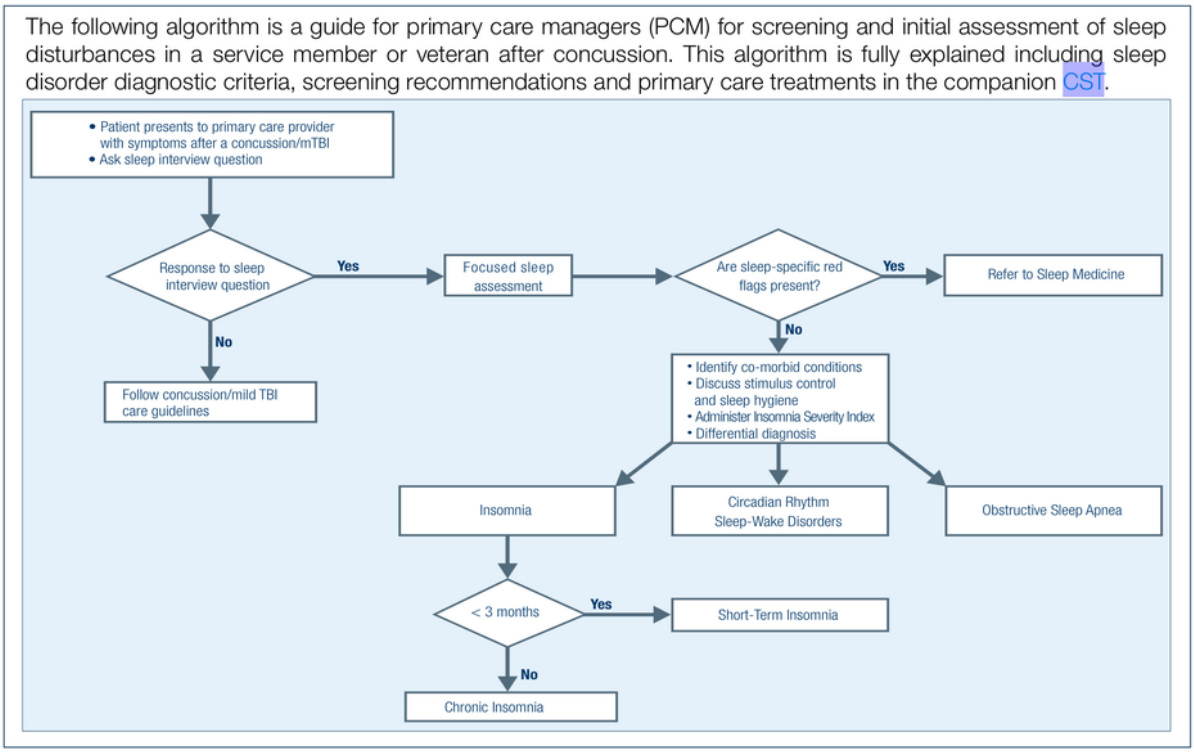
Sleep disorders can occur secondarily as a symptom of neurological (e.g. narcolepsy, restless-leg syndrome) or psychiatric diseases (e.g. depression, anxiety) or due to medicinal toxicity (e.g. drugs, anti-depressants). In terms of the Sepsis-Six, they occur especially in the context of a depression, PTSD, or polyneuropathy – in contrast to primarily organic causes like narcolepsy, restless-leg syndrome or sleep-apnea syndrome.

Guiding advice on evidence-based diagnostics and therapy of sleep disorders can be found in the S3-guideline – non-restorative sleep/sleep disorder (77). You can find this guideline on the enclosed training CD. It also includes a clinical algorism with elements that might be helpful for general practice care.

Non-instrument-based diagnostics focus on anamnesis, questionnaires for self-assessment, interviews, or sleep logs. You can download templates for sleep logs and internationally renowned self-assessment questionnaires like the Pittsburgh sleep quality index from the webpage of the German Sleep Society (78):
http://www.charite.de/dgsm/dgsm/fachinformationen_frageboegen.php

A new tool for recording sleep disorders is the Regensburg Insomnia Rating Scale (RIS) (79), which seems to be particularly suitable for primary care because it is very clear and short (10 items).
Within the context of instrument-based diagnostics, we should mention polysomnography and polygraphy in particular.

Clinical Algorithm



Clinical algorithm non-restorative sleep/sleep disorder (77)

For therapy of sleep disorders, psycho-education is crucial. A first step for this is teaching rules for sleep hygiene (80) (77):

- Go to bed only if you are tired.
- Use your bed only for sleeping; don't read, drink, smoke, or watch TV there (exception: sexual activities).
- If you lie in bed sleeplessly for more than 10 minutes, get up and go in another room. Don't return to bed until you are tired.
- Repeat this step as often as necessary
- Go to bed at the same time each day and get up on time in the morning if possible. Don't change this rhythm on weekends or vacations.
- Avoid burdensome conversations, exciting movies, etc. shortly before you go to bed.
- Establish "going-to-bed-rituals."
- Don't take naps during the day.
- Identify your individual time of sleep.

In subsequent treatment, cognitive behavioral therapy techniques and relaxation methods can provide sleep disorder therapy.

Stimulus control can be successful. Many sleep disordered patients try desperately to fall asleep, they want to force sleep to come, and consequently feel more and more angry and agitated (81). The aim of stimulus control is to break through the mental connection between the sleep environment and lying awake and to associate going to bed with pleasant feelings again.

There is often a need for information about the discrepancy between subjectively desired and objectively required length of sleeping time. Required sleeping time is very individual and can vary from ten hours to four hours or even less.
A restriction therapy might be helpful if the patient stays in bed much too long.

In summary, we recommend the following procedures for FAMILY PHYSICIANs to provide non-medical treatment of insomnia patients (81):

- Do diagnostics before treatment.
- Inform the patient about sleep and sleep disorders and give advice.
- Teach the patient sleep hygiene rules.
- Discuss rules for stimulus control.
- Motivate the patient to learn a relaxation technique.
- In case of resistance to therapy, consult an expert in the field of sleep medicine.

For medical treatment of sleep disorders phyto-therapeutics (e.g. valerian), sedative anti-depressants (e.g. Mirtazapin, Doxepin), low-potent neuroleptica (e.g. Melperon) as well as preferably newer benzodiazepine-receptor agonists (e.g. Zolpidem, Zopiclon) are available. Due to their high dependence risk and their unfavorable effect on sleep architecture (shortening REM-phases, etc.), benzodiazepines should be given only on an interim basis and in small package sizes.

8 Counseling techniques

The dialogue for finding out the patient's anamnesis is the most important diagnostic tool in general practice. At this point, 70 – 80% of all diagnoses are already made. Patient compliance and satisfaction depend crucially how this dialogue takes place.

The following chapter presents some counseling techniques for this doctor-patient-dialogue. Please take the non-verbal aspect of this kind of communication into account. It represents around 93% of information exchange. Often the patient communicates essential information not verbally but by facial expressions, gestures, or voice modulation.

8.1 Shared Decision Making

Shared Decision Making (SDM) or in German "Partizipative Entscheidungsfindung" (PEF) describes a form of doctor-patient-communication that aims to fulfill patients' desire to be involved in decisions about their health troubles.

Physician and patient discuss objective and subjective aspects of decisions, working as a partnership. The decision can have two or more options, one option sometimes being just to wait and see. Three aspects differentiate the SDM-approach from the old paternalistic and informative model of doctor-patient-communication: providing information, weighing up options, and deciding together (82).

A number of preconditions need to be fulfilled to practice SDM successfully. First of all, the patient's motivation is crucial. Does the patient want to be involved in medical decisions at all (83)?

Clinician's expertise	Patient's Expertise
Diagnosis	Experience of illness
Disease aetiology	Social circumstances
Prognosis	Attitude to risk
Treatment options	Values
Outcome probabilities	Preferences

Sharing expertise - clinician's vs. patient's experience

Furthermore, mutuality of influence and exchange between patient and doctor is decisive. Information is not only transported from doctor to patient, as in paternalistic models, but the patient also contributes information by conveying values, objectives, expectations, and fears. To encourage the patient to do so, the physician should provide an atmosphere that shows how important the patient's own point of view is and that encourages sharing subjective disease theories and preferences.

For this, the physician needs to implement several competencies:

- Develop a relationship based on partnership.
- Take account of the patient's expectations concerning the kind and content of desired information.
- Find out what kind of role the patient wants to have in decision making.
- Find out the patient's expectations and concerns and reflect on them.

In a randomized sample of 1,120 patients in 11 general practices in the Ruhr area, 76.5% of all patients wanted to participate in therapy decisions. Only 5.9% wanted the FAMILY PHYSICIAN to decide alone, and 11.3% wanted to get detailed information in order to decide on their own (84).

Among physicians surveyed, 67% voted for shared decision making, 21% preferred to make decisions alone, 8% wanted the patients to decide, and 4% made it conditional on individual cases (85).

8.2 Motivational interview (86)

Motivational counseling is defined as a client-centered but direct style of counseling that aims at building up intrinsic motivation for behavioral changes by exploring and dissolving ambivalences. Initially, this concept was developed for counseling people with addiction problems. The basic idea is to expose the conflict between the patient's current behavior with the life changes and goals that the patient desires – without urging or confronting the patient. Patients should come to their own understanding of this conflict and its inherent dissonance.

Five principles of motivational interviewing	- **Express empathy**: Employ skillful reflective listening - **Develop discrepancy:** Working to expose differences between present behavior and personal goals - **Avoid arguing for change**. Control and confrontation are counter-productive - **Roll with resistance**: In case of resistance, change the strategy - **Support self-efficacy**: A crucial component for motivational interviewing; the physician believes that changes are possible. This belief is infectious and is an important source of motivation for the patient.
Important aspects for motivational interviewing	- Ask open-ended questions - Listen reflectively - Affirm (show appreciation) - Summarize - Elicit self-motivational statements.
"Philosophy" of motivational interviewing	- Counselor and patient seek solutions cooperatively - Dialogue between two experts - Objective: support the patient in developing the motivation for change. - Everybody has a potential for change that can be set free. - Motivation has to come from the patient. - Arguing for change and confrontation are not suitable.

8.3 Spikes (87)

The Spikes scheme serves as a basic principle in counseling and is mainly applied in palliative care:

Setting	Arrange for privacy, trustful atmosphere, make connection with the patient
Perception	What does the patient know? How does the patient interpret the symptoms? How much can the patient understand? (“Before you tell, ask!“)
Invitation	Did the patient/relatives express a desire for full information (”invitation“)?
Knowledge	Explain at the level of comprehension and vocabulary of the patient. Verify understanding by open-ended questions.
Emotion/Empathy	Accept and respond to the patient’s emotions: ”I understand that this is hard for you.”
Strategy/Summary	Summarize all information. Show consequences and a perspective.

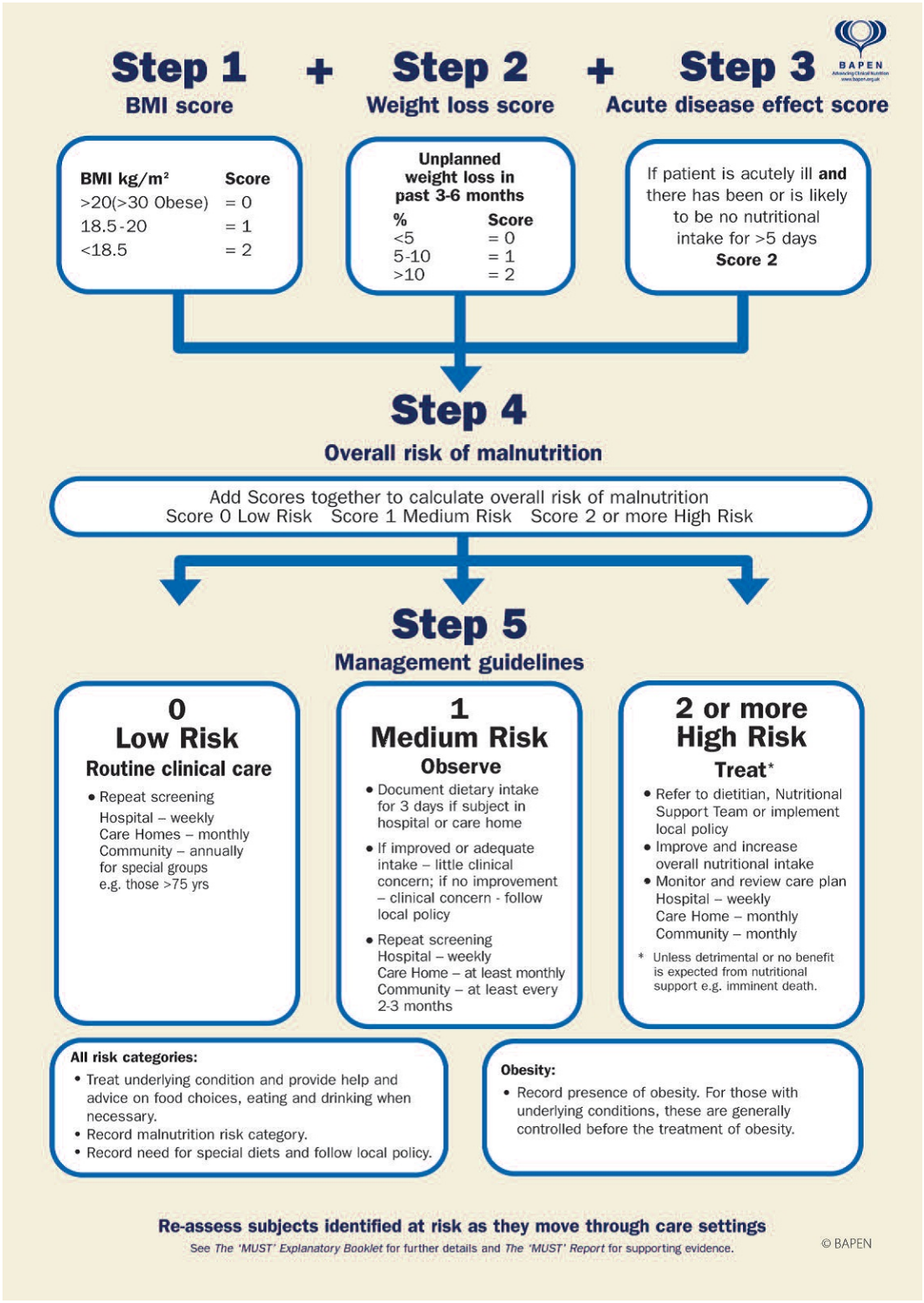
5.2 PERLS (88)

PERLS takes into account five aspects of successful counseling::

Partnership	By attitude and manner of counseling, the physician makes clear a desire work together with the patient to plan, decide, and control all actions for solving the patient’s problems.
Empathy	When talking to the patient, the physician observes and addresses the patient’s emotions. The physician tries to walk in the patient’s shoes and tries to understand the patient’s feelings. This affective feedback method makes the patient feel understood.
Respect	The physician shows explicit appreciation for patients’ efforts to solve their own problems.
Legitimization	The physician accepts the patient’s feelings as understandable; acknowledging emotions like fear, feelings of insufficiency, depression, etc. as a fact. The physician does not try to make the emotions seem exaggerated or overblown.
Support	The physician offers support and actually provides this support if the patient wants it.

9 Appendix

9.1 Malnutrition Universal Screening Tool (MUST) (37)



9.2 Subjective Global Assessment (SGA) (89)

Scored Patient-Generated Subjective Global Assessment (PG-SGA)

Patient ID Information

History (Boxes 1-4 are designed to be completed by the patient.)

1. Weight *(See Worksheet 1)*

In summary of my current and recent weight:

I currently weigh about _____ kg
I am about _____ cm tall

One month ago I weighed about _____ kg
Six months ago I weighed about _____ kg

During the past two weeks my weight has:
☐ decreased (1) ☐ not changed (0) ☐ increased (0)

Box 1 ☐

2. Food Intake: As compared to my normal intake, I would rate my food intake during the past month as:
☐ unchanged (0)
☐ more than usual (0)
☐ less than usual (1)
I am now taking:
☐ *normal food* but less than normal amount (1)
☐ little solid food (2)
☐ only liquids (3)
☐ only nutritonal supplements (3)
☐ very little of anything (4)
☐ only tube feedings or only nutrition by vein (0)

Box 2 ☐

3. Symptoms: I have had the following problems that have kept me from eating enough during the past two weeks (check all that apply):
☐ no problems eating (0)
☐ no appetite, just did not feel like eating (3)
☐ nausea (1)
☐ vomiting (3)
☐ constipation (1)
☐ diarrhea (3)
☐ mouth sores (2)
☐ dry mouth (1)
☐ things taste funny or have no taste (1)
☐ smells bother me (1)
☐ problems swallowing (2)
☐ feel full quickly (1)
☐ pain; where? (3)_____
☐ other** (1) _____

** Examples: depression, money, or dental problems

Box 3 ☐

4. Activities and Function: Over the past month, I would generally rate my activity as:
☐ normal with no limitations (0)
☐ not my normal self, but able to be up and about with fairly normal activities (1)
☐ not feeling up to most things, but in bed or chair less than half the day (2)
☐ able to do little activity and spend most of the day in bed or chair (3)
☐ pretty much bedridden, rarely out of bed (3)

Box 4 ☐

Additive Score of the Boxes 1-4 ☐ A

The remainder of this form will be completed by your doctor, nurse, or therapist. Thank you.

5. Disease and its relation to nutritional requirements *(See Worksheet 2)*

All relevant diagnoses (specify) _____

Primary disease stage (circle if known or appropriate) I II III IV Other _____

Age _____

Numerical score from Worksheet 2 ☐ B

6. Metabolic Demand *(See Worksheet 3)*

Numerical score from Worksheet 3 ☐ C

7. Physical *(See Worksheet 4)*

Numerical score from Worksheet 4 ☐ D

Global Assessment *(See Worksheet 5)*
☐ Well-nourished or anabolic (SGA-A)
☐ Moderate or suspected malnutrition (SGA-B)
☐ Severely malnourished (SGA-C)

Total PG-SGA score
(Total numerical score of A+B+C+D above) ☐
(See triage recommendations below)

Clinician Signature _____ RD RN PA MD DO Other ___ Date _____

Nutritional Triage Recommendations: Additive score is used to define specific nutritional interventions including patient & family education, symptom management including pharmacologic intervention, and appropriate nutrient intervention (food, nutritional supplements, enteral, or parenteral triage). First line nutrition intervention includes optimal symptom management.

0-1	No intervention required at this time. Re-assessment on routine and regular basis during treatment.
2-3	Patient & family education by dietitian, nurse, or other clinician with pharmacologic intervention as indicated by symptom survey (Box 3) and laboratory values as appropriate.
4-8	Requires intervention by dietitian, in conjunction with nurse or physician as indicated by symptoms survey (Box 3).
≥ 9	Indicates a critical need for improved symptom management and/or nutrient intervention options.

9.3 Neuropathy Disability Score (NDS) (40)

Neuropathy Disability Score (NDS)			
		Right	**Left**
Vibration Perception Threshold 128-Hz tuning fork; apex of big toe: normal = can distinguish vibrating/ not vibrating	Normal = 0 Abnormal = 1		
Temperature Perception on Dorsum of the Foot Use tuning fork with beaker of ice/warm water			
Pin-Prick Apply pin proximal to big toe nail just enough to deform the skin; trial pair = sharp, blunt; normal = can distinguish sharp/not sharp			
Achilles Reflex	Present = 0 Present with reinforcement = 1 Absent = 2		
	NDS Total out of 10		

Evaluation:

3-5 mild neuropathic symptoms

6-8 moderate neuropathic symptoms

9-10 severe neuropathic symptoms

9.4 painDetect (48)

painDETECT

PAIN QUESTIONNAIRE

Date: _____ Patient: Last name: _____ First name: _____

How would you assess your pain **now**, at this moment?

0 1 2 3 4 5 6 7 8 9 10

none max.

How strong was the **strongest** pain during the past 4 weeks?

0 1 2 3 4 5 6 7 8 9 10

none max.

How strong was the pain during the past 4 weeks **on average**?

0 1 2 3 4 5 6 7 8 9 10

none max.

Mark the picture that best describes the course of your pain:

- **Persistent pain with slight fluctuations** ☐
- **Persistent pain with pain attacks** ☐
- **Pain attacks without pain between them** ☐
- **Pain attacks with pain between them** ☐

Please mark your **main area of pain**

Does your pain radiate to other regions of your body? yes ☐ no ☐

If yes, please draw the direction in which the pain radiates.

Do you suffer from a burning sensation (e.g., stinging nettles) in the marked areas?

never ☐ hardly noticed ☐ slightly ☐ moderately ☐ strongly ☐ very strongly ☐

Do you have a tingling or prickling sensation in the area of your pain (like crawling ants or electrical tingling)?

never ☐ hardly noticed ☐ slightly ☐ moderately ☐ strongly ☐ very strongly ☐

Is light touching (clothing, a blanket) in this area painful?

never ☐ hardly noticed ☐ slightly ☐ moderately ☐ strongly ☐ very strongly ☐

Do you have sudden pain attacks in the area of your pain, like electric shocks?

never ☐ hardly noticed ☐ slightly ☐ moderately ☐ strongly ☐ very strongly ☐

Is cold or heat (bath water) in this area occasionally painful?

never ☐ hardly noticed ☐ slightly ☐ moderately ☐ strongly ☐ very strongly ☐

Do you suffer from a sensation of numbness in the areas that you marked?

never ☐ hardly noticed ☐ slightly ☐ moderately ☐ strongly ☐ very strongly ☐

Does slight pressure in this area, e.g., with a finger, trigger pain?

never ☐ hardly noticed ☐ slightly ☐ moderately ☐ strongly ☐ very strongly ☐

(To be filled out by the physician)

never	hardly noticed	slightly	moderately	strongly	very strongly
x 0 = 0	x 1 =	x 2 =	x 3 =	x 4 =	x 5 =

Total score ____ **out of 35**

Development/Reference: R. Freynhagen, R. Baron, U. Gockel, T.R. Tölle / Curr Med Res Opin, Vol.22, No. 10 (2006)

painDETECT

SCORING OF PAIN QUESTIONNAIRE

Date: _____ Patient: Last name: _____ First name: _____

Please transfer the total score from the pain questionnaire:

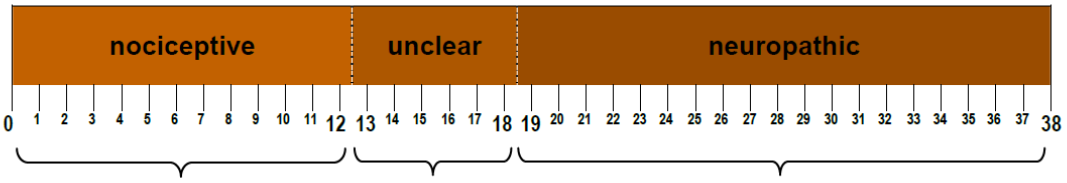
Total score | | |

Please add up the following numbers, depending on the marked pain behavior pattern and the pain radiation. Then total up the final score:

	Persistent pain with slight fluctuations	0	
	Persistent pain with pain attacks	- 1	if marked, or
	Pain attacks without pain between them	+ 1	if marked, or
	Pain attacks with pain between them	+ 1	if marked
	Radiating pains?	+ 2	if yes
	Final score		

Screening Result

Final score



A neuropathic pain component is unlikely (< 15%)	Result is ambiguous, however a neuropathic pain component can be present	A neuropathic pain component is likely (> 90%)

This sheet does not replace medical diagnostics.
It is used for screening the presence of a neuropathic pain component.

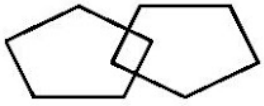
Development/Reference: R. Freynhagen, R. Baron, U. Gockel, T.R. Tölle / Curr Med Res Opin, Vol.22, No. 10 (2006)

9.5 Mini-mental State (90)

Mini-Mental State Examination (MMSE)

Patient's Name: _____ Date: _____

Instructions: Score one point for each correct response within each question or activity.

Maximum Score	Patient's Score	Questions
5		"What is the year? Season? Date? Day? Month?"
5		"Where are we now? State? County? Town/city? Hospital? Floor?"
3		The examiner names three unrelated objects clearly and slowly, then the instructor asks the patient to name all three of them. The patient's response is used for scoring. The examiner repeats them until patient learns all of them, if possible.
5		"I would like you to count backward from 100 by sevens." (93, 86, 79, 72, 65, ...) Alternative: "Spell WORLD backwards." (D-L-R-O-W)
3		"Earlier I told you the names of three things. Can you tell me what those were?"
2		Show the patient two simple objects, such as a wristwatch and a pencil, and ask the patient to name them.
1		"Repeat the phrase: 'No ifs, ands, or buts.'"
3		"Take the paper in your right hand, fold it in half, and put it on the floor." (The examiner gives the patient a piece of blank paper.)
1		"Please read this and do what it says." (Written instruction is "Close your eyes.")
1		"Make up and write a sentence about anything." (This sentence must contain a noun and a verb.)
1		"Please copy this picture." (The examiner gives the patient a blank piece of paper and asks him/her to draw the symbol below. All 10 angles must be present and two must intersect.) 
30		TOTAL

9.6 Short Screening Scale for PTSD (56)

Item	Test-retest κ
In your life, have you ever had any experience that was so frightening, horrible, or upsetting that, *in the past month*…	
1. Did you avoid being reminded of this experience by staying away from certain places, people, or activities?	0.54
2. Did you lose interest in activities that were once important or enjoyable?	0.72
3. Did you begin to feel more isolated or distant from other people?	0.81
4. Did you find it hard to have love or affection for other people?	0.50
5. Did you begin to feel that there was no point in planning for the future?	0.74
6. After this experience were you having more trouble than usual falling asleep or staying asleep?	0.78
7. Did you become jumpy or get easily startled by ordinary noises or movements?	0.63

Responses are YES=1 or NO=0. The scale is scored by summing all responses. Scale scores may range from 0 to 7.

9.7 Patient Health Questionnaire – PHQ (91)

PATIENT QUESTIONNAIRE – PHQ-9

Patient Name: _____ **MRN** _____

Physician: _____ **Date:** _____

Over the last **2 weeks**, how often have you been bothered by any of the following problems?

	Not at all	**Several days**	**More than half the days**	**Nearly every day**
	0	**1**	**2**	**3**
1. Little interest or pleasure in doing things.	☐	☐	☐	☐
2. Feeling down, depressed, or hopeless.	☐	☐	☐	☐
3. Trouble falling/staying asleep, sleep too much.	☐	☐	☐	☐
4. Feeling tired or having little energy.	☐	☐	☐	☐
5. Poor appetite or overeating.	☐	☐	☐	☐
6. Feeling bad about yourself – or that you are a failure or have let yourself or your family down.	☐	☐	☐	☐
7. Trouble concentrating on things, such as reading the newspaper or watching television.	☐	☐	☐	☐
8. Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual.	☐	☐	☐	☐
9. Thoughts that you would be better off dead or of hurting yourself in some way.	☐	☐	☐	☐
	0	_____	_____	_____

A. How difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

☐ Not difficult at all ☐ Somewhat difficult ☐ Very difficult ☐ Extremely difficult

B. In the past **two years** have you felt depressed or sad most days, even if you felt okay sometimes?

☐ Yes ☐ No

Symptoms _____ **Severity Score** _____

10 Literature

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