It is important to get medical attention if you feel unwell, experience obvious symptoms of an infection or have a high temperature. Prompt treatment with antibiotics will usually prevent any recurrence of sepsis.

#### **Returning to work**

You may be apprehensive about returning to work. If you feel you are not fully recovered, you should speak to your employer to see if you can have a phased return to work or change your role to something that would be more suitable.

#### **Finances**

Sick pay varies between employers. There is a benefit called 'Personal Independence Payment (PIP)' that is designed for people who have experienced a life changing illness or disability. However, you can only claim after a three-month period from the start of your illness.

- <u>Citizens Advice's benefits web pages</u>
  provide lots of useful information on
  claiming benefits, and in some cases will
  assist with claims and form filling.
- The <u>UK Sepsis Trust</u> also provides useful information for patients and relatives. Contact 0808 800 0029 or emailinfo@sepsistrust.org.





To find out more about our Trust visit <a href="https://www.royalberkshire.nhs.uk">www.royalberkshire.nhs.uk</a>

Please ask if you need this information in another language or format.

RBFT Haematology/Oncology, June 2022 Next review due: June 2024

## Post Sepsis Syndrome

Information for patients, relatives and carers

Compassionate

Aspirational

Resourceful

Excellent

"You may not control all the events that happen to you, but you can decide not to be reduced by them."

Maya Angelou

This leaflet provides information and advice for patients with post sepsis syndrome, and their friends and families.

#### Who gets sepsis?

Anyone can get sepsis but it is more common in older people, those with diabetes or a kidney condition and people with cancer, especially those receiving chemotherapy or immunotherapy.

### What is sepsis?

Sepsis is a life threatening medical emergency. You probably had an infection such as a lung or urinary tract infection. This triggered an inflammatory response that was so large that your immune system ended up attacking your body.

#### What is post sepsis syndrome?

After recovering from sepsis, you may experience post sepsis syndrome (PSS), which can cause a variety of physical, psychological and emotional problems. It usually lasts between six and 18 months, but sometimes people have symptoms for longer.

### **Physical symptoms of PSS:**

- Lethargy / excessive tiredness
- Poor mobility / muscle weakness
- Breathlessness / chest pains
- Swollen limbs (excessive fluid in the tissues)
- Joint and muscle pains
- Insomnia
- Hair loss
- Dry / flaking skin and nails
- Taste changes
- Poor appetite
- Changes in vision
- · Changes in sensation in limbs
- Repeated infections from the original site or a new infection
- Reduced kidney function
- Feeling cold
- Excessive sweating

# Psychological and emotional symptoms of PSS:

- Anxiety / fear of sepsis recurring
- Depression
- Flashbacks
- Nightmares
- Insomnia (due to stress or anxiety)
- PTSD (post-traumatic stress disorder)
- Poor concentration
- Short term memory loss
- Mood swings.

#### Recovery

Most people do recover from post sepsis syndrome but it can be a difficult time, as although you have left hospital and look better, you are still not feeling well. This may cause problems with your employer, family or doctor, who may expect you to be back to normal. It may help if you share this leaflet with them or ask them to visit UK Sepsis Trust website. Fortunately, with time you are likely to recover completely. Returning to normal life can be very daunting and you may benefit from psychological or physical support. It is important to talk to your GP to discuss the diagnosis. They may decide to refer you to other specialists such as a pain specialist to manage your pain, a counsellor or psychiatrist to manage mental health and emotional problems, or a physio or occupational therapist to manage fatigue. UK Sepsis Trust also has a support line you can call and educational material.

#### **Recurring infections**

Some people who have had sepsis find that they are more prone to infections afterwards. This is because the immune system is not as effective in the years following sepsis. This is particularly true if you have underlying health problems. This can be very frightening as you may be concerned that every time you have an infection, you could get sepsis again.