

Post-sepsis syndrome: the after-effects one cannot see



Sepsis is a traumatic condition, from which the body and mind may take a good deal of time to recover from. Some sepsis survivors experience a variety of physical, psychological and emotional challenges, known as post-sepsis syndrome (PSS), which may last between 6 and 18 months, sometimes even longer.

For some, the after-effects of sepsis are visible but, for many people, there are lasting after-effects that you can't see. It is crucial that friends, families and employers understand the symptoms of PSS. The physical symptoms of PSS are:

- ▶ 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.

The psychological and emotional symptoms of PSS are:

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

WHAT TREATMENT IS AVAILABLE?

There is no specific treatment for PSS, most people will get better with time. Some survivors find that their immune system is not as effective in the

year following their sepsis. They may be prone to infections, e.g. coughs and colds, recurring urine or wound infections.

This can be worrying as many fear that they may get sepsis again. Seek early medical consultation and treatment with antibiotics to make sure the infection does not progress to anything worse. It's important not to neglect any infections — make sure you, and those close to you, know the signs of sepsis and seek urgent medical attention if concerned.

Mark Stock, a strategic advisor to the Trust, is a sepsis survivor who suffered from PSS. Here is his journey to recovery:

"I didn't really understand the enormity of what I had endured; my body had 'attacked itself' and so, as with a major operation, it would take time to recover. A voyage of discovery, self-education and listening to those around me over the following 12 months enabled me to realise that I was not 100% better and that just because I looked OK did not mean I was OK. Three years on, when asked "have I now fully recovered", I have learned to respond that I am about 95% recovered and I have also come to terms with the likely fact that I may never be 100%. I am sure my post-sepsis body is a different body to the one I had before and it has taken me three years to get to know my post-sepsis self and accept that I will not get my pre-sepsis body back. Being able to talk about this in the UKST Sepsis Support groups has been helpful in my own rehabilitation and in coming to terms with my new self. I may not have the same body, and I may have to ask people to repeat themselves as I'm not able to process what's being said as quickly as before but as someone who is known for positivity, to accept the mental impact was tough but has given me renewed focus to ensure others do not suffer in silence and I will continue to encourage employers not to assume that the external appearance tells all."

We take pride in supporting those affected by sepsis and we are happy to report that our reach has grown exponentially. This week saw the opening of our new Somerset Support Group, and we are proud to announce that we have opened eleven new support groups around the UK since January. **WUK**

Sepsis Trust Helpline

If you or someone you know are struggling with recovery from Sepsis, call our helpline and speak to a member of our support team on:

0808 800 0029

Calls will be answered by trained nurses with an understanding of sepsis and the problems that can occur during recovery.

Alternatively, you may find guidance on our website at:

www.sepsistrust.org/get-support