

Chronic Fatigue Following Sepsis



What is chronic fatigue?

Chronic fatigue is the term used to describe the excessive tiredness which affects an individual most of the time and has continued for a long period. This tiredness or exhaustion is not relieved by sleep or rest periods and can affect someone physically, psychologically and emotionally. It can be life changing. Chronic fatigue is extremely common following sepsis and can last for several months, even years, making recovery very difficult. It is part of Post Sepsis Syndrome (PSS).

What causes fatigue following sepsis?

The exact cause of chronic fatigue after sepsis is unknown but the following are thought to be contributing factors:

Physical

- Loss of body's physical reserves following sepsis
- The need for extra energy to repair and heal the body after a life threatening illness
- A poor nutritional state due to the initial critical illness, followed by taste changes and a reduced appetite afterwards
- Muscle wastage which causes weakness
- Pain and breathlessness which aggravates insomnia
- Oedema (excessive fluid in the tissues) which makes the affected limbs very heavy to move
- A poor functioning immune system where repeated infections delay recovery
- Any serious pre-existing medical conditions

Psychological

- Anxiety and depression
- Flashbacks
- Post Traumatic Stress Disorder (PTSD)
- Insomnia due to nightmares, anxiety and depression

How does it affect you?

The signs and symptoms of chronic fatigue can take many forms and will vary from person to person. Many people only have a few symptoms. The most common are:

- Being excessively tired nearly all of the time
- Feeling dizzy, faint and /or sweating
- Feeling nauseous
- Muscle and /or joint pain which is sometimes associated with low vitamin D levels
- Finding it hard to sleep and not feeling refreshed when you wake
- Not being able to concentrate or make decisions
- Not being able to remember things
- Finding it physically difficult to speak properly at times
- Feeling very weak, sometimes with shaking limbs
- Experiencing changeable moods, often being tearful or irritable for no apparent reason
- Finding relationships hard

- Loss of sex drive
- Finding normal daily tasks too much eg. getting dressed
- Being susceptible to further infections

How long is it likely to last?

If you are affected by chronic fatigue after sepsis it may only last for a few weeks but usually it lasts for several months and in a small number of cases, for years. Your recovery in general can be affected by the severity and duration of your initial illness, how long you were in hospital for and how fit you were beforehand.

How do you manage chronic fatigue?

Diet

Eat a nourishing diet and take supplement drinks eg. Build Up, Ensure or Fortisip drinks or desserts. These can be bought from chemists or larger supermarkets. Diabetics can also drink these, provided you sip them slowly over a least 20 minutes, so they don't affect your blood sugar too much. Even one a day will provide extra nutrition and help reverse any weight loss.

Alternatively, try adding unflavoured, high energy powders to your meals which add calories without extra volume. All of the above can be prescribed by your GP.

Eat foods that you fancy and taste good to you. Have small, frequent meals so your body isn't overwhelmed by large meals. Then gradually work up to normal meal sizes.

Ask your GP for medication to ease nausea or to refer you to a dietitian for advice if you are struggling to eat enough. Drink plenty of fluids (provided you don't suffer from heart failure or kidney failure) but avoid sweet, fizzy drinks which have empty calories, alcohol and drinks containing caffeine at bedtime, as these may aggravate insomnia.

Exercise

Stay as active as your condition allows. Try taking short walks when you are able. You may only manage to the end of your driveway initially. You could ask a friend to come with you if it helps and gives you confidence.

Pick a type of exercise you enjoy and ask your GP if it would be suitable for you eg. walking, yoga or swimming. S/he can refer you to a physiotherapist who can suggest exercises to strengthen your muscles and loosen up stiff joints. Exercise may even improve your appetite.

Graded Exercise Therapy (GET)

This exercise programme involves setting goals which will help you gradually increase the time and difficulty of the exercise you can do. Exercise such as walking or swimming are often used. This should always be overseen by a trained specialist. Speak to your GP if you think this might help.

Pacing

Pacing is a way of balancing exercise or activity with rest periods to ensure you don't over exert yourself. You gradually increase the amount you do within safe limits. Doing too much before you're ready may actually slow down your progress. Pacing can help you make the most of the energy you have and plan your day accordingly, so when you feel more energetic you do activity, then rest when you're tired. Keeping a diary of the highs and lows in your energy levels and what seems to affect it will help eg. amount and quality of sleep. Again, this should be done with the supervision of a trained specialist, so ask your GP if there are any in your area.

Rest

Allow yourself time to rest sufficiently for your needs. Let friends and relatives help you with housework, shopping and childcare. Listen to your body and rest when you've had enough and try again later when you feel better.

Try and relieve insomnia by creating a bedtime routine so you go to bed and rise in the morning at similar times each day, so your body clock will know when to expect sleep and wakeful periods. If you need a nap during the day, try not to sleep for too long in case it ruins your sleep at night.

Have a warm, milky drink before bedtime (not caffeine based) with a couple of biscuits as hunger may keep you awake.

If you can't sleep, get out of bed and go into another room to read, do a jigsaw or listen to music, anything that relaxes you. Some people find writing down any problems they have reduces their anxiety levels and breaks their problems down to a manageable size.

If you struggle to get off to sleep, try leaving a radio on very quietly in the bedroom, so your brain will be distracted and not churn any anxieties over and over in your head.

Pain

Your GP should be able to help with any pain issues and prescribe analgesia if appropriate. This would hopefully allow you to rest more effectively. They may recommend you see a physiotherapist or an osteopath or possibly try relaxation techniques or acupuncture. Ask your GP what exercise would be suitable for your condition which would not aggravate any pain issues. If you are struggling to cope with the pain, s/he may refer you to a pain clinic for specialist advice.

Dizziness

Sepsis survivors can often feel dizzy even when they are lying down. This is thought to be connected to a mal function in the body's 'autonomic nervous system' which controls automatic functions like your pulse, blood pressure, bladder, gut and sweating mechanism. If you feel dizzy frequently and for no apparent reason, ask your GP to check your pulse, blood pressure and balance etc to see if it's normal. Problems with balance can be caused by conditions in your inner ear.

Work and Finances

It may be helpful to consider a change in your work commitments if the fatigue lasts for a significant time. You may be better reducing your hours temporarily or even permanently to fit your new situation. Obviously, this will depend on your employer. You may find your employer has never heard of sepsis and doesn't have any insight into how long your recovery will take. It can help to show your employer our booklet 'Sepsis: A Guide for Patient's and Relatives' so they have greater understanding of what you're going through. Most employers are fairly reasonable about having **some** time off sick but eventually you will have to review your work situation. You may even have to accept not returning to work at all because the 'new you' may not be quite fit enough.

Finances may be stretched while you are recovering. Many employers will continue paying your salary for several months and then ask for your situation to be reviewed. Others will only pay for a few weeks. Some people will have to rely on statutory sick pay. The government now provides a benefit called Personal Independence Payment (PIP) which 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. The Department for Work and Pensions GOV.UK (DWP) will be able to advise you. Go to their website and then click on 'Benefits' and 'PIP'

Anxiety and Stress

Anxiety and stress increases the work load for the body and so uses up vital energy resources. Techniques which encourage you to relax will help with chronic fatigue. This can be relaxation techniques using exercises and tapes or complementary therapies like meditation or reflexology. If your anxiety becomes too difficult to cope with, Cognitive Behavioural Therapy (CBT) may be appropriate.

This therapy aims to change the way you feel about your condition and helps you break your problems down into smaller, manageable ones which can reduce the impact your physical condition has on your life. This should only be done by a trained therapist. Your GP will be able to refer you but there may be a long waiting list.

Where can I get help?

You have experienced a 'life changing' illness and it will take some time before you feel 'near normal' again. Chronic fatigue is one of the most difficult symptoms you may have to deal with but if you understand why it's happening, it should be easier to manage. The months following sepsis can be a very lonely, isolating time and it may be hard to know where to go to for help, or even what help is available. Remember, informal help and support can be as beneficial as any qualified input. Below are listed people who should be able to help you:

- Family and friends
- Hospital Long Term Follow Up clinics
- UK Sepsis Trust: for advice and information, booklets, one to one support, 'IN Touch' service support groups, Forum, Social media
<http://sepsistrust.org/> or phone 0800 389 6255
- GP: physiotherapist, occupational therapist, dietitian, counsellor or psychologist, pain or dizzy clinics
- Religious / spiritual support
- Government Department of Work and Pensions www.gov.uk/pip/overview

Acknowledgements

NHS Choices : Your health, your choices www.nhs.uk – Chronic Fatigue

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UK Sepsis Trust.

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