After meningitis

A guide to coping with life after meningitis and/or meningococcal disease

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National Meningitis Trust

Fighting meningitis through research, information and support
TAKING TIME TO RECOVER

Just because meningitis and meningococcal septicaemia patients are well enough to leave hospital, it doesn’t mean they are always ready to return to normal life. Meningitis and sepsis can be followed by a variety of after effects. Some of these effects are permanent and can cause physical disabilities and some are less obvious, affecting the individual emotionally.

Although many people will make a fast and complete recovery, others will need a lot of support and care over the weeks and months following their illness. Unfortunately, it is impossible to predict which of the after effects, if any, a person may suffer. With a serious illness like meningitis, even when treatment is complete, people of any age can take some time to recover. This leaflet explains what to look out for and where to go for help with different problems.

A GUIDE TO WHAT CAN HAPPEN

People who have had viral meningitis are just as likely to suffer after effects as those who have had bacterial meningitis and meningococcal septicaemia. The symptoms and possible long-term complications of all forms of meningitis and septicaemia can be similar (although people will be affected in different ways).

With over 10 years’ experience of helping individuals affected by meningitis and meningococcal septicaemia, we have been able to make a list of the after effects they may face. Some people may not have any of these complications and will make a fast and problem-free recovery. The after effects are listed with the most common at the top and so on (based on cases reported to us over the last few years). Remember, treat this list as a guide.

Young children

A child could get any of the after effects listed below after experiencing a serious illness.

- Babyish behaviour, being extra clingy.
- Temper tantrums.
- Forgetting skills they have recently learned.
- Demanding attention.
- Wetting the bed.
- Waking up during the night, nightmares and sleep walking.

The younger the child, the harder it is for them to tell you how they feel. They may behave differently, be more clingy, have unexpected temper tantrums or demand attention in unexpected ways. Some children may seem to get one minor illness after another when they have had a major infection such as meningitis. All this is quite common and will improve in time if you give the child plenty of patience and understanding.

With very young children it is difficult to know how many of the after effects are caused directly by the illness, and how many are caused by them staying in hospital.

All children and adults

- General tiredness
- Headaches
- Finding it difficult to concentrate
- Short-term memory loss
- Forgetfulness
- Giddiness
- Balance problems
- Depression
- Violent temper tantrums
- Bouts of aggression
- Mood swings
- Learning difficulties and falling behind in some areas of school work. (It is important to talk to your child’s teachers, or lecturers at college or university, if he or she is having any problems at school or college)
- Deafness
- Tinnitus (ringing in the ears)
- Sore or stiff joints
- Eyesight problems
- Epilepsy
- Brain damage

THE MOST SERIOUS COMPLICATIONS

One of the most common after effects is deafness. It affects around one in 10 people and can be temporary or permanent.

Anyone who has had meningitis should have a hearing test. This is especially important for young children because deafness is often more difficult to detect in them. Children’s hearing tests can be arranged through your family doctor or the local ENT (ear, nose and throat) department. It is important that you keep the appointment for this test.

Other serious complications can include brain damage, epilepsy and changes in eyesight. Behavioural problems such as violent temper tantrums, aggression, mood swings and learning difficulties can also be long-term problems.

During the illness, some people can develop septicaemia (blood poisoning), and in extreme cases, they may require skin grafts or even have limbs, fingers or toes amputated. The rash, which is a symptom of septicaemia, can leave scarring on the skin, in most cases this may fade with time.

BEING PATIENT

As the list shows, some of the most common after effects are emotional, not physical, but they can still affect the individual’s quality of life dramatically. For example, if a sufferer is left feeling tired, depressed and unable to concentrate, it may be weeks or even months before they can return to a normal routine.

The less stress the sufferer has while he or she is recovering, the sooner he or she will improve. It is important that the sufferer does not rush themselves and listens to what their body is telling them. Don’t try too much too soon. “Complementary” medicines, such as acupuncture and aromatherapy have helped many sufferers deal with the after effects.

CAN ANYONE GET MENINGITIS AGAIN?

Yes. But it is unusual for anyone to get the disease more than once. Sometimes it is possible for someone to suffer pneumococcal meningitis more than once, because of a tiny fracture or problem in the skull.

SOCIALISING WITH SUFFERERS

People who have been in close, prolonged contact that is living or sleeping in the same household, or intimate kissing contacts eg boyfriend or girlfriend, with someone who has contracted meningococcal disease, will be offered a short course of antibiotics. This should reduce the risk of the bacteria being passed on to other people. The patient will also be given antibiotics as part of their treatment to make sure they can no longer pass on the bacteria.

If the patient has got meningococcal group A or C disease then the close contacts may also be offered a vaccine.