

A guide to recovering from meningitis and meningococcal sepsis/septicaemia for adults

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What are meningitis and sepsis?

Meningitis and sepsis can be caused by viruses, bacteria and fungi. Bacterial causes can be very severe and may be rapidly fatal if not treated quickly.

Meningitis: the swelling of the meninges (the lining around the brain and spinal cord).

Sepsis: is the body's overwhelming response to infection that can lead to tissue damage, organ failure and death. **Sepsis is sometimes referred to as septicaemia.**

Meningitis and sepsis can occur separately or together.

1: INTRODUCTION

Bacterial meningitis and meningococcal sepsis are relatively uncommon, but when they do occur they can be very serious life-threatening diseases. Although most people who get meningitis and/or sepsis recover, around a third of those who survive will be left with after effects. While most after effects are either short term or relatively minor, they can be as severe as deafness, brain injury, or damage to limbs leading to amputation. After effects may be temporary or permanent, physical or emotional.

While babies, pre-school children and adolescents are at high risk of contracting bacterial meningitis, it affects all ages. Some strains of meningitis are more common in adults.

The information in this booklet has been written specifically for adult survivors of meningitis and meningococcal sepsis and their families. If you need information about recovery in children, Meningitis Research Foundation provides specific information on this in a booklet called 'Your Guide' which comes with a Journal where you can make specific notes about your child's recovery.

Everyone responds to their own situation differently but many people are unsure of what to expect after meningitis and sepsis. Those around them such as relatives, friends, colleagues and employers may also be unsure of what will happen next. People recovering from this illness often need a great deal of support and it can take a long time to recover.

Although many problems improve and disappear over time, other after effects may be permanent. Physical disabilities may be obvious but subtle neurological and emotional problems can also be persistent and debilitating.

Viral meningitis can also be problematic for a significant number of patients. It is rarely life threatening (except where encephalitis is also a factor) and usually resolves without treatment, but it can leave survivors with short and long term after effects (see section 6).

Meningitis Research Foundation has been working with individuals and families affected by meningitis and meningococcal sepsis since 1989. With the knowledge gained through our ground-breaking research many important steps have been taken to improve prevention, detection and treatment, but for those who have experienced the diseases, our support can make a real difference. Because meningitis is often thought of as a disease which affects children, we know it can be difficult for adults to find information relevant to them. This booklet gives information about after effects

based on our experience with patients, their families and friends, as well as the doctors, nurses and scientists who deal with these diseases. It has been written with the help of health professionals representing the range of disciplines involved in looking after patients recovering from meningitis and meningococcal sepsis.

If you would like to talk through your experience of after effects please contact us via our website www.meningitis.org or call the free helpline 080 8800 3344 (UK), 1800 413344 (Ireland), which is open Monday – Friday, 9am – 5pm . Many people find it helps to talk to someone who understands their experience and the MRF team can help.

2: WHO HAS AFTER EFFECTS?

Meningitis and meningococcal sepsis can cause a range of after effects:

- Memory loss/lack of concentration/difficulty retaining information
- Clumsiness co-ordination problems

- Headaches
- Deafness/hearing problems/tinnitus/dizziness/loss of balance
- Epilepsy/seizures
- Weakness/paralysis/spasms
- Speech problems
- Loss of sight/vision problems

After effects most likely to be caused by meningitis

- Arthritis (joint and pain stiffness)
- Scarring/skin damage
- Amputations
- Organ damage (such as kidney damage)

After effects most likely to be caused by meningococcal sepsis

Most people recover with no after effects and even for those who are left with after effects, not all are permanent. The likelihood of getting after effects from meningitis and sepsis depends on several factors, including the type of bug that caused the illness, the age of the person who is unwell and how severe the illness was. People who have been seriously ill may have spent a long time in Intensive Care and this can be distressing for the patient and for their family, resulting in a type of post-traumatic stress disorder; this is well described in NICE guideline Rehabilitation after Critical Illness[1]. Patient information about the guideline is available from <https://www.nice.org.uk/guidance/cg83/resources/rehabilitation-after-critical-illness-pdf-314007525061>

The majority of cases of bacterial meningitis in adults are caused by pneumococcal bacteria, but meningococcal bacteria are also a major cause. Serious complications of meningitis and sepsis such

as deafness, brain damage, digit or limb loss and skin damage, happen during the acute phase of the illness. Most people who go home from hospital without any obvious effects, particularly adults, need not worry that new problems will develop after the illness. If you develop some of the known after effects many years later there is likely to be another cause, so you should seek medical advice.

3: INITIAL STAGES OF RECOVERY

DISCHARGE FROM HOSPITAL

It is important for clinicians planning the discharge of patients after bacterial meningitis or associated sepsis to understand typical patterns of recovery, potential after effects and specific recommendations for follow-up care.

A guideline on the diagnosis and management of acute meningitis [2] recommends that:

- All patients should be assessed for potential long term physical and psychological after effects before discharge from hospital
- Patients who received treatment in critical care should have their rehabilitation needs assessed in alignment with the NICE guidance on rehabilitation after critical illness [1]
- Patients should have a hearing test before discharge from hospital or within 4 weeks of being well enough if the patient, their family or the clinician thinks the patient's hearing has been affected
- All patients with confirmed or probable bacterial meningitis should be offered a follow up appointment six weeks after discharge from hospital
- Patients with rehabilitation needs at discharge should be given a rehabilitation plan
- Patients and their families should be provided with contact details of support organisations such as Meningitis Research Foundation.
- All patients should have an HIV test as a precaution because this is a potential cause of meningitis.

FOLLOW-UP

A follow-up appointment should be offered to anyone who has had bacterial meningitis

Follow-up care is important because difficulties with co-ordination, mood, concentration and memory may not be immediately obvious when a patient is in hospital and follow-up appointments provide an opportunity to discuss any problems and get support if needed.

Several studies have shown that follow-up appointments are not always routinely offered. In a study of adolescents with meningococcal disease [3] only half were offered any post-discharge follow-up care, although those who had been treated in ICU were more frequently followed up than other patients. No patients were given extra support for school or college work or referred to a mental health professional, although 20% had findings in the clinical range for depression. In a more recent study of parents whose children recovered from bacterial meningitis and meningococcal disease, respondents reported that aftercare needs were only met in about 50% of cases [4].

GOOD AND BAD DAYS

It can take many months to recover from meningitis and sepsis, although it is also possible to be completely back to normal within a matter of weeks.

Many patients feel well at discharge from hospital and don't realise that they will not be able to slot back into their normal life immediately [5]. They are often shocked to discover they are very tired and lacking in energy. If you feel this way, it is important to pace yourself and build up activity levels slowly because the body needs time to recover. Returning to work or college too early, or too energetically, can be overwhelming and slow down recovery. If it's possible to return to work or study part time at first, so as not to over-tire, your recovery is likely to be smoother. It is important to explain to employers or teachers that you may need extra time off, and your doctor should be able to support you with this.

It is quite normal to experience headaches and fatigue when you first go home but these should improve in the first few weeks.

DEALING WITH NEGATIVE EMOTIONS

A small number of patients are left with severe and permanent after effects following meningitis and/or sepsis. Coming to terms with a disability can be very difficult. Everyone copes in their own way and the experience can provoke all sorts of emotions. It is striking how many people maintain a positive and determined attitude while recovering, but it is not unusual to feel angry, saddened or uncertain about the future. Don't underestimate the impact on other family members as well. They may also feel angry or even guilty that they didn't 'do more' to help, however unfounded this may be.

Sharing these feelings may be helpful. Some people are able to talk to friends and family while others find talking to someone outside their close network is more helpful. Your GP can refer you for NHS-funded counselling (for which there will be a waiting list); there are private options (you can find a registered therapist via the British Association for Counselling and Psychotherapy [6]); or if you would just like to talk to someone who has been through a similar experience rather than a qualified counsellor, you can contact MRF and ask about our Telephone Befriending Network. MRF's support services staff can also provide a listening ear.

4: NEUROLOGICAL, BEHAVIOURAL AND EMOTIONAL AFTER EFFECTS

Bacterial meningitis and meningococcal sepsis are severe illnesses so it is completely natural to have emotional problems while getting over the ordeal of being so ill. If recovery is prolonged, that in itself can lead to frustration and depression.

The illness itself, which causes swelling around the brain and spinal cord, can also lead to an acquired brain injury, not dissimilar to the kind of injury you may have if you've hit your head in a car accident for example. This can lead to after effects such as epilepsy, headaches and problems with movement or speech. It can also result in loss of short-term and working memory, poorer performance in executive functioning skills (such as planning, attention and multi-tasking) [5] and cognitive slowness [7, 8]. Sleep can also be seriously disrupted [9]. Other reported after effects

include loss of confidence, anger and aggression, increased anxiety and depression. Some people have very subtle neurological after effects and say that they 'no longer feel like themselves'.

A Norwegian study indicated that neurological disturbance following meningococcal disease may be more common amongst adults compared to children. When followed up one after 7 of 52 adults (13.5%) and 1 in 41 (2.4%) children showed abnormalities in neurological examination [10].

Usually emotional and psychological disturbances get better over time without outside help, but it is important to seek help for emotional problems that do not improve, for example, feeling continuously upset and crying, or withdrawn. For cognitive, memory and executive functioning problems, neuropsychological assessment can help to identify which functions of the brain are not performing as well.

If you have any concerns it is important to speak to your GP, or raise these with the hospital clinician during the follow up appointment as they will be able to refer out to more specialist help if this is required. Patients should have access to neuropsychological and neurological assessment if there are concerns about a brain injury following meningitis[2].

Headway, the brain injury association, has many excellent publications with practical tips on coping with the effects of acquired brain injury such as:

- Managing Anger after brain injury
- Managing Fatigue after brain injury
- Memory problems after brain injury
- Psychological effects of brain injury
- Problem with movement after brain injury
- Supporting children when a parent has had a brain injury

<https://www.headway.org.uk/about-brain-injury/individuals/information-library/>

5: PHYSICAL AFTER EFFECTS

Bacterial meningitis and meningococcal sepsis can cause temporary or permanent physical after effects. It is important for clinicians planning the discharge of patients after bacterial meningitis or sepsis to explain potential physical after-effects and make specific recommendations for follow-up assessment and treatment.

HEADACHES

Severe headaches during meningitis happen as a result of inflammation of the meninges, nearby nerves and raised pressure within the head.

Headaches are also frequently reported in those who have recovered from bacterial meningitis [11]. After meningitis, headaches may take a while to go away, even though the infection itself has been cured. These headaches may recur for months or even, rarely, years. This can be very frightening for

someone who has had meningitis because the headaches may make them feel as if they are becoming ill again.

If headaches persist you should discuss them with the hospital doctor during the follow up appointment. If headaches recur after this then it is important to talk to your GP who can decide if painkillers might help, or if a referral to a specialist is needed.

Some people find alternative therapies, such as acupuncture or cognitive behavioural therapy (CBT), helpful in dealing with recurrent headaches.

The “Headaches in over 12s: diagnosis and management” guideline from NICE can be useful in helping to understand what your GP can do: <https://www.nice.org.uk/guidance/cg150>

HEARING LOSS AND TINNITUS

Deafness, tinnitus (ringing, hissing, buzzing or other noises in the ears or head) and other hearing problems can occur after meningitis or meningococcal sepsis. Hearing loss is the most common long-term after effect of bacterial meningitis.

Hearing impairment in adults can be mild or affect only one ear. Hearing loss usually happens early in the course of the illness and may be noticeable to the person recovering from meningitis, their family or the clinicians treating them. If hearing loss is suspected it is important to get a hearing test as soon as possible.

It is possible for hearing loss to be temporary following meningitis so hearing tests should be repeated to review the situation if the initial test indicates hearing loss.

Delayed hearing loss after bacterial meningitis is extremely uncommon but has been reported [14].

PROBLEMS WITH MOVEMENT OR POSTURE

Brain injury from meningitis can damage the nervous system and affect the signals sent from the brain to the muscles in the body. This type of damage is called neuromotor impairment, and while it is rare for this to happen in adults who have had meningitis, it can occur. This can affect muscle activity and could make everyday activities, such as walking, speaking or gripping, more difficult.

The affects could be subtle or more severe, but if you notice any changes to the way your muscles seem to be working – such as weakness, changes to the way you move or difficulties performing everyday actions – you should speak to your doctor so that they can help you.

While damaged brain cells do not regenerate, the brain can reorganise itself to some extent to help you regain lost function. Rehabilitation after brain injury from meningitis can help the brain learn new ways of sending signals to your muscles or cope with any changes to the way they are working.

You can find out more information on rehabilitation after brain injury in a guide from Headway, the brain injury association: <https://www.headway.org.uk/media/4001/rehabilitation-after-brain-injury-e-booklet.pdf>

SKIN AND ORGAN DAMAGE, SCARRING AND AMPUTATIONS AFTER MENINGOCOCCAL SEPSIS

Large numbers of bacteria in the bloodstream release toxins which cause blood vessels to become leaky. Physical damage from sepsis is caused by reduced blood supply and increased blood clotting in various parts of the body. If the blood supply is cut off for a prolonged period it can cause permanent damage to skin, muscle, bones and organs.

Skin and muscle damage may need skin grafts to improve the appearance and restore the function of injured areas. More severe cases of meningococcal sepsis may result in the loss of fingers and toes, or if larger areas of the body are affected surgical amputations of limbs or parts of limbs may be necessary.

FURTHER INFORMATION AND SUPPORT

At Meningitis Research Foundation, we have many years' experience in providing emotional and practical support to people affected in any way by meningitis and sepsis. We also run a dedicated befriending service to put you in contact with someone who has been through a similar experience. Please reach out and make contact with us if you are struggling – you do not have to feel alone.

6: VIRAL MENINGITIS

Viral meningitis is more common than bacterial meningitis. Many different viruses can cause it, but the enteroviruses (which can also cause stomach upsets and respiratory illnesses) and herpes viruses (such as those that cause shingles, cold sores and genital herpes) are the most common causes of viral meningitis in the UK. Cases of viral meningitis are difficult to differentiate from bacterial meningitis based on clinical features alone, so patients may initially be treated with antibiotics until results of lumbar puncture give a diagnosis of viral meningitis and antibiotics are stopped.

There are currently no treatments with a proven benefit for the common causes of viral meningitis. Some clinicians treat patients who have herpes meningitis with the antiviral medications aciclovir or valaciclovir, but there is no strong evidence to support this practice and it is not effective against other viruses such as enteroviruses [16].

Viral meningitis is often reported as a benign, self-limiting illness. However, there is mounting evidence that some patients can experience after effects such as cognitive dysfunction [17], sleep disturbances [9], Chronic Fatigue Syndrome [18], persistence of headache (more than 21 days) [19], anxiety and depression [16]. One study, funded by MRF, found that compared to the general population patients recovering from viral meningitis had reduced quality of life for at least 1 year after the acute illness [16].

It seems that the management of patients with viral meningitis varies considerably and for many people the feeling of 'not being believed' can add to the stress and frustration of an already difficult recovery period.

Rarely, viruses (principally HSV-2) can cause recurrent episodes of meningitis [20] (sometimes referred to as Mollaret's meningitis), which can be very debilitating and impact on work and family life. Patients with recurrent episodes of viral meningitis should be assessed by an infection or neurological specialist [2].

Meningitis Research Foundation's support services are regularly contacted by people who have had viral meningitis and reporting their experience of recurring headaches, fatigue, irritability, reduced concentration, memory loss, mood swings, anxiety and depression. In the early weeks after the acute illness recovery can often be up and down and it is important to 'listen' to the needs of your body, build up activity levels gradually and not try to do too much too soon. Where possible, a phased return to work generally leads to better outcomes.

If the after effects persist beyond a few weeks then a visit to your GP is necessary. They may wish to refer you to a neurologist, an infectious diseases specialist or a specialist clinic, such as a headache

clinic or memory clinic. If the fatigue last longer than 3 months your GP may consider referral to a specialist chronic fatigue clinic.

7. USEFUL LINKS

AMPUTATIONS AND SCARRING

Changing Faces

Telephone: 0300 012 0275

www.changingfaces.org.uk

Offers advice and support to people living with facial and other disfigurements and also to their families. UK wide.

Limbless Association

Telephone: 0800 644 0185

www.limbless-association.org

Provides information, advice and support for people of all ages who are without one or more limbs. UK wide.

Steps

Telephone: 01925 750271

www.steps-charity.org.uk

Helpline for people with hip and lower limb conditions. UK wide.

ARTHRITIS

Versus Arthritis/Arthritis Care

Telephone: 0800 5200 520

Email: helpline@versusarthritis.org

<https://www.versusarthritis.org>

Providing information/support for people with arthritis, their families, friends, carers and health professionals. UK wide.

BRAIN INJURY

Headway

Telephone: 0808 800 2244

Email: helpline@headway.org.uk

www.headway.org.uk

Works with individuals and their families to improve life after brain injury. UK wide.

CARERS

Carers UK

Telephone: 0808 808 7777

www.carersuk.org

The helpline provides information on all aspects of caring for someone with a disability or illness, including benefits, services and local contacts for carers. UK wide.

CHRONIC PAIN

Pain Association of Scotland

Telephone: 0800 783 6059

www.chronicpaininfo.org

Network of self-management training groups, education and peer support for people with any chronic painful condition. Scotland only.

Pain Society

Telephone: 020 7269 7840

www.britishpainsociety.org

Publishes booklets to help sufferers of chronic pain.

DEPRESSION/PSYCHOLOGICAL EFFECTS

Depression Alliance

Telephone: 0845 123 2320 answerphone for information pack

Telephone: 0808 802 2020 (Scotland only)

www.depressionalliance.org

Offering information and support for people and their carers affected by depression. UK wide.

SANEline

Telephone: 0300 304 7000

www.sane.org.uk

info@sane.org.uk

Helpline providing information and support for people with mental ill health, their families, carers, friends and professionals. UK wide.

Mind Infoline

Telephone **0300 123 3393**

<https://www.mind.org.uk/>

info@mind.org.uk

Text: 86463

Telephone, text and online service that offers support around mental health issues, where to get help, medication, alternative treatments and advocacy

DISABILITY

Disabled Living Foundation Helpline

Telephone: 0300 999 0004

www.dlf.org.uk

Helpline for people with disabilities and their carers, offering advice and information on all aspects of equipment for daily living. This organisation also has a display centre of disability equipment in London. UK wide.

REMAP

Telephone: 0845 130 0456

<https://www.remap.org.uk/>

data@remap.org.uk

Retired engineers use their expertise to make one off technical aids, free of charge, to help disabled people of all ages. UK wide.

Department for Work and Pensions

www.gov.uk/rights-disabled-person

www.gov.uk/financial-help-disabled

Provides information for people with disabilities on their civil rights and benefit entitlement. UK wide.

ENCEPHALITIS

Encephalitis Society

Telephone: 01653 699599

www.encephalitis.info

Telephone support and information for people affected by encephalitis, their families, friends and health professionals. Comprehensive information on the website. UK wide.

EPILEPSY

Epilepsy Action

Telephone: 080 8800 5050

www.epilepsy.org.uk

helpline@epilepsy.org.uk

Helpline which offers advice and information for people with epilepsy, their family, doctors and other health professionals. UK wide.

National Society for Epilepsy

Telephone: 01494 601400

www.epilepsysociety.org.uk

enquiries@epilepsysociety.org.uk

Helpline offering confidential information, time to talk and emotional support for people with epilepsy and health professionals. Can provide written information. Also offers translation service.

HEARING PROBLEMS

Hearing Link

Telephone: 01323 470185 (minicom) or 07526 123255

www.hearinglink.org

helpdesk@hearinglink.org

The UK hearing loss organisation that helps people find the right information, appropriate services, and meaningful connection with others.

Action on Hearing Loss Information Line

(Formerly RNID)

Telephone: (voice) 0333 240 5659 (voice)

Telephone: (textphone) 0808 808 9000

SMS 0780 0000 360

www.actiononhearingloss.org.uk

informationline@hearingloss.org.uk

Information service for deaf and hard of hearing people, their carers, families and professionals. UK wide.

Hear Together

<https://www.hear-together.org.uk/>

info@hear-together.org.uk

Community-based support and information and social, learning and well-being activities to bring together adults, children and families with experience of hearing loss.

HYDROCEPHALUS

SHINE (Spina Bifida, Hydrocephalus, Information, Networking, Equality)

Telephone: 01733 555988

www.shinecharity.org.uk

firstcontact@shinecharity.org.uk

Provides information and a range of support services for people with hydrocephalus and their carers. Covers England, Wales and Northern Ireland.

SIGHT PROBLEMS/VISUAL IMPAIRMENT

RNIB Helpline

Telephone: 0303 123 9999

www.rnib.org.uk

Helpline offering information, support and advice for anyone with a sight problem. UK wide.

TINNITUS

British Tinnitus Association

Telephone: 0800 018 0527

www.tinnitus.org.uk

helpline@tinnitus.org.uk

Helpline providing information for people with tinnitus, their families, and details of self-help groups.
UK wide.

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