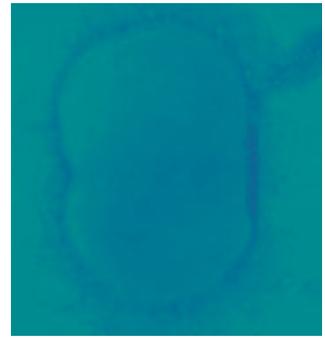


Meningitis and Septicaemia

What happens next?



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INTRODUCTION

Bacterial meningitis and meningococcal septicaemia are relatively uncommon, but are very serious diseases which claim hundreds of lives every year. Most people who get meningitis and septicaemia survive, often without any after effects, but sometimes these diseases cause a range of disabilities and problems that can alter people's lives. After effects may be temporary or permanent, physical or emotional.

People respond to their own situations differently, but frequently are unsure of what to expect after meningitis and septicaemia. Relatives and friends may also feel the need for information, because the person who is recovering often needs a great deal of support. Getting over meningitis and septicaemia makes major demands on people. Fortunately, many problems improve and disappear over time.

Meningitis Research Foundation has over ten years experience of working with and supporting individuals and families who have survived meningitis and septicaemia. This booklet gives information about after effects based on our involvement with patients, their families and friends, and doctors 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 septicaemia.

You might like to read the whole of this booklet, or just read the specific sections that apply to you. If you would like to talk through anything you read here, or about the difficulties you or a loved one are experiencing in the aftermath of meningitis and septicaemia, please ring the Foundation's **Freefone** 24 hour helpline - 080 8800 3344. Many people find that it helps to talk to someone who has been through a similar experience and the Foundation's helpline team may be able to put you in touch with someone to talk things over or provide a listening ear.



Health professionals who look after patients recovering from meningitis and septicaemia have helped to develop this booklet.

WHO HAS AFTER EFFECTS?

Most people recover with no after effects and not all after effects are permanent. The likelihood of getting after effects from meningitis and septicaemia depends on several factors, including the type and severity of the illness. People who have been desperately ill may have spent a long time in intensive care. Research has shown that intensive care can be a distressing experience both for the person who has the illness and for their family.

A person recovering from viral meningitis may experience similar problems to someone who has had bacterial meningitis, but will rarely have severe after effects. Section 4 discusses in more detail problems that may occur after viral meningitis.

Several types of bacteria can cause meningitis. Currently the majority of cases of bacterial meningitis and septicaemia are caused by meningococcal infection. This produces severely disabling after effects in about one in twelve survivors, although patients who have severe meningococcal septicaemia tend to have a worse outcome. After meningococcal disease, pneumococcal meningitis is the main type and it is more likely to produce serious damage. Neonatal meningitis (occurring in the first month of life) also carries a higher risk of after effects than meningococcal disease.

Serious complications of meningitis and septicaemia such as deafness or brain damage, or limb or skin damage, happen during the acute phase of the illness. Most people who go home from hospital without any obvious effects need not worry that new problems will develop after the illness, although in some cases damage from the acute illness is not noticed until later. Careful and early follow up of patients discharged after meningitis and septicaemia is important. An estimated 25% of people who survive will have less obvious after effects, such as difficulties with co-ordination, concentration and memory.



Tonia contracted pneumococcal meningitis six years ago.

These are usually temporary. If you discover problems a long time after recovering from the illness, it is not always possible to be certain that they are the direct result of meningitis and septicaemia. Not knowing the exact cause of problems can be distressing for some people, especially if their performance at school, work, or other activities is affected.

GOOD AND BAD DAYS

It can take many months to recover from meningitis and septicaemia, 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. They are often shocked at how tired they are. Extreme tiredness can be very debilitating, with symptoms of fatigue persisting for several months.

Most people find that they have days when they feel very good, and others when they feel so bad that they worry they are becoming ill again. This can be frightening. Although it is a normal pattern, it can be very dispiriting. Generally, people find that the number of days when they feel ill or tired gradually decreases over time.

It is important to 'listen' to the needs of your body. Exercise may help you on the road to recovery, but it is very important to pace yourself. There is no magic formula to feeling better, because the body needs time to recover fully. Returning to work, school or college too early, or too energetically, can be very tiring and may slow down recovery. You might prefer to return to work or study on a part time basis at first, so as not to exhaust yourself. It is important to mention to employers and teachers that you may need time off. Help and support from your family doctor can be invaluable, and a doctor's note will be necessary if you need a longer period of rest.

DEALING WITH NEGATIVE EMOTIONS

A small number of patients are left with severe and permanent physical or mental after effects following meningitis and septicaemia. Coming to terms with a serious physical or mental disability can be very difficult. Everyone copes in their own way, and the experience may provoke many different sorts of emotions. It is striking how many people maintain a positive and determined attitude while recovering, however it is not unusual to feel angry, saddened or uncertain about the impact of a disability on your life. Young children in particular sometimes avoid talking about what happened to them, to the extent of leaving the room or hiding when other people talk about the illness. It is important to be sensitive to these feelings rather than adding to any stress they already feel.

Sharing these feelings may be helpful. Some people are able to talk to friends and family, others find that talking to someone outside the family network is more helpful. Trained staff and nurses on Meningitis Research Foundation's helpline, your GP or health visitor, or other organisations listed in this booklet, may provide help.

NEEDS OF PARENTS AND CARERS

From time to time parents and carers may also feel angry, guilty or desperate, especially as dealing with the needs of a loved one can be emotionally and physically exhausting. Taking time for yourself and seeking support from family and friends may help restore your sense of well being. The Foundation's helpline staff can also provide a listening ear.

Courtesy: Western Daily Press.



*The Foundation runs a
Freephone 24 hour helpline service.*

BEHAVIOURAL AND EMOTIONAL AFTER EFFECTS

Because meningitis and septicaemia are life-threatening illnesses, the traumatic nature of the events may have emotional and behavioural effects on both patients and their families.

Psychological problems may develop as physical recovery progresses. These can be very worrying for patients as well as their families and friends, particularly if changes in character or behaviour are involved. It is completely natural to have emotional problems while getting over the ordeal of being so ill. Coping with the frustration of trying to get back to normal can be stressful.

Parents often continue to feel anxious after bringing their child home from hospital. This can affect the way they relate to their child and the way families relate to each other. Many parents become more lenient, protective, worried, less confident and find it more difficult to be separated from their child than they did before the illness. This behaviour is normal and usually goes away over time. Research has shown that about 50% of mothers report disagreements with their partner about managing their child's behaviour.

Both children and adults can become despondent, especially if recovery is prolonged. Usually emotional and psychological disturbances get better over time and rarely require outside help, but it is important to seek help for emotional problems that don't seem to be getting better, for example, feeling continuously upset and crying, or withdrawn. Your GP or the hospital doctor will be able to help you or refer you to a psychiatrist, psychologist or other specialist.

EMOTIONAL AFTER EFFECTS THAT MAY OCCUR AFTER MENINGITIS AND SEPTICAEMIA INCLUDE:

- **Clinginess**
- **Temper tantrums**
- **Moodiness or aggression**
- **Disturbed sleep/nightmares**
- **Bed-wetting**
- **Changes in character**
- **Learning difficulties**
- **Depression**
- **Fear of doctors and hospitals**
- **Other behavioural and emotional problems**

Emotional and psychological problems may also occur as a result of serious physical after affects of meningitis and septicaemia. Although uncommon, where physical damage that dramatically alters the lives of patients and their families occurs, it can be very difficult to cope with. It is important that the person who is recovering, along with their carers, gets the practical and emotional support they need.

CHILDREN, PARENTS AND INTENSIVE CARE

For children, the experience of getting meningitis and septicaemia, being in hospital, or in intensive care can be confusing and distressing. Young children in particular can find it difficult to explain how they feel and sometimes express this through temper tantrums, clinginess, bed-wetting, nightmares, mood swings, or aggression. Some may forget skills that they have recently acquired. Toddlers who were speaking fluently before their illness may go back to baby talk, crawl instead of walking, or need nappies even though they were potty-trained before they went into hospital.

When patients are in hospital for a long time their families may find it helpful to talk about their feelings to a counsellor or other specialist in the hospital, who has experience of talking to families in these circumstances and can bring objectivity to a situation in which different family members may feel strong and conflicting emotions.

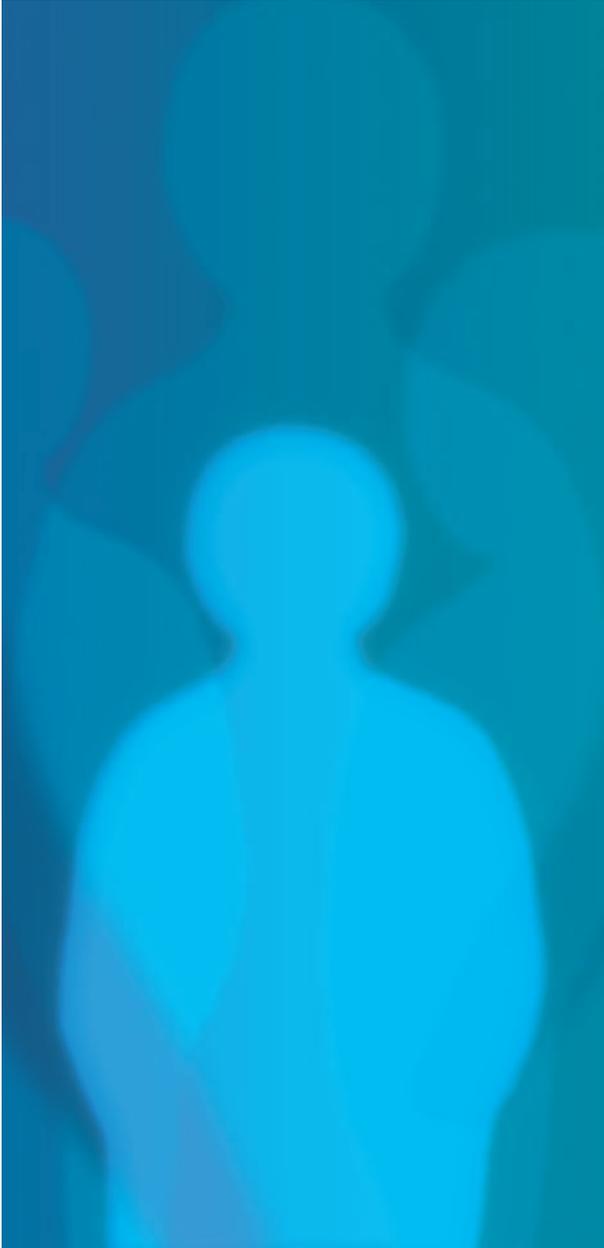
BROTHERS AND SISTERS OR OTHER CHILDREN IN THE FAMILY

Brothers and sisters, particularly younger children, may feel the same sort of anxieties as older family members, but may not be able to express them. They may develop emotional disturbances just like the child who is recovering from meningitis and septicaemia. As well as feeling worried and upset about the brother or sister who is dreadfully ill, siblings can sometimes feel neglected by parents who, quite understandably, are more focused on supporting the child who is recovering.



Courtesy: Evening Standard.

Experiencing a range of emotions is usual when in hospital or intensive care.



PHYSICAL AFTER EFFECTS

This section gives an overview of some of the physical after effects that an individual may experience as a result of meningitis and septicaemia.

It is important to remember that permanent physical after effects are uncommon, most of them improve over time.

AFTER EFFECTS MOST LIKELY TO BE CAUSED BY MENINGITIS

- **Memory loss/difficulty retaining information/lack of concentration**
- **Clumsiness/co-ordination problems**
- **Residual headaches**
- **Deafness/hearing problems/tinnitus/dizziness/loss of balance**
- **Learning difficulties (ranging from temporary learning deficiencies to long term mental impairment)**
- **Epilepsy/seizures (fits)**
- **Weakness, paralysis or spasms of part of body (if permanent, sometimes called cerebral palsy)**
- **Speech problems**
- **Loss of sight/changes in sight**

Some of these after effects may follow either meningitis or septicaemia.

AFTER EFFECTS MOST LIKELY TO BE CAUSED BY SEPTICAEMIA

- **Memory loss/difficulty retaining information/lack of concentration**
- **Clumsiness/co-ordination problems**
- **Arthritis/stiffness in joints**
- **Scarring/skin damage**
- **Amputations - for example, fingers, toes, arms or legs**
- **Kidney damage**
- **Lung damage**

Some of these after effects may follow either meningitis or septicaemia.

HEARING LOSS/TINNITUS

Deafness, tinnitus (ringing, hissing, buzzing or other noises in the ears and head) and other hearing problems can occur after meningitis or septicaemia. Hearing loss is the most common long-term after effect of meningitis. Loss of hearing ranges from moderate to profound, can be permanent or temporary and may affect one ear or both. If the damage is temporary, hearing usually comes back within a few days of being treated, although rarely it can take several months to return. Deafness is not as common an after effect of meningitis as it was 10-20 years ago, mainly because immunisation has nearly eliminated Hib meningitis, which frequently caused deafness. However, meningitis is still the most frequent cause of acquired deafness in childhood.

Hearing damage from meningitis usually happens when toxins produced by the bacteria attack the inner ear. The inner ear is made up of two parts: the cochlea, which is the organ of hearing, and the vestibular system, which contains the organs of balance. Damage to the inner ear usually happens within the first couple of days of illness. Hearing damage from septicaemia is unusual, but can happen if blood supply to the cochlea, or to the nerve cells associated with it, is interrupted when bacterial toxin attacks the blood vessels.

Balance problems from damage to the vestibular system can also occur. These problems are often temporary as other brain mechanisms compensate.

Hearing Tests

People who have had meningitis and septicaemia should have a hearing test as soon as possible after leaving hospital even if their hearing appears normal. This is particularly important in young children who may not be able to explain that they cannot hear properly. Hearing tests are normally arranged by the hospital, but if a test is not offered it is important to ask for one. Most units aim to perform hearing tests within four to six weeks after hospital discharge.

An audiologist will do a number of tests to find out whether there is any damage to hearing, and if so, how much. The tests are very sensitive and can detect small problems. If a hearing problem is found, the audiologist will go through the range of options available, which may include a hearing aid, or rarely a cochlear implant. The sooner hearing problems can be identified, the sooner help or treatment can be given. This is particularly important in young children who are learning language skills.



Undertaking a hearing test.

Courtesy: CC StudioScience Photo Library.

Hearing Aids

Hearing aids amplify sounds to make them louder and easier to hear. They are made up of a microphone that picks up sounds, an amplifier that increases their volume and a speaker that transmits the sound. In particular, they can help people with mild to severe hearing loss who have trouble hearing the frequencies of normal speech or high frequencies. They can't give you perfect hearing, but can make conversations easier to have. Hearing aids should not make hearing worse. There are many different types, and the audiologist can give advice as to the best available option. Hearing aids may also help to lessen the ringing, hissing or buzzing noises that occur with tinnitus.

Cochlear Implants

A cochlear implant is a device which is surgically inserted into the ear and uses electrodes to stimulate the nerves of hearing. Part of the device is worn externally.

Implants may be suitable for a person who is profoundly deaf and cannot benefit from a hearing aid. Although they can't transmit sound as well as a normal cochlea, they can provide a certain level of benefit to hearing. Benefit depends on the individual and the extent of damage to hearing: some people will be able to lip-read better, some will be able to hear without lip-reading, and some will be able to speak on the telephone. Cochlear implants can also help people to adjust their own voice so that their speech is easier for others to understand.

Not all people who are profoundly deaf choose to have a cochlear implant, preferring other methods of communicating including sign language, lip-reading and finger spelling.



Michael was implanted at Great Ormond Street Hospital 2½ years after contracting Group B streptococcal meningitis.

AFTER EFFECTS INVOLVING THE BRAIN

Brain-related after effects caused by meningitis and septicaemia are not always permanent. In some patients the damage is repaired over time or neighbouring areas of the brain take over from the damaged areas. When this happens, the person may regain some, or all, of the function that was lost. Some people have very subtle after effects that may be the result of brain damage, but the cause is not always clear. This is often the case with after effects such as problems with co-ordination, concentration and memory, and normally they go away on their own.

How is the Brain Damaged?

The brain is made up of distinct areas. Each area controls different body functions, such as speech or aspects of movement. During meningitis, there is inflammation of the lining around the brain (meninges), and blood vessels within the brain are injured by bacterial toxins which make them leaky. Fluid leaking from blood vessels into the brain tissue causes brain swelling, putting pressure on the brain which can damage it. Raised pressure inside the skull may interrupt the supply of oxygen to brain tissue. Brain cells cannot survive without oxygen, so some areas of the brain may be injured or destroyed.

In septicaemia, the blood supply to the brain may be reduced because toxins produced by the bacteria attack the blood vessels, so the heart cannot function normally and blood pressure is low. Therefore the brain may be starved of oxygen and nutrients, causing injury to brain cells.

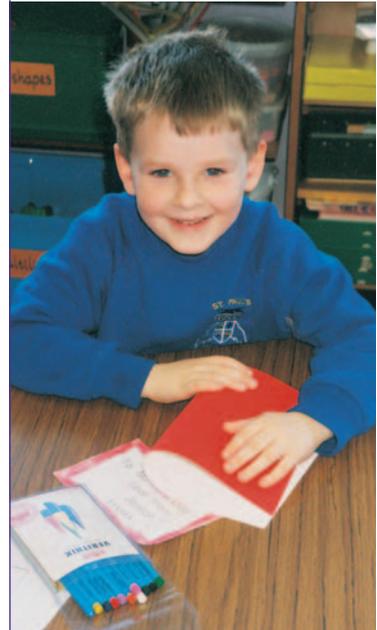
Damage caused by raised pressure and oxygen starvation can occur anywhere in the brain, 'knocking out' or interfering with whichever body function the injured area controls. This can cause after effects including: clumsiness or lack of co-ordination, memory loss, learning disability, difficulty retaining information, inability to concentrate, loss of balance, uncontrolled movements, speech problems, epilepsy, cerebral palsy, loss or changes in sight, loss of ability to write and partial paralysis.

It is not always possible for doctors to predict whether damage to the brain will occur, or what sort of damage is likely when a person is ill in hospital with meningitis and septicaemia. Even after recovery, it can be difficult to tell how severe, or long lasting these after effects may be. Feeling impatient and frustrated at this point is natural, but it can take time for the full picture to emerge.

Learning Disability

Most people recover with no long-term problems affecting their ability to learn. Although rare, permanent learning disability can occur in some cases, with levels of impairment ranging from moderate to profound.

When babies or very young children get meningitis and septicaemia, they may be left with slight learning difficulties which are only noticed when they start school. It is important to speak to your child's teachers if you are at all worried about any changes in learning or behaviour patterns, and ask to be kept informed of their progress. You may also wish to talk to your GP about these concerns as he/she can organise more specialist help if needed.



Joseph contracted meningococcal meningitis and septicaemia when he was three years old. He has some learning problems from the disease.

Headaches

Severe headache during meningitis happens as a result of irritation of the meninges, inflammation of nearby nerves and raised pressure within the head.

After meningitis, headaches may take a while to go away, although the infection itself is cured. These headaches may recur for months or more 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 the follow up visit, then it is important to talk to your GP who can decide if painkillers might help, or if referral to a specialist is needed.

Some people find alternative therapies helpful in dealing with recurrent headaches.

Hydrocephalus

Hydrocephalus or 'water on the brain' is a rare after effect of meningitis. Tuberculosis meningitis, which is very uncommon, is the form of the disease most likely to cause hydrocephalus. It happens when cerebrospinal fluid (CSF) builds up within the ventricles (fluid-containing spaces) in the brain. Normally, the body continuously produces CSF, which bathes the surfaces of the brain and spinal cord, and is then absorbed back into the bloodstream. CSF has important life-sustaining functions: it acts as a cushion or shock absorber, protecting the brain from damage and it delivers nutrients to the brain tissue and removes waste. When the balance between production and absorption of CSF is disturbed, hydrocephalus develops.

Meningitis can cause hydrocephalus by scarring the meninges so that the flow of CSF is restricted, or by damaging the surface where absorption of CSF takes place, so that fluid accumulates.

Sometimes this can be treated over weeks or months by repeated lumbar puncture, along with drug therapy. Otherwise the treatment is to drain CSF through a shunt from the ventricles to another surface within the body where it can be absorbed. This involves surgical placement of a shunt system. Shunt systems are not perfect, and may fail mechanically, become infected, or need replacement, especially in a growing child. Generally they require monitoring and regular medical follow-up.

SKIN DAMAGE

During septicaemia, bacteria multiply in the bloodstream and release toxins which cause blood to leak out of the tiny blood vessels under the surface of the skin. This bleeding causes the red or brownish pinprick rash of septicaemia, which can develop into purple bruise-like marks. As blood leaks out of the blood vessels it clots and may also clot within the small blood vessels near the skin surface, stopping blood flow and the delivery of oxygen to the skin. Because the skin cells are starved of oxygen they may die. This most often happens to the skin on the hands, feet, arms or legs.



Tyler underwent repeated hospitalisation after contracting meningococcal septicaemia.

Smaller areas of skin usually heal on their own, but when large areas of skin are affected, the dead skin must be removed, leaving large wounds which need skin-grafting. Over time these scars will fade, although very severe scars do not totally disappear. In severe cases, plastic surgery may be needed more than once to restore the function of injured areas, and improve the appearance of the skin. Sometimes scarring can cause stiffness of joints in the arms or legs which will need a lot of massage, physiotherapy and very occasionally surgery to release the joint. Pressure garments may have to be worn over areas with bad scarring to help flatten and soften the scars.

Undergoing multiple operations involving repeated hospitalisation and prolonged physio- or occupational therapy can be very upsetting for someone who has just undergone a traumatic illness in hospital. Family and friends may also worry about their loved one having to spend further time in hospital. When operations are needed after septicaemia, patients and their families may find it helpful to talk to a clinical psychologist who deals with people coming to terms with a different/unusual appearance. Talking with someone who has been through a similar experience can be particularly helpful in this situation. The Foundation's helpline team may be able to put you in contact with an individual or family who has gone through a similar experience.

AMPUTATION AND MUSCLE DAMAGE

In very bad cases of septicaemia, blood clotting can extend into the muscle, causing blockage of major blood vessels. Sometimes the limb is so swollen due to clotting and fluid leaking from blood vessels into the tissue, that pressure has to be released to prevent the muscle dying. This rare procedure is called fasciotomy and it involves splitting the skin and muscle. The skin will later need grafting.

Blockage of major vessels cuts off the blood supply so that large areas of muscle, fingers and toes, or more rarely hands, feet, legs or arms may be destroyed by gangrene. Depending on the extent of the injury, muscle grafting may be possible, but in more severe cases the affected area may need to be amputated as a life-saving procedure. Sometimes dead skin and muscle tissue will have to be cleaned away by a procedure called debridement, so that the affected parts can heal properly.

When skin grafts, plastic surgery, amputation and/or the fitting of artificial limbs is necessary after septicaemia, it is extremely important to let the tissues heal fully. The skin is so fragile that it breaks down very easily, so if you rush things you can suffer setbacks which can be very frustrating. However, as soon as the tissues can tolerate it, moving and exercising the affected parts, and massaging the scar tissue are essential to regain mobility and flexibility. Usually patients need at least three months of physiotherapy before fitting of artificial limbs can begin. Becoming active again can be very difficult, especially as skin grafts can heal slowly, and if multiple operations are required, this delays the use of the affected limbs. The sooner you begin to move around, however, the better your overall functioning is likely to become over time.



Helen had multiple amputations from meningococcal septicaemia. She now works for a television company.

Occasionally severe septicaemia can damage the growing parts of bones in the arms or legs so that the affected limb does not grow properly. This can mean that one limb ends up shorter than the other one. This can usually be corrected later but will involve surgery.

ORGAN DAMAGE

The toxins produced by bacteria that cause meningococcal septicaemia attack the blood vessels so that the blood supply to vital organs is disturbed. As a result, organs such as the kidneys, liver and lungs may become starved of blood and oxygen. When vital organs fail, the patient is treated in intensive care, where machines take over the function of these organs while the person is ill. Usually the organs recover completely. However, in rare cases septicaemia can cause permanent damage to organs. For example, a very small number of patients may require long-term kidney dialysis or a kidney transplant.

ARTHRITIS/STIFFNESS IN THE JOINTS

Arthritis can occur when a person is ill with meningitis and septicaemia, but more often it follows recovery from the illness, caused by an immune reaction by the body to the bacteria that cause meningitis and septicaemia. There may be severe pain in joints in the first few weeks after the acute illness which may limit return to full activity. Usually this gets better with just rest and simple painkillers that may be prescribed or be available from the chemist. Arthritis nearly always disappears after a few weeks, but very rarely there may be permanent damage to joints.

PAIN

Some of the physical problems which meningitis and septicaemia can cause are painful, but it is important to remember that in nearly all cases, pain can be relieved. Pain normally disappears over the course of recovery, but in rare cases may become chronic. People who are recovering from meningitis and septicaemia may have recurrent headaches after meningitis, for example, or pain from damage to skin and muscle or joints after septicaemia. In rare cases, pain may result from damage to nerves.

Pain that is persistent and interferes with daily life should be discussed with the doctor during the follow up appointment at the hospital where treatment was given. In rare cases when pain continues to be unmanageable after follow up, it is important to talk to your GP who may organise more specialist help if it is needed.

VIRAL MENINGITIS AFTER EFFECTS



Clare contracted viral meningitis when she was a teenager.

Many different viruses can cause viral meningitis. It is thought to be more common than bacterial meningitis. Most cases are relatively mild and get better on their own without hospital treatment. Although viral meningitis can be very unpleasant at the time, most people recover within one to two weeks. A very small proportion of people who get certain types of viral meningitis will have repeated bouts. Although they recover spontaneously each time, the attacks can be very debilitating.

After viral meningitis some people can experience prolonged after effects, which may include recurring headaches, tiredness, irritability, reduced concentration, mood swings and depression. Recovery is often very up and down and it is important to 'listen' to the needs of your body. If after effects do not disappear within a month or two, or if you are concerned, it may help to consult your GP.

Encephalitis - infection of the brain tissue itself - is a life-threatening disease which can also be caused by viruses. It can damage the brain permanently. (See Section 3, page 15, After Effects Involving the Brain).

24 hour helpline

Freefone 080 8800 3344

Meningitis Research Foundation's helpline team takes calls from people who have had meningitis and septicaemia, their families and friends, and health and educational professionals dealing with these diseases. Our trained staff and nurses respond to calls day and night from people who want to know more about meningitis and septicaemia, or are worried about someone who is ill. The team provides on-going support and a listening ear to those who are recovering, or who are bereaved. The Foundation also offers additional support to its members (individuals or families with personal experience of meningitis and septicaemia) through its befriending

programme. The Charity's **Freefone** helpline is available 24 hours a day, every day of the year. Health professionals may wish to inform patients of these services.

If you would like to talk through any of the information given in this booklet, or find out more about the additional services the Foundation offers, including how to become a member, our helpline team would be happy to hear from you and can be contacted on the **Freefone** number above.



If you would like to order further copies of this booklet, or other Foundation public information resources, please contact your nearest office or visit our website.

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