Viral meningitis, the facts

Meningitis **NOW**

This fact sheet provides information about viral meningitis and answers some frequently asked questions. This should be read in addition to our 'Meningitis can affect anyone' leaflet, which provides more information on signs and symptoms and emergency action to take. All our information can be found at www.MeningitisNow.org. You can also request any information materials by contacting our Meningitis Helpline on 0808 80 10 388.

Words highlighted in **blue** are explained in a glossary on the back page.

Key points

- Viral meningitis can affect anyone
- Many thousands of cases occur in the UK each year
- Although most people will make a full recovery, some are left with serious and debilitating after-effects

What is viral meningitis?

Viral meningitis is an infection that causes **inflammation** of the membranes that surround the brain and the spinal cord. These membranes are called the **meninges** – they help protect the brain from injury and infection. Viral meningitis is more common than bacterial meningitis and although rarely life-threatening, it can make people very unwell. Most people make a very good recovery, but for some recovery can be slow and after-effects long lasting.

As viral meningitis rarely threatens life, generally a lot less is understood about it and the effect it has on sufferers. People can be left feeling that they are not taken seriously and are often not offered information and support during their recovery. This fact sheet can help you explain to others what can be expected following viral meningitis.

Experts believe there are several thousands of cases of viral meningitis each year in the UK. Most are not severe enough to need hospital admission, but even in those needing hospital treatment it is often not possible to identify the specific viral cause.

What causes viral meningitis?

Many different **viruses** can cause meningitis; the most common are a group called **enteroviruses**.

These viruses live in the intestines and can commonly cause colds, sore throats, stomach upsets and diarrhoea. Only rarely do these viruses spread through the body to the meninges and cause meningitis.

Other viruses that cause meningitis include mumps and measles. A MMR vaccine (measles, mumps and rubella) is available as part of the routine immunisation schedule to protect against meningitis caused by mumps and measles.

Mollaret's meningitis is a recurrent form of meningitis – a rare condition believed to be caused in many cases by infection with a member of the herpes family of viruses. If you have experienced viral meningitis more than once, we would encourage you to ask your GP to investigate it to try and determine the cause.

Who gets viral meningitis and why?

Viral meningitis can affect any age group, but it is most common in young children as their body's defences are not fully developed. If a virus invades the body their immune system cannot provide resistance to fight off infection.

Because many different viruses can cause meningitis, the way in which the virus is spread will depend on its type.





For example, enteroviruses are carried harmlessly in the intestines of both children and adults, and carriage of these viruses helps us to build up natural immunity to infection. Spread of these viruses is common and they can be passed from person to person by coughing, sneezing and on unwashed hands. Practising good hygiene, such as washing hands after going to the toilet, will help to prevent the spread of viruses that are passed in faeces.

How does viral meningitis develop?

Occasionally, viruses defeat the body's defences and cause infection. If this occurs, the virus can spread through the body to the meninges and cause meningitis. When the virus infects the meninges, tiny blood vessels in the membranes are damaged. This allows the virus to break through and infect the **cerebrospinal fluid** (CSF). The meninges become inflamed and pressure around the brain can cause nerve damage. Pressure on the brain can produce the specific symptoms associated with meningitis such as:

- Severe headache
- Dislike of bright lights (photophobia)
- Neck stiffness
- Nausea and vomiting
- Confusion and drowsiness
- · Loss of consciousness
- Convulsions/seizures

You can request our symptoms card by calling our helpline.

Many people will only experience flu-like symptoms and will never be diagnosed with viral meningitis. For others, the symptoms can be more severe and they may be hospitalised with suspected bacterial meningitis. In hospital, various tests can be carried out to confirm the type of meningitis and treatment is started accordingly.

One of the main investigations carried out to test if someone has meningitis is a lumbar puncture. This allows the doctor to quickly make a diagnosis of meningitis by analysing the CSF that bathes the meninges. This fluid becomes infected when a patient has meningitis.

Viruses may also cause inflammation of the brain itself, a condition called encephalitis. This is a very serious condition, sometimes resulting in severe brain injury.

How is viral meningitis treated?

Antibiotics are not effective against viruses, although, in some instances, antibiotics may be started on admission to hospital because the cause of meningitis is not known. Antibiotics are usually discontinued if viral meningitis is diagnosed.

There is no specific treatment for most cases of viral meningitis. Patients need to be hydrated with fluids, given painkillers and allowed to rest in order to recover.

What happens when there is a case?

Viral meningitis is not generally considered to be contagious; therefore contact with someone who has the illness does not increase the risk of disease to others. Although viruses spread from person to person, linked cases of viral meningitis are extremely unusual and almost all cases occur on their own.

What happens after viral meningitis?

The majority of people who get viral meningitis will make a good recovery with no long lasting after-effects. However, a number of people will be left with a range of difficulties, some serious enough to cause permanent disability.

The after-effects of meningitis usually reflect damage to various areas of the brain. While the after-effects of viral meningitis are not usually as severe as those of bacterial meningitis, they can still be long-lasting. Commonly occurring after-effects include:

- Exhaustion
- Headaches
- Memory loss
- Anxiety
- Depression
- Dizziness/balance difficulties
- Hearing difficulties

Various other after-effects have also been reported including personality changes, aching limbs or joints, noise intolerance, light aversion and difficulties with speech, language and learning.

Because viral meningitis is very rarely lifethreatening, many sufferers feel that their illness is taken less seriously and the after-effects they experience are not always acknowledged.

Whatever the after-effect, mild or severe, viral meningitis can change a person's life forever.

A viral meningitis survey commissioned by Meningitis Now was carried out in 2012, with over 450 people taking part. The results have shown the real impact of the disease, the lack of support and information available from healthcare professionals and the need for Meningitis Now to raise awareness about the disease. It has also helped us understand the best ways we can offer help and support following viral meningitis. A summary of results is attached to this fact sheet.

Follow-up care

There is no specific guidance for hospitals for the follow-up of viral meningitis patients. Our survey showed that only a third of respondents received a follow-up appointment, and 80% were either not given any information or not enough information about viral meningitis. The result is that many people face their recovery alone. If you have not been offered a follow-up appointment, we would always recommend that you make an appointment with your own GP, giving you the opportunity to ask questions and make them aware of what you have been through. Taking this fact sheet and survey results with you, could help you discuss some of the questions raised and any concerns you may have.

Find out more

 Meningitis Now www.MeningitisNow.org
Information about meningitis and the work of Meningitis Now.

Glossary

Cerebrospinal Fluid (CSF)

A protective fluid that flows around the brain and spinal cord, helping to maintain healthy cells.

Enteroviruses

A group of viruses that can cause meningitis. When an enterovirus is identified it is usually either a coxsackie virus or an echovirus.

Inflammation

A response of the body tissues to injury or irritation. The response is characterised by redness, swelling, heat and pain.

Lumbar puncture

A procedure to remove CSF from below the base of the spinal cord.

Meninges

Three protective membranes (layers of tissue) that surround the brain. These are called the dura mater, arachnoid mater and pia mater.

Routine immunisation schedule

A planned programme of vaccines which provides protection against a range of infectious diseases.

For more information, visit www.nhs.uk.

Vaccine / vaccination

A preparation, usually an injection, given to encourage the body to produce antibodies which help fight infectious disease. The preparation commonly contains a harmless extract prepared from the disease-causing organism.

Viruses

Microbes that are smaller than bacteria. There are many types, some of which can cause disease in humans, e.g. enteroviruses.

Meningitis Now is here to help you. We are saving lives and rebuilding futures through awareness, research and support.

We offer ongoing support for all those living with the impact of the disease. We support individuals, and their families, including those who have been bereaved, helping to rebuild lives after meningitis and meningococcal septicaemia.

We can:

- Listen; and answer your questions about meningitis and meningococcal septicaemia
- Talk to you about your individual experience and how we can tailor our help to you
- Provide support locally to you
- Put you in touch with others who have been through it too
- Support you and those closest to you; children, teenagers and adults
- Provide financial contributions towards unexpected costs following meningitis through our Rebuilding Futures Fund

If you have any questions, or are interested in finding out how we can help, please get in touch.

Meningitis Helpline: 0808 80 10 388 (UK)

Email: helpline@meningitisnow.org

We are proud of the work we do, but we can't do it alone. We rely on voluntary donations and need help from people like you. Every penny, pound, hour and day given makes a big difference. Find out how you can help www.MeningitisNow.org

Meningitis Now

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References for the content of this fact sheet are available on our website.



Meningitis Now Viral meningitis survey results



Experts believe there are several thousands of cases of viral meningitis each year in the UK. A *survey conducted by Meningitis Now** has shown that viral meningitis is leaving 97% of those responding with debilitating after-effects.

Often compared to bacterial meningitis as the 'milder strain', with a short recovery period, viral meningitis is leaving sufferers with exhaustion, headaches, memory loss, depression, anxiety and hearing difficulties – many people have to take long periods off education or work and struggle with day-to-day tasks that so many people take for granted.

At Meningitis Now we too often hear people say that they were made to feel less important because they 'only' had viral. Our survey shows that people are suffering with after-effects long after their experience, confirming what we've always believed – that viral meningitis is not always a 'mild' disease. We will be using these findings to help us further improve the support we provide, educate health professionals and the public and empower sufferers.

*Online survey completed by over 450 people who have experienced viral meningitis, July - September 2012. The survey was conducted by Picker Institute Europe on the Meningitis Trust's website

Summary of results

- After-effects were experienced by 97% of respondents:
 - > Exhaustion (78%)
 - > Headaches (70%)
 - > Memory loss (50%)
 - > Anxiety (37%)
 - > Depression (37%)
 - > Dizziness/balance difficulties (37%)
 - > Hearing difficulties (23%)

(Respondents were asked to tick all that were applicable to them)

- A range of other after-effects were reported by smaller numbers of respondents and included personality changes, aching limbs or joints, noise intolerance, light aversion and difficulties with speech, language and learning.
- Over half of all respondents said that viral meningitis had caused them difficulty at work or in education:
 - Many felt that family, friends, health professionals or employers did not understand the impact of viral meningitis, with the comments reflecting many people's experience
 - Made to feel 'a fraud' because of the assumption that most people make a full recovery
 - Difficult to communicate the impact to others
 - Memory problems had a significant impact on daily life





^{**}In 2013 Meningitis Trust and Meningitis UK merged to become Meningitis Now

- 10% of respondents were still experiencing after-effects 6–12 months after the initial illness, and an additional 7% had after-effects that lasted for more than a year
- Only a third of all respondents were offered a follow-up appointment with the hospital (although two thirds of under 16s were offered hospital follow-up)
- Over 40% of respondents were not given any information about viral meningitis and a further 46% were not given enough information
- The internet was the main source of information if respondents searched for themselves
- 60% used our website following this search
- Just under a third of respondents had treatment or therapies for the after-effects of viral meningitis. Of these;
 - over half had received them from the NHS
 - over a third were privately funded
 - almost a fifth were funded by a charity or support organisation

Treatments or therapies included:

- > Physiotherapy
- > Occupational therapy
- > Speech and language therapy
- > Counselling
- > Acupuncture
- > Cranial osteopathy
- > Aromatherapy massage
- > Homeopathy
- Respondents would like:
 - More information about the disease and its potential after-effects; for themselves, their family and friends, and for health professionals
 - Access to aftercare and follow-up appointments
 - To be taken seriously
 - Support and advice for sufferers
 - Support for family and carers
 - Signposting to Meningitis Now

These results show the real impact viral meningitis can have. They will help us raise the profile of the disease and inform health professionals, schools, employers, family and friends of the potential long-term difficulties that sufferers can face.



Meningitis Now

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