

**Meningitis
now**

After meningitis

*Recovery following meningitis
or meningococcal septicaemia*



Recovering after meningitis or meningococcal septicaemia



"Being given information about Meningitis Now when I was leaving hospital was invaluable."

Stephanie had bacterial meningitis in 2010

After receiving expert care in hospital, you can understandably feel anxious about returning home.

Meningitis* is a life-changing disease and can affect anyone at any time. At Meningitis Now we understand that while most people are pleased to be recovering at home, it can be an uncertain and worrying time.

Depending on the cause and severity of the illness, time spent in hospital varies. For some people it can be just a few days, for others it can be weeks or even months. Sometimes a diagnosis of viral meningitis can mean there is no admission to hospital at all.

This leaflet provides general information about what to expect when leaving hospital or recovering at home, along with how we can help and support you. To talk about your individual experience and for more information about meningitis, please call our helpline or email us.

Meningitis Helpline 0808 80 10 388 (UK)

Helpline Email helpline@meningitisnow.org

Most people who have bacterial or viral meningitis do make a good recovery but some will suffer physical and emotional after-effects that can change their lives forever. Serious and potential long-term after-effects are usually identified while the person is still in hospital and can include hearing loss, acquired brain injury, skin damage and limb loss. In these cases, long-term treatment, follow-up and support should be made clear and discussed before leaving hospital. Many people who are left with long-term after-effects experience mental health difficulties including anxiety and depression.

Even for those without long-term complications, the recovery process following viral or bacterial meningitis can be slow. Headaches, fatigue and memory loss can be quite common. While they usually reduce over time they can have a huge impact on daily life. It is not uncommon for people to experience emotional difficulties following meningitis as the impact of the disease can be overwhelming and stressful.

Follow-up care

- Hearing loss is a common after-effect following bacterial meningitis. All children under the age of 16 who have had bacterial meningitis should have a hearing test as soon as possible, preferably before leaving hospital or within four weeks of being well enough to test. If you are concerned that your hearing has been affected by meningitis, and are over 16, we recommend that you request a hearing test. Some levels of hearing loss may not be obvious, but can have an impact.
- Everyone should also have a follow-up appointment within 4-6 weeks of leaving hospital. This visit provides an opportunity to discuss the recovery process and any complications causing concern. The doctor will also look for any signs of after-effects that may need further follow-up.

If these appointments have not been arranged by the hospital, ask your GP to arrange them for you.

Sometimes it's only when trying to get back to everyday activities that it becomes apparent that life is not the same.

If you are concerned about your recovery or possible complications, speak to your GP or ask to be referred back to the hospital where you received your care.

More information about the after-effects of meningitis is available on our website

www.MeningitisNow.org

*Meningitis is used to describe meningitis and meningococcal septicaemia

Recovery in babies and children

It can often take many months for babies and children to recover from meningitis, although some can be back to their normal activities within weeks. Children recovering from such a serious illness can be weak and tire more easily, but also have difficulty sleeping. They can also, depending on their age, experience behavioural problems such as temper tantrums, clinginess, bed wetting, mood swings, aggression and restlessness. It is not always possible to be sure if very young babies have after-effects when leaving hospital, as they are yet to reach developmental milestones.

For children and young people, returning to education is a big goal. This can be a difficult time, trying to catch up on work missed and seeing friends again. Even with a good recovery, problems can occur as children grow and their brains develop; meaning that it can take months - or even years - for complications to become apparent. Problems can sometimes show themselves at particular milestones, such as starting school, or moving from primary to secondary school.

If you are concerned about the recovery of your baby or child, including follow up appointments, ongoing hospital or rehabilitation visits and after-effects, please speak to us about the ways we can support you.

"Speaking to someone from Meningitis Now soon after leaving hospital was of great comfort. I was put in touch with someone who had a similar experience to me and hearing the words 'I know how you feel' really helped."

Recovering after meningitis or meningococcal septicaemia

Recovery in adults

Many people still consider meningitis to be a childhood illness. Having meningitis as an adult can be difficult to come to terms with, particularly when others rely on you.

Even when there are no long-term after-effects identified, recovery can take weeks or months. As a result of meningitis, headaches, tiredness, aching joints, memory problems and emotional difficulties are just some of the after-effects you might experience. These may be short-term, but for some can be permanent.

Getting back to work can be a huge pressure, keeping employers happy and money coming into the household. You should listen to your body and try not to rush back. Most people find a gradual return allows them and their employer time to adjust. We have resources that can help your employer understand what meningitis is and the effect it can have.

Support for you

We help and support thousands of people every year throughout the UK; answering questions, providing information and offering emotional, practical and financial support. We recognise that each person's experience differs greatly, so finding the right help and support when you need it is vital.

We know that the impact of meningitis can be complex, frightening and leave you feeling alone and unsupported. We can help reduce these feelings and assist you on the road to recovery; back to feeling independent and self-reliant. If you are recovering from meningitis and want to know more about your recovery and the support we offer, please contact our helpline.

Your initial questions may be answered straight away, or we can give you a follow-up call or email with any further information required. This may be enough to put you on the right track to recovery. If further support is required we can discuss options available, which include; speaking to one of our community support team, joining one of our support events or putting you in touch with others who have had a meningitis experience.

Further information about all our support can be found on our website.

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Lyndon (centre) with his brothers. Lyndon had meningococcal septicaemia aged 8 months



Pictured on front cover: Lillie Mai was 14 weeks old when she contracted meningococcal septicaemia in 2010.

Meningitis Now is the UK's largest meningitis charity. We are saving lives and rebuilding futures through awareness, research and support.

We couldn't do this without your invaluable support, determined spirit and dedication.

Here's how you can help:

Become a volunteer

If you have some spare time or energy, there are many ways you can help us reach more people and raise awareness of meningitis.

Share your experience

Sharing your experience of meningitis can empower others to ask for the information and support they need to help with their own recovery.

Raise some money

Take part in one of our challenges or simply host afternoon tea with friends - there are so many ways you can raise money and have fun doing it.

Make a donation

By giving a single donation, setting up a direct debit or leaving a legacy, you can help make a real difference.



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