

# Meningitis – coping with the after-effects

Meningitis can be a devastating disease, particularly for children under five years old, and often has long-lasting adverse effects for both the patient and their family. The Meningitis Trust is committed to alerting the public to the symptoms of meningitis in order to ensure prompt and effective treatment as well as helping families to cope with the impact of the disease.

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**M**eningitis can strike unexpectedly. The speed at which people become ill and the dramatic course of events, make meningitis and meningococcal septicaemia alarming diseases, which affect thousands of individuals and families each year. Although meningitis and meningococcal septicaemia can affect anyone at any time, babies and young children are at high risk due to their immature immune systems. Every year, 3,000 cases of meningitis or meningococcal disease are reported in the UK alone, although experts believe that this is just half of the true number of cases, as viral meningitis often goes unreported. Meningitis kills more children under five years of age than any other infectious disease in the UK.

## What is meningitis?

Meningitis is the inflammation of the meninges; the protective membranes surrounding the brain and spinal cord. Meningitis can occur on its own, or more commonly together with septicaemia. It is commonly caused by bacteria or viruses. Fungal meningitis is a rare form of the disease.

The two main types of meningitis are:

**Viral meningitis** – the most common.

Causative organisms include: enteroviruses and herpes simplex. The mumps virus was the most common known cause of viral meningitis in young children under five years of age before the introduction of the MMR vaccine.

Viral meningitis is rarely life-threatening, but it can make babies and infants feel very unwell. Most will make a full recovery, but sufferers can be left with after-effects such as headaches, tiredness and memory loss.

**Bacterial meningitis** – is potentially life-threatening and needs urgent medical treatment. Causative organisms include: meningococcus (the most common cause of bacterial meningitis is meningococcal group b), pneumococcus, *Haemophilus*

*influenzae* and streptococcus. The bacteria that cause tuberculosis can also cause meningitis. Most people who suffer from bacterial meningitis recover, but 10% of all bacterial cases will sadly result in death. An estimated 15% of those who survive this devastating disease will be left with debilitating lifelong after-effects.

Both adults and children can carry meningococcal bacteria harmlessly in the back of the throat. Carriage of the bacteria can help build natural immunity to infection. Around 10% of the general population will be carriers at any given time. Only occasionally, do these bacteria pass the body's defences and cause infection.

## Who's at risk?

Meningitis can affect anyone, of any age, and at any time. Many reported cases occur in children under five years of age and they are considered an 'at risk' group. Babies and young children are more at risk because their body's defences are not fully developed.

## Signs and symptoms

Meningitis and meningococcal septicaemia can be difficult to recognise. In the early stages, signs and symptoms can be similar to other more common illnesses like 'flu. Symptoms can appear in any order and some may not appear at all. Meningitis and septicaemia often occur together, so it's important to be aware of all the signs and symptoms and to trust your instincts. As babies aren't able to say how they are feeling, it's important to remain vigilant of the tell-tale signs. Signs and symptoms for babies and toddlers include:

### Meningitis

- Fever
- Refusing food or vomiting
- Fretful, dislike of being handled
- Pale blotchy skin

## Keywords

meningitis; meningococcal septicaemia; meningococcal B; after-effects

## Key points

**Penning H.** Meningitis – coping with the after-effects. *Infant* 2009; 5(1): 20-22.

1. Children under five years of age are particularly vulnerable to infectious diseases such as meningitis due to their immature immune systems.
2. Meningitis kills more children under five years of age than any other infectious disease in the UK.
3. An estimated 15% of those surviving meningitis will be left with debilitating lifelong effects such as brain damage, loss of hearing and sight, cerebral palsy, epilepsy and, where septicaemia has occurred, loss of limbs.
4. There is currently no vaccine available to protect against meningococcal group B bacteria, although research is continuing to produce an effective vaccine.

- Listless, unresponsive
- Drowsy, difficult to wake
- Unusual high-pitched cry, moaning

#### Septicaemia

- Fever, cold hands and feet
- Refusing food or vomiting
- Pale blotchy skin
- Spots or rash that does not fade under pressure (**FIGURE 1**)
- Floppy, listless, unresponsive
- Rapid breathing or grunting
- Drowsy, difficult to wake

#### After-effects

After-effects and complications can happen with any type of meningitis, but are more common after bacterial meningitis. The length and severity of after-effects vary from one individual to another. Many of the after-effects are lifelong and can change the individual and family's life and other people around them in an instant.

Serious and debilitating after-effects can include:

- Loss of hearing
- Loss of vision
- Cerebral palsy
- Epilepsy
- Severe brain damage
- Where septicaemia has occurred, loss of digits and limbs, skin damage and organ failure

Less obvious after effects, which in many cases gradually improve with time, can include:

- Speech problems
- Memory loss and concentration problems
- Learning difficulties and behavioural problems
- Headaches and joint pain

#### How meningitis can affect a family

In 2005, at just three months old, Hannah Goodier contracted *Haemophilus influenzae* meningitis and sepsis. Her parents, Darren and Lucy, were holidaying in Cornwall with Hannah and her brother, Harry, at the time.

Hannah had been showing signs of being unwell for two days, and although Lucy had been keeping an eye on Hannah, she became concerned when Hannah was not getting any better.

Lucy monitored Hannah closely, but realised something was seriously wrong when Hannah started to scream when she was put down and lost interest in her food. Her skin started to look grey and clammy and it was at that point that Lucy decided that she needed to find a doctor immediately. Hannah's hands and feet were very cold and her cry became very high pitched. Lucy and Darren frantically threw everything into the car and drove around looking for a doctor's surgery. Although Lucy was thinking that it could be meningitis, she was too scared to say it out loud to her husband, knowing that it would panic him.

They found a doctor, who took one look at Hannah and asked them to go straight to hospital. After a desperate 45 minute drive, they arrived at the hospital where staff were waiting for Hannah to arrive.



**FIGURE 1** The glass test can be used to detect a rash that doesn't fade under pressure. Image courtesy of Dr Petter Brandtzaeg.

Lucy says that the next ten minutes were a blur; "I was pushed to one side, whilst a team of doctors and nurses came running into the room and began working on Hannah, giving her a concoction of antibiotics and drugs. They didn't have time to explain, so I waited quietly, weeping, not quite believing what was happening to our daughter".

Lucy continues; "The next 48 hours were critical, as we waited in a quiet room in the high dependency unit, with dimmed lights and all kinds of machines and wires around our tiny three month old baby, praying for her to fight and for the machines to work".

After two days of extensive tests, Hannah was diagnosed with *Haemophilus influenzae* meningitis and sepsis. Hannah spent the next 11 days recovering in hospital, which also became home for Darren and Lucy during this time.

Thankfully, Hannah made a good recovery and has been left with no obvious after-effects. Unfortunately this isn't always the case and Lucy knows how differently things could have been. Looking back at the traumatic experience, Lucy says; "When you think of meningitis, the rash is the first thing that comes to mind – but Hannah didn't have a rash (**FIGURE 2**). Although, looking back, Hannah displayed some of the tell-tale symptoms associated with the disease, at the time they were not completely obvious. There is nothing more intuitive than a Mother's instincts, so I have now learned to always go with what I feel and not hesitate when it comes to my children's health".

Lucy continues; "It's been really hard to come to terms with the whole experience – Darren and I were once carefree and relaxed parents who were calm when the



**FIGURE 2** Hannah, recovering from meningitis in hospital. Names and photographs in this article are used with permission of the family.





**FIGURE 3** Hannah with her Mum Lucy, brother Harry and their Gran.

children became ill. Following the experience, we became the exact opposite, but counselling from the Meningitis Trust has helped us deal with that and it's getting better" (FIGURE 3).

## Who can help?

### The Meningitis Trust

Like Lucy and Darren, many people can be left feeling shocked, confused and traumatised following an experience of meningitis. For many, the suddenness of the disease and the speed at which it develops can be overwhelming.

Most people know very little about meningitis and septicaemia until they are affected by it. Many unanswered questions about the disease can cause confusion for individuals and families who are trying to piece their lives back together.

The Meningitis Trust is the UK's longest established meningitis charity; helping people to rebuild their lives following meningitis. It provides a range of professional support services to anyone affected – offering a lifeline at a time when it's needed most.

The Trust's unique range of services include:

- A freephone 24-hour helpline manned by nurses 0800 028 18 28
- Professional counselling
- Financial support grants
- Home visits
- One-to-one contacts

Although meningitis can strike in an instant, its impact can last a lifetime. The impact of the disease spreads much wider than the individual concerned and often

families, friends, neighbours and even whole communities can find themselves left to cope with lifelong changes caused by meningitis. The Meningitis Trust has 22 years of knowledge and understanding which enables it to offer specialist care to those who need it most.

## Protect yourself and those around you

The Meningitis Trust produces a range of awareness information materials, such as a handy credit card sized signs and symptoms card. They are available free by calling the Trust's Freephone 24-hour helpline on 0800 028 18 28.

Education is paramount – the Meningitis Trust urges people to talk about meningitis; to children, parents and fellow child-carers. Knowledge can save lives – look out for the symptoms and act quickly if concerned.

## Helping families struggling to cope with the impact of the disease

Along with the support services that it offers, the Trust has recently produced a 'Home from Hospital' leaflet, designed to offer information, support and reassurance to individuals and families who are leaving hospital after experiencing meningitis and who may be unsure what the future may hold for them. Although many people survive meningitis, thousands are left with debilitating after-effects. The impact of the disease means that lives are turned upside down within a few hours.

Claire Donovan, Community Nurse Manager for the Meningitis Trust, says;

"Everyday we work with people who are struggling to cope with the impact of meningitis. We see first-hand the trauma that the disease can cause to an individual, their family and even a whole community. We are here to offer support and information to anyone affected by the disease and we don't want people to suffer in silence".

Claire continues: "The 'Home from Hospital' leaflet gives people clear and simple to understand information on the disease, signposting the Trust's other literature and free professional support services – at a time when they need it most. Leaving hospital following meningitis can be a daunting experience as nurses and doctors have managed the treatment up until then, so going home can be scary and lonely. We wanted to change that and tell people that we are here to offer support, 24 hours a day".

## Conclusion

A recent survey carried out by the Meningitis Trust indicates that as many as 500,000 people living in the UK today have had meningitis<sup>1</sup>. The same survey suggests that up to 10 million adults in the UK personally know of someone who has contracted the disease – that's one in four adults.

Although the vaccine for meningococcal C introduced in 1999 has saved many lives, there is currently no vaccine available to protect against meningococcal group B bacteria, the most common cause of bacterial meningitis. It is hoped that a vaccine will become available within the next five years. However vaccines will not eradicate meningitis completely. There will always be meningitis in some form and there will always be people struggling to cope with its impact and after-effects.

## Reference

1. Survey carried out online by CCB fastMap Ltd, London. Of 22,000 adults, reflecting the UK's population in terms of age and geography, 3,600 people responded.

## Meningitis Trust details

Freephone 24-hour nurse-led  
helpline: **0800 028 18 28**

Website: **[www.meningitis-trust.org](http://www.meningitis-trust.org)**