

A photograph of a family of four and their dog. In the foreground, a young boy with brown hair and a mustache, wearing a black polo shirt, sits on a couch. To his left, a woman with short blonde hair, wearing a blue patterned top and a colorful necklace, sits with her arms around him. To her right, a man with short dark hair, wearing a blue polo shirt, sits with his arms around her. In the foreground, a young boy with brown hair, wearing a tan t-shirt, sits with his arms crossed. A black and white speckled dog with floppy ears sits on the couch between the woman and the man. The background is a plain white wall with a red floral patterned curtain on the right.

**Meningitis  
now**

# **Meningitis and Me**

The devastating and life-long impact of a brutal disease

# Welcome

**Around half a million people in the UK have had meningitis — many more family members and friends will have felt its impact on their lives. It's a devastating disease that can destroy lives and futures overnight. Many survivors, long after the infection has gone, will live with the impact of lifelong after-effects.**

Meningitis Now, the founder of the UK meningitis movement, is here for all of these people, offering support wherever and whenever they need us. No one needs to face meningitis alone.

With our 30th anniversary approaching, we commissioned 'Meningitis and Me', an important research project designed to inform us on the best way to move towards our long-term goal — where no-one in the UK dies from meningitis and everyone gets the support they need to recover fully from the disease.

This report highlights the key findings from that research. It tells a compelling story. You'll read heartbreaking accounts and may have some of your views challenged. But there are also tales of determination, courage and hope, as people fight back against the devastation meningitis leaves in its wake.

I'd like to thank everybody who took the time and trouble to contribute to this report. Your experiences will directly influence all that we do, as we work towards a brighter future for everyone affected by meningitis.



**Liz Brown, Chief Executive**

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# Introduction

Around 500,000 people in the UK have had meningitis. Bacterial meningitis kills more under-fives than any other infectious disease in the UK<sup>1</sup> – but it can affect anyone, of any age, at any time. The disease can kill within hours and for those who survive, the aftermath can be devastating and lifelong.



## Who is at risk?

Meningitis can affect anyone, of any age, at any time. However, some groups are more at risk. At risk groups include babies and children under five, teenagers and young people between 15-24 years, and the over 55s.

At Meningitis Now we are at the forefront of the fight against meningitis in the UK. This report is the culmination of a major research project which heard from over 1,000 people – including people who have had meningitis themselves and their friends and family. Each and every story reminds us of the brutal impact of the disease, and the vital importance of our vision – a future where no-one in the UK loses their life to meningitis and everyone affected gets the support they need to rebuild their lives.

'Meningitis' (used to describe meningitis and meningococcal septicaemia in this report) is the inflammation of the membranes that surround and protect the brain and spinal cord. It is usually caused by bacteria or viruses. Septicaemia is blood poisoning and some bacteria that cause meningitis also cause septicaemia – meningitis and septicaemia often happen together.

The words used by people who took part to express how they feel about the disease:

WORRIED HORRENDOUS HATE HORRIFIC SCARED HELPLESS DESTRUCTIVE HORRIBLE QUICK KILLER CRUEL FRIGHTENING ANGRY DEVASTATING EMOTIONAL DEADLY EVIL FEARFUL TERRIFYING HEARTBREAKING LIFE CHANGING FRUSTRATED SHOCKING

1. Office for National Statistics. Mortality statistics: Deaths registered in 2010 [Series DR] Table 5.1. Available at: [www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcn%3A77-230730](http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcn%3A77-230730) [accessed 26 October 2015].

# Every moment matters

Meningitis takes hold at terrifying speed, and it can be hard to spot and diagnose. In some cases, it can be a matter of hours between realising a person is ill, and their death.



**In 60% of cases meningitis was not recognised by the first healthcare professional people came into contact with**

Meningitis begins innocently enough, sometimes with flu-like symptoms. However, the speed with which this can develop into a life-threatening scenario is terrifying.

With symptoms including fever, headache, vomiting and muscle pains, meningitis can be hard to spot in the early stages and is easily mistaken for flu.

*"Any time a loved one or I ever get even a cough I can feel anxiety sweep over me."*  
From someone whose friend died from bacterial meningitis

Due to the need to act fast, treatment is usually started before a diagnosis is confirmed. However, in 60% of the cases we heard about in our research, meningitis was not recognised by the first healthcare professional people came into contact with. For some, this means a diagnosis comes too late.

*"The first on call doctor said it's nothing to worry about she's teething, a second doctor said it was just a virus. The THIRD doctor diagnosed meningitis but by then we now know it was far too late."*

From the parent of a baby girl who died from bacterial meningitis

Meningitis can be fatal, particularly if not picked up quickly, and around one in ten people with bacterial meningitis die<sup>2</sup>. For those who survive, the disease can leave devastating long-term after-effects in its wake.

*"It happened so quickly, just four hours between me receiving the phone call from my dad, when he'd realised she was seriously ill, and her dying."*

From a woman whose mother died from bacterial meningitis aged 50

2. Public Health England: Guidance for public health management of meningococcal disease Available at: <https://www.gov.uk/government/publications/meningococcal-disease-guidance-on-public-health-management> [accessed 26 October 2015].





## **“I didn’t make it back to the hospital in time.”**

“I tried to ring Mum that day to ask her to look after my little boy for a bit, but her phone was off the hook. I didn’t think anything of it, but that evening my dad rang and said that he was at the hospital and my mum was really ill.

She was too ill and confused to talk by the time we got there. We found out later that she’d woken up that morning thinking she had flu. She had phoned the emergency doctors but they told her to wait until her own surgery opened. She waited a couple of hours and rang her surgery, who told her to ring an ambulance.

**It wasn’t until late that evening that they started to think it could be meningitis.**

She was moved to intensive care and treated through the night and the next day. The night she died we went home for a bit because I was exhausted and I had a young baby. We got a phone call in the middle of the night to go back, but unfortunately I didn’t make it back to the hospital in time.”

**Sarah’s mum died from bacterial meningitis in May 2006.**

# Devastating after-effects

Meningitis can be treated, but often those who survive are left with severe physical and emotional after-effects. Devastating damage left in the wake of meningitis leaves people changed forever.



**Almost 1 in 2** people who survived have been left with long-term after-effects

Just under half of people who survived meningitis, that we heard about as part of 'Meningitis and Me', have been left with long-term after-effects. Some of these changes are very visible to the world – septicaemia can mean limbs have to be amputated to stop the spread of infection.

*"I lost both hands and both legs. I lost my career, my home, my boyfriend and worst of all I lost myself."*

*From a woman who had bacterial meningitis at the age of 22*

Some changes are less easy to see – meningitis can leave people with an acquired brain injury, which can have a severe impact on their emotional and mental health.

If there is an injury to the brain it can affect the person's ability to control their body, or can cause other damage such as learning difficulties, cognitive problems and behavioural changes.

These changes might mean that as an adult, you lose the ability to walk, talk or think like

you used to. As a parent, you might watch your child lose the life they would have had – their ability to run, play or hold your hand.

*"My child is seventeen but still only mentally a baby. She can't do anything for herself, she can't roll over, sit up or stand."*

*From the parent of a teenager who had bacterial meningitis as a baby*

Hearing and sight can be affected too – the senses that connect you to the world and people around you. In addition, headaches, fatigue and memory loss can be severe and have a significant impact on daily life.

*"I struggle to look after my three beautiful boys and have no energy to run around with them like I used to. Even simple tasks like washing my hair leave me shattered."*

*From a woman who had viral meningitis at the age of 35*

The potential consequences can be extensive and destructive, but in cases where there have been after-effects, just 44% of people have access to good information about managing them.



### After-effects of viral meningitis

Often dismissed as a less serious disease, respondents to the survey who reported after-effects from viral meningitis were just as likely to report that it affected their day-to-day activities as those who had contracted bacterial meningitis.

The far-reaching impact of viral meningitis is highlighted by a number of the case studies and personal quotes in this report.

## After-effects of meningitis (both viral and bacterial)



% shown based on people who have experienced after-effects






**“You miss what you used to have; you miss being able to do whatever you wanted to do.”**







# “Because it was viral meningitis, everybody was like ‘oh you’re fine, aren’t you?’ — but you don’t feel fine.”

“After about day three of being in hospital, I’d not really been told anything about meningitis, they just kind of discharged me – they didn’t give me any information about recovering.

Then it’s three weeks down the line and you still feel dreadful; and then months down the line I’m still plagued with headaches.

I struggled a bit with depression afterwards. I was really struggling with the fact that something so serious had happened to me – it was unbearable to think about.

If I have a particularly bad headache I get so panicky and I’ll ring my mum in tears. I’m terrified of getting it again; honestly I can’t even explain to you how scary that thought is.

You don’t understand why it’s happened to you, why your life’s been affected so much, and why you can’t do the things you used to.

I was really fit before; I was really active. That all stopped because I just don’t have the energy.

I’m actually an opera singer, so I used to be out rehearsing at least twice a week and I’d be dancing all the time. It was so hard to keep up when you’re not well. Now singing just reminds me of really struggling, which is bizarre, but it does.

You miss what you used to have; you miss being able to do whatever you wanted to do.”

**Jessica had viral meningitis when she was 22.**

# The emotional toll

Surviving meningitis can leave people severely emotionally affected. The trauma, fear and guilt can be crippling. Family and friends live with the memories, and the nightmares, of the experience too.



**“I was suicidal from the emotional trauma of it all.”**

The emotional impact of meningitis can be overwhelming. At best, even with a full recovery, the memory of a near-death experience, or the memory of watching a loved one fight for their life, never goes away.

*“I blame myself, I can’t get rid of the images of his little body lying there in intensive care.”*

*From the parent of a baby boy who made a complete recovery from bacterial meningitis*

Around two-thirds of people who have recovered from meningitis experienced an emotional impact. This rises to nine in ten people with long-term after-effects, many of whom describe a severe impact on their mental health.

*“It’s very scary to face death at 28 with two small children... I have come to terms with that. But still, writing this now I have started to cry...”*

*From a woman who had viral meningitis at the age of 28*

People can suffer from depression as a result of the trauma and may have to come to terms with a body – and a life – changed forever.

*“I suffered from bouts of deep depression for many years that I have only recently been able to control to a level of not affecting my life anymore.”*

*From a woman who made a complete recovery from bacterial meningitis at the age of 16*

Many of the people who shared their experience with us talked about a constant fear that meningitis would return. For some, this fear and anxiety can be overwhelming.

Relationships and social lives are affected too, as personalities, bodies and circumstances are changed dramatically. Many people said the experience had impacted on their relationships with friends and family members. In fact, around one in three people with long-term after-effects described facing severe social isolation.



**3 in 4 survivors**  
say meningitis has  
impacted on them  
emotionally



**1 in 3 people**  
with long-term  
after-effects are  
facing severe  
social isolation



### Impact on friends and family

Friends and family live with the memories, and the nightmares, of their loved one being ill.

In fact, the friends and family of those who have survived are more likely than people who had meningitis themselves to say the experience has affected them emotionally.

Sometimes, friends and family blame themselves for not acting more quickly, or doing enough to protect their loved ones. They may also be coping with a friend or relative who has been physically or emotionally changed by the disease.

People who have lost someone they love to meningitis shared with us their heartbreak, anger, devastation and overwhelming sense of loss.



**79% of friends and family**  
say the experience has  
impacted on their  
mental health




Steven and his mum, Margaret. Steven had viral meningitis when he was 22, and later had bacterial meningitis too.





**“Thomas didn’t tell us he was still getting severe headaches a year later.”**





**“Thomas just exploded and told us that he’d had terrible headaches for a long, long time. He asked me if I’d help him commit suicide.”**

“To see Thomas on a life support machine was just horrendous: the worst thing I’ve ever seen in my life. To sit there with him, just holding his hand, not knowing if I was going to get our Tom back...

We didn’t know there could be after-effects, and Thomas didn’t tell us he was still getting severe headaches a year later.

The lad I’ve got now, is not the lad I had before. It can be great, and one minute we can be laughing and joking, the next minute he can just flip.

We really didn’t realise how bad things had got until we had some friends of his round for a party and things got totally out of hand. Thomas just exploded and told us that he’d had terrible headaches for a long, long time and asked me if I’d help him commit suicide.

None of his friends had a clue what he was going through – none of us realised what he was going through and how he had covered it up.

We went through hell. There was a massive ripple effect through the family with it, not just here in this house. We were constantly worrying about him, just not knowing what was going to happen next.

I planned one night that I wasn’t going to be here either – I couldn’t put up with this anymore. I couldn’t cope with the way it was pulling the family apart. I felt so mortified over this happening to us.

**I ended up on anti-depressants and had counselling because I just didn’t want to be here; I felt like I’d failed everybody.**

I found Meningitis Now, who organised counselling for Thomas. He’s so much better now he’s finding ways to cope. We’re all coping much better now that we understand that the after-effects of the meningitis are behind what has been happening.”

**Jayne and her son Thomas.  
Thomas had bacterial  
meningitis when he was 16.**

# Ruined lives

Lives are turned upside down by meningitis — it is a thief that can take away your ability to learn, to play, to work. It takes away futures people had hoped and planned for, and dreams parents had for their children.



**“I’ve had to let go of the person I was, I know I will never be the same again. I have lost my life, my career I studied so hard for at university, my friends, my social life, my health, my happiness, my freedom...”**

Meningitis takes so much away, that even those who survive can feel they have lost the person they once were.

On a daily basis, the physical and emotional after-effects can change lives dramatically. The infection may have been treated, but disability, cognitive problems, severe headaches, fatigue, anxiety and much more can remain. As a result, 58% of people with long-term after-effects have some difficulty with the day-to-day tasks we take for granted, such as cooking, cleaning, or personal care.

*“I have gone from being the family ‘diary’ to having to be prompted to do most things. I have alarms to tell me when to take medications, when to eat etc. I have to have help with the simplest of tasks like putting a pizza in the oven, as I forget that it’s cooking.”*

*From a woman who had viral meningitis at the age of 42*

Half of people who were in education (or planning to be) when they had meningitis

saw their education affected. If nothing else, meningitis may cause people to miss large chunks of school or university. If they do return, they may need extra support, and some young people are forced to leave mainstream education entirely.

Meningitis can have a similar effect on those who are working. Forty-one per cent of people (who were in work or planning to be) had their working lives affected, rising to two-thirds of those with long-term after-effects. Amongst other things, the impact on working lives can have a knock-on financial impact: meningitis has had an impact financially on half of people with long-term after-effects

*“I had to give up work. I worked full-time as a legal assistant following my law degree, and was working hard towards my career as a solicitor. I am barely able to leave the house, and financially the future is very scary, as we are barely scraping by.”*

*From a woman who had viral meningitis at the age of 28*





### The wider impact on friends and family

The life-changing impact of meningitis ripples out far beyond just the person who was ill. This is true whether a loved one dies, survives with long-term after-effects, or makes a full recovery.

Two-fifths of parents whose children had meningitis (and who were in work or planning to be) had their working lives affected, and people talked about the immense strain the experience put on their relationship with their partner.

Siblings who watch a loved one fighting for their life can be left traumatised by the experience too, with some telling us of severe depression, anxiety and anorexia resulting from what they have been through.



**58% of people** with long-term after-effects have some difficulty with day-to-day tasks



**1 in 2 people** in education (or planning to be) have seen their education impacted



**2 in 3 people** in work (or planning to be) who have long-term after-effects have seen their working lives impacted



Charles, who had viral meningitis when he was 24.



**“Our baby girl, Rubie Jane, was born on the 8th April, 2015. We lost her to meningitis when she was six weeks old.”**

“Life has changed forever — you can’t put it into words, really. We’ve been through a lot since we’ve been married, but this is way off the scale.

We were just lost. We still are. It’s just an empty feeling. We don’t go into town, even to just go to the shop, because we don’t have the confidence to do that anymore.

Everything just seems so daunting now. We try and do everything together, to try and comfort each other.

We have to carry on for our son’s sake — we have to — he’s only three and a half. It’s hard for us to get out of bed in the morning, but we do, because he wants us.

We explained to Alfie that Rubie is now a star in the sky. He said that he was going to ask a fireman to get a big ladder and bring her back.”

**Russ, Kerry and Alfie lost Rubie Jane to meningitis in 2015.**



**“We explained to Alfie that Rubie is now a star in the sky. He said that he was going to ask a fireman to get a big ladder and bring her back.”**





# A fight left to fight

The people who took part in 'Meningitis and Me' bravely shared their personal stories of this brutal disease. They told us about loss, and lives changed forever. They convinced us there is still so much left to do.



**Around  
500,000**  
people in the  
UK have had  
meningitis

Meningitis strikes fear into people's hearts because of the speed at which it can take hold, and how hard it can be to spot. It is not selective about who it targets – meningitis can affect anyone, of any age, at any time. Around 500,000 people in the UK have had meningitis.

It is a killer, but even those who survive are changed forever. Some are left with life-long debilitating after-effects, and some face a daily struggle with anxiety and depression.

Whilst viral meningitis has sometimes been seen as less serious than the bacterial form, the stories we have heard show that both forms of the disease, and the impacts they have, must be taken seriously.

It is important to remember that friends and family may find their lives are changed forever too. Memories of loved ones fighting for their lives never go away, and neither does the fear that meningitis will strike again. Parents struggle to work when their children are ill, siblings can become depressed and anxious, and relationships suffer under the strain.

The experiences shared as part of 'Meningitis and Me' have shown there is much left to do.





**“I’m waiting for the day  
when a vaccine is ready  
that prevents all types  
of meningitis —  
then I will rest easy.”**

# Meningitis and us

Meningitis Now is the founder of the meningitis movement and the only charity dedicated to fighting meningitis in the UK. The people we help everyday, and the people who support us in return, are at the heart of everything we do.

With decades of experience Meningitis Now is fighting the disease on all fronts:

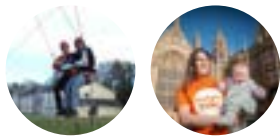
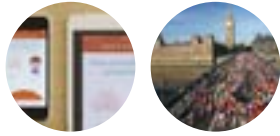
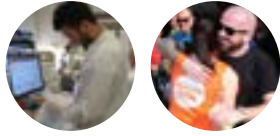
- Providing a powerful, united voice for people fighting meningitis
- Saving lives by funding vaccine and preventative research
- Reducing the disease's impact through awareness
- Rebuilding futures with dedicated support
- Fundraising to deliver our plans

As a charity that receives no public funding, we're entirely reliant on the energy, enthusiasm and initiative of our supporters to raise the funds we need each and every day to continue our vital research, awareness and support work.

**Our vision is a future where no-one in the UK loses their life to meningitis and everyone affected gets the support they need to rebuild their lives.**







"We really appreciate all of the help and support that we have been given. When nobody else listened or believed us, Meningitis Now did."

"The support has been invaluable...! don't know how I would have got through this without them."

"The grant we received helped at a time of great hardship."

"It was amazing to talk to a dedicated team with vast knowledge on meningitis."

"I don't know where we would be as a family without the help they gave."

"A meningitis leaflet saved my life. My Mom had read it in a queue in a supermarket a few weeks before I became ill."

"I will be eternally grateful that we were not left on our own to deal with the aftermath."

"It has been a lifesaver for me - without the counselling and also my volunteering I would have felt life too hard to keep living."

"The only people who truly understood the living hell we were going through."

The 'Meningitis and Me' research project was commissioned by Meningitis Now and delivered in partnership with Alterline, an independent research agency.

Our survey covered many aspects of people's lives and was open to those who had meningitis, and their friends and family members.

In total 1,131 people took part (400 people who have had meningitis, 469 friends and/or family of someone who survived, and 262 friends and/or family of someone who died).

**We would like to thank the 1,131 people who took part and shared their personal stories with us.**

Questionnaires were completed between 9th June and 1st July, 2015, and explored a whole range of topics, including diagnosis and treatment, after-effects, and the impact of meningitis on people's education, working lives and relationships.

The questionnaire was distributed via email by the charity. It was also promoted via their website, newsletter, social media, volunteers and healthcare professional networks. Alterline also asked people to complete the questionnaire through a Facebook advertisement campaign, to reach out to those who might not have come into contact with the charity.

Following the survey, ten face-to-face interviews were conducted with people about their experiences. These interviews explored topics in more depth.

**All of the quotes used in this report are the real words of people who took part.**

# Meningitis and you

What we have already achieved, and what we will achieve in the future, is only possible because of our supporters. Join us in saving lives and rebuilding futures.

## Get involved

 [www.meningitisnow.org](http://www.meningitisnow.org)

 [@meningitisnow](https://twitter.com/meningitisnow)

 [Fb.com/meningitisnow](https://fb.com/meningitisnow)

With enthusiasm and energy our supporters raise the funds to deliver our life-saving and life-changing research programme, to reduce the disease's impact through our ongoing awareness campaigns and bring public pressure to bear on the policy-makers. The recent successful introduction of a vaccine for meningococcal group B disease (Men B) for infants is a good example.

We are at the forefront of the fight to beat meningitis, but we can't reach our vision alone – we need your help, to build a future where no-one in the UK loses their life to meningitis and everyone affected gets the support they need to rebuild their lives.

Despite significant recent advances there's still so much to do. Please join us and our amazing volunteers to drive forward our awareness-raising programme, promote what we do and help raise the vital funding we need.



### Talk about meningitis

Help bring the disease to people's attention by talking to family, friends and colleagues.



### Partner with us

Help save lives and rebuild futures. We have a range of opportunities where you can make a difference.



### Support our work

Donate, take part in one of our events or organise your own – join the fight.

**“Ever since losing  
our son George,  
we’ve tried to  
help Meningitis  
Now like they  
helped us.”**



Emma's son George died  
from meningitis as a baby.

Pictured: George's brother Henry,  
his mum Emma and his grandparents  
Lesley and Chris .



## **Our vision**

A future where no-one in the UK loses their life to meningitis and everyone affected gets the support they need to rebuild their lives.

Join the Meningitis Now family, make a difference to people's lives, and help us drive towards our vision with energy, commitment and determination.

## **Contact us on**

Phone: 01453 768000

Email: [info@meningitisnow.org](mailto:info@meningitisnow.org)

Meningitis helpline: 0808 80 10 388

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[Fb.com/meningitisnow](https://fb.com/meningitisnow)



[@meningitis\\_now](https://www.instagram.com/meningitis_now)

The logo consists of an orange circle containing the text 'Meningitis now' in white. 'Meningitis' is in a standard sans-serif font, while 'now' is in a larger, bold, lowercase sans-serif font.

**Meningitis  
now**