Strategic Plan 2021-26

Making a difference, every day

Meningitis now
The fight against meningitis goes on

Meningitis is a terrible and devastating disease. Since 1986, Meningitis Now has fought it relentlessly by funding research, raising awareness and providing support to people whose lives have been affected. We’ve made a difference in so many ways.

Our research and campaigning has helped the development and introduction of five lifesaving vaccines now available on the NHS – reducing the number of UK meningitis cases every year since the 1990s.

And we’ve raised awareness of the risks and signs and symptoms of meningitis to help ensure people know what can be done to prevent it, and how to respond should it strike. Our aftercare and support has brought comfort and practical help to thousands of families across the UK.

Our work is far from over

Cases of meningitis are thankfully falling, yet as many as 2,000 people a year still contract bacterial meningitis in the UK – while 6,000 contract viral meningitis¹. That’s 22 people, every day. And some estimates suggest that as many as 500,000 people have experienced meningitis in the UK. Many people will continue to need our aftercare and support, both now and in the future.

The effectiveness of vaccines in preventing meningitis – and people’s access to those vaccines through the NHS – must be improved. And until meningitis is eliminated from the UK, it remains vital that we raise lifesaving awareness of the disease.

Fighting meningitis has been this charity’s driving force for four decades. We’re making a difference now. Over the following pages, we set out how we’re going to continue to make a difference – for as long as it takes.

Dr. Tom Nutt
Chief Executive Officer


Covid-19

When the Covid-19 pandemic struck in 2020, our lives were changed in unimaginable ways. For our charity, the shock was no less dramatic.

Our income fell by over £1m, and we were forced to significantly reduce expenditure to survive. Much-valued events, such as Family Days, the Five Valleys Walk and our Gloucester Cathedral Christmas Concert, had to be cancelled due to lockdown and social distancing. It was a frightening and difficult time for all.

But we soon adapted to this new world. The Meningitis Now family pulled ever-closer together. We shifted many of our services online, meaning we could provide tailored and timely support to people living under lockdown. We created virtual fundraising events so that people could continue to support our vital work, and we launched the Covid-19 Young Futures Fund to ensure young people up to the age of 25 had the resources they needed to continue their education, learning, and development during these difficult times. And having restructured, Meningitis Now starts 2021 in a relatively stable financial position.

More positively, lockdown and social distancing has caused a significant reduction in cases of meningitis. This is a cause for celebration, although the future incidence of disease is unknown. The one thing that is certain is many people in the UK will continue to need our help and support.

Much of the work underpinning this Strategic Plan was undertaken in the year before the pandemic, and we have taken time in 2021 to re-assess our aims in light of Covid-19. We believe this plan remains right for our times. The fight against meningitis goes on.
How we’ll achieve our vision

Our vision is a future where no one in the UK loses their life to meningitis, and all those affected get the support they need to rebuild their lives

… we exist to save lives and rebuild futures

It’s a bold ambition, but we’re determined to get there. We have set out three key priorities to make sure we continue to make a difference, every day.

Over the next five years, we will:

1. Fight to defeat meningitis in the UK within a generation
2. Reach out to everyone who needs help, support and information
3. Be recognised as a centre of expertise for aftercare and support

Each year, the charity will produce an Operational Plan that sets out how we intend to deliver these priorities. We will evaluate and publish our progress in our Annual Report.

Michelle and Stuart’s story

Michelle’s husband Stuart became ill shortly before Christmas 2017.

“My life has changed completely without my husband. We only got married in February 2017 although we had been together for ten years – married and widowed in the same year!

“My whole future was wiped out. It was devastating and very difficult to get my head around.”

The first support Michelle received was from one of our Community Support Officers.

“She brought with her a pack full of leaflets and information on what Meningitis Now can do, plus leaflets from other organisations.”

“The home visit helped us to get a better understanding of what had happened to Stuart and also offered us support going forward.”

Since then, counselling, paid for by Meningitis Now, has helped Michelle come to terms with the changes in her life and to cope with feelings of guilt.

“The counselling stopped me from feeling guilty for surviving this traumatic experience and that it had been Stuart that got ill and not me.”

“It helped me to move forward with my life.”

For Michelle, we really were there when she needed us most – and she wants others to know how important it is to seek help when you need it.

Michelle also attended one of our Forever Days events. “I can really see how these days can help grieving families come together and help each other.”

Christine Mather, Meningitis Now’s Community Support Officer, said: “It’s good to hear that Michelle found our support so helpful; it’s what we are here for.”
“When I lost my son Spencer to meningitis and septicaemia in 1982, I knew practically nothing about meningitis, despite this terrible disease taking away my little boy. I knew something had to be done to raise awareness, to support those affected by the disease and above all to raise funds to support scientific preventative research. We must end the devastation this awful disease can cause.”

Steve Dayman, Executive Founder and father of Spencer Dayman, who died of meningococcal septicaemia aged 14 months.

Why now? Because – for the first time ever – we have the prospect of a generation of youngsters growing up in the UK vaccinated against nearly all of the major causes of bacterial meningitis. We support the World Health Organisation’s ambitious aim to defeat meningitis globally by 2030.

How will we make a difference? By investing in research to prevent disease and improve diagnosis and treatment. And by ensuring that lifesaving vaccines are as accessible as possible by raising awareness of them and by influencing the government and NHS.

Investing in lifesaving research

Over the last 35 years, we’ve funded over £12.6 million of research – contributing to the development and introduction of lifesaving vaccines in the UK. Yet new cases of meningitis cause death and disability every year, and many people continue to live with the lifelong impact.

We will continue to fund scientific research into the prevention, diagnosis and treatment of meningitis and sepsis, until we defeat it. We believe this research will one day end the devastation caused by meningitis forever.

Improving awareness of vaccines

Vaccines are the only way to prevent meningitis. Five lifesaving vaccines that protect against meningitis are now part of the NHS routine immunisation schedule – but it is crucial that people are made aware that they exist and that there is equitable access to them.

We will raise awareness and work with the NHS and public health authorities to promote access to these lifesaving vaccines. Vaccination rates are currently falling in the UK, and we will fight to make sure everyone has the same opportunity to get vaccinated.

Influencing policy-makers and clinical practice

Through our close relationships with the Department for Health and Social Care, the NHS, and public health authorities in England, Scotland, Wales and Northern Ireland, we will continue to influence policy decisions and clinical practice. We aim to improve early diagnosis and treatment of meningitis, while ensuring that people who have experienced the disease receive the care and support they need to rebuild their life.

We are the people’s voice for meningitis in the UK. We will hold the government and authorities to account for any decisions that could compromise the safety and wellbeing of the people we exist for.
In 2016 my daughter Izzy died of meningitis. She was just 16. Meningitis Now reached out to my family offering help and support – a lifeline of compassion and practical support during what was our darkest hour. Since then, the charity has helped me in so many ways to ensure that Izzy’s death wasn’t in vain. This includes supporting my efforts to improve the way the NHS treats suspected meningitis and raising awareness of this awful disease. I recognise the value of the work the charity does and feel that it is important to ensure they have the essential funds to keep going. I can’t bring Izzy back, but I can change what happens in the future.”

Paul Gentry, father of Izzy Gentry, who died of meningococcal disease aged 16.

Why now? Because vaccines do not protect everyone against all forms of meningitis. Awareness of the signs and symptoms of the disease can help save lives. And because there are many people affected by meningitis who are unaware of the help and support we can give them.

How will we make a difference? By raising awareness of the signs and symptoms of meningitis, and what to do when you suspect them. And by ensuring that the help and support that we offer is as well-known and as accessible as possible.

Raising awareness to save lives

We will work tirelessly to improve meningitis and sepsis awareness. We aim for every person in the UK to hear or read about meningitis three times a year. We want them to be aware that the disease exists and is serious, and that vaccines are important.

Some groups are at increased risk, such as under-5s, adolescents and the over 65s. We aim to make these groups and the people who care for them, such as parents, aware of this. We want them to have a basic awareness of symptoms and to know to respond quickly by seeking urgent medical help. We will aim to address health inequalities where possible.

Making more people aware of our support

We’re here to provide emotional, practical and financial support for everyone in the UK who has been affected by meningitis, completely free of charge. However, we estimate that we’re only reaching one in four people affected each year. All too often we hear people say they wished they had known about us sooner.

Over the next five years, we will focus on promoting our aftercare and support services more widely and ensuring they are accessible to all. We will make it simple and straightforward for people to access services, so that we can help as many people as possible – at the right time and for as long as people need us.

Providing the right information

Our nurse-led Helpline will continue to provide people with emotional support and answer their questions. We will explain the support we provide and communicate in a way that works for as many people as possible – whether that’s by phone, email, web or social media.

We are an authority for meningitis information in the UK. With our simple signs and symptoms card, our factsheets, posters and leaflets, digital materials and bespoke awareness programmes for childcare providers and universities, we will continue to provide information that organisations and individuals can trust and rely on.
"I contracted meningitis when I was 2 years old – I lost both my legs, part of my left arm and fingers as a result. Growing up being so different from my pals was a challenge. At this time I was largely unaware of Meningitis Now and the support the charity had been giving me, and my mum and dad. I was 8 before their importance became apparent to me – when I did my first media interview to help improve awareness. Sixteen years on, the charity remains an important part of my life – having supported me, for example, to become an Irish equine Paralympian. More recently they helped me transition from my home in Belfast into Uni in England and have helped me secure employment after I graduated. Today, I’m part of the charity’s Young Ambassadors’ team – helping to support other young people who have sadly experienced meningitis."

Louise Greer, who experienced meningococcal septicaemia aged 2 years.

Direct support for people affected by meningitis

We understand that life after meningitis is tough and that everyone’s journey is different. We will listen and ask the right questions so we can focus on where we can make the biggest difference. Our personalised approach reduces the isolation that many feel and helps increase their confidence.

The people we support already tell us that we provide invaluable practical support, helping them to feel reassured and to be heard and understood. We will continue to evaluate and invest in our support services, with a growing knowledge of how to improve the health and wellbeing of those affected by meningitis. And by continuing to foster independence and resilience, we will empower people to face the future with hope and confidence – and cope with whatever life after meningitis throws at them.

Broadening the scope of our research

Over the next five years, we will broaden our current research programme to include life-changing as well as lifesaving research. Life-changing research will help us understand more about the impact meningitis has and provide evidence of how best to support people who are affected.

We will focus on improving our understanding of the physical, sensory and cognitive after-effects of meningitis, in people of all ages. We will address the financial, psychological, social, emotional and educational impact on individuals and their families.

Increasing understanding across all sectors

We will work closely with policy-makers, scientists, health and care professionals and charity partners to share information and knowledge. By combining our expertise, we will improve our common understanding and evidence-base of what works when dealing with meningitis and its after-effects.

Bringing together knowledge and skills means we can give people affected by meningitis the best possible help and information – so they’re able to understand and access the aftercare and support they need to rebuild their lives.
A future built on our history

"From the moment that group of parents met in my living room, I knew we would achieve something special. From the support we provided to each other in those early days, to the professional and impactful charity of today, Meningitis Now has always made a difference."


1986 The Meningitis Trust is formed by a group of parents including Steve Dayman and Jane Wells, in Stroud, Gloucestershire. Despite being told that preventing meningitis might not be something they’ll ever see in their lifetime, the group was determined to help save lives and rebuild futures.

1990 Our nurse-led Helpline launches. We’ve now taken over one million calls – providing emotional support and explaining more about the support we provide.

1992 With our support the first major vaccine (Hib) against the disease is introduced, supported by our research. Since then, the charity has funded research leading to the introduction of five lifesaving vaccines into the UK’s NHS routine immunisation schedule.

1993 Our first symptoms card is introduced. Do you have one of the 22 million we have distributed since then? More people than ever before now know about the risk and signs and symptoms of meningitis.

1997 We provide financial support for the first time ensuring that people living with the after-effects of meningitis get financial help when they need it most. Today this service is called the Rebuilding Futures Fund.

2002 The £500,000 state-of-the-art Spencer Dayman Meningitis Laboratories are officially opened at the University of Bristol’s School of Medical Sciences.

2007 We run our first Family Day. Thousands of people affected by meningitis continue to benefit from our programme of events that bring people together. This includes Forever events for people who have experienced bereavement.

2011 Our Young Ambassadors programme is introduced, followed later by Community Ambassadors. These unique voluntary roles recognise the difference that people with lived experience make in powerfully raising awareness of meningitis within their own communities and across the media.

2013 Meningitis Now is created by the merger of Meningitis UK and the Meningitis Trust, two charities renowned for pioneering scientific and medical research and compassionate support for people affected by meningitis.

2015 A MenB vaccine is introduced to the UK’s NHS routine childhood immunisation schedule. Our Beat It Now! campaign influenced key policy-makers to protect newborn babies – sadly adolescents and young adults remain unvaccinated and at risk.

2017 Our Believe & Achieve programme introduces the first-ever programme of tailored support for 14 to 25-year-olds, to help them meet others, build confidence and self-esteem, and regain control over their lives.

2018 We launch Adults Get It Too, a pioneering campaign drawing attention to the fact that the disease burden of meningitis is shifting towards older adults. This campaign supplements other successful awareness campaigns targeting parents, adolescents and students and young adults.

2018 We know that peer support is critical to help people feel less alone and enables them to connect with a community of people with similar or shared experiences. Our unique Facebook Peer Support pages create a safe space for people to communicate, share information and access the help and support they need.

2020 Public health data shows the introduction of the MenB vaccine has led to a 75% reduction in cases in young children. But there’s still work to do. We’ll continue to fight for a future where no one in the UK loses their life to meningitis – and where all those affected get the support they need to rebuild their life. We haven’t lost sight of the vision of those parents over 35 years ago. We’re still making a difference, every day.
Making it happen, every day

The fight against meningitis simply couldn’t happen without the support and hard work of the many people and organisations connected to the charity – the community we like to think of as family.

Fundraising delivers our work

We rely on fundraising to deliver our work – we need to raise millions of pounds each year to save lives and rebuild futures. Marathons, bake sales, direct debits, gifts in wills and working with grant givers, companies and celebrities – they all bring us closer to achieving our vision. We’ll continue to offer a broad range of ways for people to get involved. This also helps us avoid relying too much on any one type of fundraising.

And fundraising is not just about money – it’s often a way for people affected by meningitis to fight back and do something positive to help others. We want as many people as possible to play their part in the fight against meningitis.

Volunteering makes all the difference

Our network of Volunteers and Ambassadors plays a vital role in our work, from raising awareness and helping with fundraising to the day-to-day running of the charity. We will continue to support our Volunteers to use their experiences and their passion for our cause. We’re so grateful to all those who donate their time or their money – our past achievements and vision for the future simply wouldn’t be possible without them.

Patrons and Trustees donate their expertise

Our Patrons are leaders in their professional fields and kindly lend us their support, expertise and profile. We are especially grateful for the support of our Royal Patron, HRH The Countess of Wessex. Our Trustees oversee the good governance of the charity by ensuring our resources are focused on impactful activities. Some of our Trustees have their own experience of meningitis.

Our team give their best, every day

All our team help to deliver the research, awareness, support, fundraising and volunteering activities that enable our charity to make a difference. Some staff have been with us over many decades.

We aim to be professional, inclusive, understanding and hopeful at all times. We work tirelessly. And our important back office team – responsible for finance, HR, and administration – work as efficiently and effectively as possible, so that our resources are focused on making a difference now and every day.

Ethan and Martina’s story

Ethan contracted pneumococcal meningitis at 13 weeks.

Mum Martina said: “He was very poorly in hospital and we were effectively told to wait and see how he would develop. Over time we noticed differences between him and his peers – with his development, his speech, his ability to understand. It wasn’t until he was 7-years-old that we were aware there might be more significant problems and tests confirmed he has an Acquired Brain Injury.

“This has particularly affected his education and has been quite a challenge for him in terms of school. As work has got harder as he’s got older it’s been such a problem.”

The family’s first contact with Meningitis Now was some 10 years ago when Ethan’s sister Ella had art therapy. This helped her and the family to process some of the events that had gone on.

“Since then Meningitis Now has had an incredible impact in helping us come to terms with Ethan’s brain injury and providing a family-like environment around us.”

Ethan and Martina have been on numerous Believe & Achieve weekends, invaluable for Ethan to meet with other young people. “It’s really become like a family with a group of people who understand each other but also with the staff, who provide incredible insight and support.”

Meningitis Now also provided educational equipment and, most significantly, helped Martina acquire an Education, Health and Care Plan for Ethan, providing a far better learning environment.

“Without Meningitis Now I think we would have struggled and not known what to do or where to go. For that, we’re very grateful.”
Help us make a difference, now

We’ve set out our vision for the future. But we won’t be able to defeat meningitis, reach out to the people who need us or be recognised as a centre of expertise without you. Help us save lives and rebuild futures today by:

- Making a donation
- Taking part in an event
- Posting and sharing our content on social media
- Volunteering your time
- Sharing your story

Visit www.meningitisnow.org and help us make a difference, every day.

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