



**Meningitis  
now**

*Thomas and Emily Squires*

**Vision 2020**  
our strategic priorities



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# Vision 2020

**Vision 2020 sets out our goals and priorities through to 2020, moving us ever closer to 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.**

Much has been achieved in our fight since we founded the meningitis movement and Meningitis Now was formed in 1986. Our significant impact includes funding vital research, campaigning for and supporting the introduction of five vaccines, providing support to thousands of individuals and families, and delivering lifesaving, awareness-raising activities across the UK. However, there is still much to be done. It is not just us saying this, it is the people who we exist for who told us through our Meningitis and Me\* research in 2015 and at our Chief Executive's roadshows.

As the only organisation entirely focused on saving lives and rebuilding futures in the UK, we are determined to continue to drive forward with the people we exist for at the heart of everything we do.

# Meningitis now

## Our name reflects:

- Our clear focus on **meningitis**
- The need for action **now**, whether that is developing and introducing vaccines, taking action if meningitis is suspected or providing timely support
- The need to use our voice to address whatever the issues are **now** and issues that will change over time
- The fact that we will be here **now**, whether we are talking today or in the future, for as long as meningitis, and its impact, remains an issue in the UK

\*Over 1,100 people took part in our commissioned Meningitis and Me research. You can read about the key findings in the report, just ask us for a copy.



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## 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.**

## Our Mission

- To provide a powerful, united **voice** for individuals, families, communities, experts and professionals who know just how devastating meningitis can be
- To save lives and rebuild futures by funding **research**
- To reduce the impact of the disease by raising **awareness**, empowering people with the knowledge and information they need to enable a fast diagnosis of meningitis
- To rebuild futures by providing dedicated **support** to people living with the impact of meningitis
- To raise the **funds** we need to deliver our vision, inspired by the individuals and families at the heart of the organisation



# Our Values

We believe in what we do and that's how we achieve so much. The way we work defines who we are:

**Supportive**  
**Passionate Inspiring**  
**Influential Focused**  
**Innovative United Bold**

# The challenge we face

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There is a misconception that meningitis is a thing of the past. This complacency puts lives at risk. Our achievement in securing the introduction of the Men B vaccine for newborns in 2015 makes this complacency worse. The far-reaching impact, whether bacterial or viral, is significantly underestimated - especially the non-physical impact - leaving people isolated and struggling.

About 500,000 people living in the UK have had meningitis. The impact on wider family means many more have seen their lives changed, whatever the outcome has been with a loved one. Every year thousands more lives are impacted. One in 10 who contract bacterial meningitis lose their life and one in three are left with lifelong disability. And whilst you are less likely to lose your life to viral meningitis, its impact can be significant and long term but often completely overlooked.

Our 'Meningitis and Me' research highlighted many of the challenges from diagnosis through to life after meningitis, for the individual contracting the disease and those around them.

These included:

- Getting a prompt diagnosis - sometimes literally the difference between survival and death
- Lack of follow up and information along the journey after meningitis, resulting in issues of isolation and reduced quality of life
- The 'hidden' non-physical impact not being recognised and/or linked back to the meningitis - meaning that effective support is not accessed

**About 500,000 people living in the UK have had meningitis.**

# Jack's story

Natalie's son, Jack, was grumpy, hot and sleepy. His temperature continued to rise. When it reached 41C, Natalie was so concerned she took him to a local drop-in centre. Whilst waiting to be seen, he became drowsy and developed a pin-prick rash all over his body. Recognising this as a symptom of meningitis, Natalie alerted the nurses and things began moving fast. Jack was given antibiotics and immediately rushed to A&E by ambulance, where a resus team was waiting for him. After three days of treatment, doctors decided Jack was well enough to finish his treatment at home.

Natalie believes their family was very lucky. *"I am glad I took him to the walk-in centre when I did. If I had left it, I can't even think about that."*

***Because of the work Meningitis Now has done in the past, my son survived...***

***"Meningitis Now was a great support. I found their facebook page, which linked me to the website and gave me lots of help and advice. I applied for a copy of My Journal, which has helped me monitor my son's recovery."***

***"If it wasn't for the doctor and nurse at the drop-in centre recognising the symptoms, I don't think Jack would have made such a good recovery, if at all. Because of the work Meningitis Now has done in the past, my son survived."***





# Our goals and priorities

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Informed by the people we exist for, we are committed to having the biggest impact we can. Our strategy has two over-riding goals:

- Saving lives and preventing disability through improving prevention and rapid diagnosis
- Rebuilding futures and improving quality of life through increased recognition of the impact of meningitis and provision of timely, effective support

We will deliver these goals through campaigning, research, awareness and support. With limited resources, we will focus our efforts on the areas where we can have maximum impact.

The external context in which we seek to achieve our vision will have a significant impact on our activities. We must consider the opportunities and manage the risks that arise from political, economic, health and social demands and from advancing technology.

With relentless pressure on government funding, coupled with rising patient expectations of care, health policy is becoming more open to innovation. In this environment, we will be pioneers in our field and initiate and facilitate a united voice for change at a policy level, including working closely with partner charities and organisations. Together we can have greater impact for the people for whom we exist.

Technology has transformed our economy, the ways in which we learn and live, enabling quick and easy communication regardless of location. We will continue to use these developments to help us broaden and improve our communications and enhance the way we provide information and support, whilst taking care to ensure those less technically able can also access our support.

By 2020, when we will repeat our Meningitis and Me research with those whose lives have been affected by meningitis across the five years, we aim to have positively influenced the apparent previously faced challenges of prompt diagnosis, lack of follow up and hidden non-physical impact. Vision 2020 shows the steps we will take to achieve this.



# Thomas' story

Thomas woke from a nap distressed and with a high temperature. At the doctors, his parents were told there wasn't anything obviously wrong. His condition deteriorated so they rushed him to hospital. He was quickly given antibiotics, wired up to a drip and blood was taken. At this stage no one could determine meningitis. Mum Emily says: *"We kept looking for a rash to appear but it never did. We were then told it was meningitis."*

*"His infection levels were the highest they had ever seen at the hospital. Thomas was barely conscious. After a few days he became more aware, even managing a smile. We knew at this point he was going to get better. It was a very slow process."*

## ***Meningitis Now was a great comfort to us...***

*"The hospital raised concerns that Thomas may have lost some hearing and we found out that he was left profoundly deaf. He was fast-tracked for cochlear implants. The operation was carried out within a month. Unfortunately this process brought further anguish. The first operation was aborted after two hours. We waited two weeks for the next six hour operation, which was initially successful, only to find one of the implants had slipped. We then had to go back in for a final four-hour operation."*

*"Thomas has pulled through and is a healthy and happy boy. Whilst his loss of hearing is devastating, we were blessed to be amongst the lucky ones who make it through this dreadful disease."*

***"Meningitis Now was a great comfort to us throughout a difficult year and also awarded us funding under their financial grants scheme to do sign language, allowing us to learn alongside Thomas. The charity's website was a brilliant source of information for us."***



# Goal 1: Saving lives and preventing disability

## Priority 1: Improve prevention

To achieve this, we will:

- Invest in research for new and improved vaccines
- Campaign for introduction of new and improved vaccines as they become available
- Campaign to extend the availability of vaccines free of charge
- Support high vaccine uptake through awareness campaigns and supporting initiatives from Government health departments



## Jemma's story

Jemma was a second year law student when she contracted meningitis Y and encephalitis in 2013. She had been feeling unwell and was advised by the doctor to rest. Her symptoms developed to include headaches, stiff neck, sickness, photophobia and feeling faint. She was in severe pain and drifting in and out of consciousness. Her family rushed her to A&E. Tests confirmed meningitis and, after emergency brain surgery, she

spent over three months in intensive care and eight months in a specialist neuro rehab unit.

When she returned home, after almost a year in hospital, her life had changed dramatically. Re-learning how to walk and increasing her muscle strength is an ongoing challenge and she remains significantly weaker than she was before. Meningitis Now has been able to support Jemma in this long process, and help her maintain a positive approach to her recovery.

## Priority 2: Support early diagnosis

To achieve this, we will:

- Deliver the Meningitis Awareness Recognition Mark programme for universities, pharmacies, schools, early years and workplaces to empower individuals to recognise the need for urgent medical attention
- Create and deliver a programme of targeted public awareness campaigns
- Form and maintain partnerships with organisations and companies; reaching at-risk groups to raise awareness
- Support and educate health professionals including the development and delivery of e-learning resources
- Secure commitment to initial and refresher training for frontline health professionals
- Campaign with other charities to get healthcare professionals to listen to parents, who know their children best

### *Jemma's life had changed dramatically...*

*"Meningitis Now has helped tremendously. A support officer visits regularly, and they have funded the counselling that is helping me come to terms with what has happened. Now I'm getting a bit stronger they've provided a grant for me to start horse riding therapy for the disabled. The future is beginning to look hopeful again."*



# Goal 2: Rebuilding futures

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## Priority 3: Provide direct support to people affected and their families

To achieve this, we will:

- Work proactively and effectively with individuals and their families on a supported journey after meningitis and recognise the value of timely and appropriate information
- Make appropriate support accessible to everyone who can benefit from it; recognising volunteering and fundraising as forms of support
- Undertake commissioned research to provide evidence of impact and help inform policy decisions and support provision
- Listen and respond regularly to the needs of our beneficiaries and demonstrate the impact of our support

### Tracy's story

Tracy was 36 when she collapsed with viral meningitis. Twelve months on, she is still battling with the impact:

*"I felt funny and woke with an immense headache, followed by dizziness and photosensitivity. I managed to waddle to a pharmacy, where I collapsed. An ambulance was called and I was taken in.*

*"Two days later I was given a lumbar puncture and was initially treated for*

*bacterial meningitis. They realised it was viral and I was released. It took four months before I went back to work. Then, one day, the shooting pains started, then dizziness, photosensitivity and my body went weak again. I could only just whisper, couldn't open my eyes or move, so off to hospital I went.*

*"I was told it was the viral meningitis and I had done too much. I went back to work on a phased return and have been doing that since then. Although I've had extreme fatigue and headaches, I've been working through it and getting stronger each day. Recently I got a headache, shooting pains, photosensitivity*

## Priority 4: Influencing knowledge and policy to improve quality of life

To achieve this, we will:

- Work with organisations and Government health departments, to achieve compliance with professional guidelines, standards and measures for hearing tests, aftercare and signposting to patient groups
- Extend the existing guidelines to all forms of meningitis and all age groups
- Support GPs by increasing their knowledge of impact, encouraging and facilitating provision of information to patients and referral to Meningitis Now
- Secure more effective continuity and ease of care for young people as they transition from child to adult services
- Establish wide recognition in medical and lay communities of the severity and long-term impact of viral meningitis for some sufferers and their families
- Improve understanding and acknowledgement of the impact on carers and families of sufferers, supporting them in accessing help and meeting their needs
- Establish meningitis-aware communities to create an environment of greater recognition for those coping with the impact

*and collapsed. I was taken to hospital and released hours later when I could walk again. I couldn't speak or move my arms.*

***"Meningitis Now has helped me no end. I've had support through the helpline when no one else would or could understand. My local support officer's expertise is invaluable. He knows others who have been through similar experiences, which is reassuring and helpful as the GPs don't seem to understand this illness. He organised reflexology, which helps so much - I feel wonderful after it."***



# How we will tackle the challenge

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Our goals are clear and their success will be built on:

- **Sustainable funding** - we will ensure we have an effective, diversified fundraising programme, offering flexible ways for people to support us as individuals, families, organisations or businesses.
- **Smart communications** - we will produce compelling, engaging, targeted and cost-effective communications to raise national brand awareness and keep meningitis high on the agenda. Focusing on our digital and traditional media presence, we will maintain our sector leadership in social media activity and work with media partners wherever possible.
- **A strong and effective organisation** - we will be lean and efficient, business-minded whilst keeping our personal approach. We will set objectives and targets for our activities and measure impact continually. Our capacity will continue to be enhanced across all aspects of our work by a strong, engaged team of volunteers, including those with personal experience. We will partner with other charities where it can improve our impact.
- **A high-performing team** - we will continue to attract, grow and keep a positive, productive team. We will support leaders at every level of the organisation as they define clear goals and build a shared vision of the future, encouraging autonomy and forward thinking. We will involve those with the right skills in each project and work collaboratively. We will apply these principles to our wider team of volunteers, advisors and board of trustees.
- **Learning culture** - we will embrace a learning culture to increase knowledge, competence and performance. We will do this through structured and peer-to-peer learning experiences, encouraging staff development through innovative working practices and creative thinking.



# The difference we make

**We believe the best way we can show you how we make a difference is to share quotes from people we have supported:**

*"I feel more supported and understood.....before I felt isolated and alone. You gave me hope and understood where I was coming from."*

*"Thank you for providing counselling. It really helped me and impacted on my life in such a positive way. You are a fantastic charity which offers such a vast range of support."*

*"You helped me express how I was feeling without being judged, priceless."*

*"Thank you so much for the grant. It has made a difference to my quality of life, improving it enormously. I can't put into words how much this means to me. Your contribution enabled me to go ahead and for that I will be eternally grateful. Thank you so much."*

*"Thanks for your excellent advice and prompt action following our phone conversation. The surgery has now agreed that my daughter is entitled to have the meningitis vaccine. In addition to this, the practice manager is updating all receptionists accordingly, so that similar cases can be dealt with in future."*

Vision 2020, informed directly by the people we exist for, sets out our priorities through to 2020. We will be brave and bold as we drive forward making sure our voice is heard. With your support, we will keep driving towards our ultimate vision and make sure that, as we move forward, we continue to save lives and rebuild futures.



**Meningitis  
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saving  
lives,  
rebuilding  
utures

Meningitis  
now

**Join the Meningitis Now family and  
make a difference to people's lives.**

Just contact us on:

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