



Support after meningitis and childhood deafness

Ffion Haf and Cathy Hill introduce Jasmine and describe the work of Meningitis Now in supporting young people and their families



Jasmine's story

"I'm Jasmine, I'm 15 and I'm a meningitis survivor. My experience of meningitis was in 2001 when I was diagnosed with pneumococcal meningitis and became profoundly deaf.

I contracted meningitis a week after my first birthday. At first I was misdiagnosed with gastroenteritis as I didn't display textbook symptoms of meningitis. It was only due to the gut instincts of a young registrar who asked to do a lumbar puncture and administered antibiotics that I was saved from any further damage. It took six weeks for a precise diagnosis of profound hearing loss, which came as a shock to my mum. It was such a tough time for her.

I was fast tracked for a cochlear implant as hearing aids were of no use as I had no residual hearing, and I was 'switched on' at 18 months old. After that, and with the help of Meningitis Now, we were able to access Auditory Verbal Therapy in central London at Christopher Place

in Euston. I now have knowledge of sign language and passed Level 1 BSL, but I still prefer to communicate through oral speech. Speech has always been a more natural form of communication for me and has allowed me to fit well into mainstream education albeit with a statement of support.

We moved to Plymouth in 2004 and Mum became involved in the Plymouth & District Deaf Children's Society. In 2011 she became the Chairperson of the Society, which inspired me to become Youth Spokesperson for the charity, helping other deaf children and their families.

Meningitis Now has always been a big part of my life, and probably always will be. Meningitis never goes away and keeps surprising me with new challenges I'm not expecting, such as acquired brain injury.

Meningitis Now has helped me and my mum through some very tough times. My mum accessed specialist counselling very soon after the meningitis and this was



fully funded by Meningitis Now. I was given Art Therapy when I was in Year 6 and it was really helpful to get through a difficult period in my life. Meningitis Now even funded singing lessons with a young theatre group to help improve my voice quality. More recently, at a Teenagers' 'Believe and Achieve' Weekend in Swindon, I got to meet other young people who had meningitis as children. It was really comforting knowing other young people were out there too.

Mum and I have been supported collectively and continually over the 14 years of surviving meningitis and these gifts have made a world of difference to our lives. We are so grateful for everything Meningitis Now has offered. So becoming a Young Ambassador for Meningitis Now is my way of giving something back to them for all their support. As a Young Ambassador, I've had the opportunity to speak in the House of Commons about my experience and explain about the after-effect of the disease.

Although I am deaf because of meningitis, I don't consider it a negative part of my life as I have been given the chance to help others, whether it's through Plymouth & District Deaf Children's Society or Meningitis Now."

As Community Support Officers for Meningitis Now, we meet courageous young people like Jasmine every day, young people who have battled with so much in their short lives, and still continue to do so every day.

Meningitis is a life-threatening disease, which usually strikes quickly and unexpectedly. It can affect anyone, but babies and young children are most at risk, with around half of all cases occurring in the under-5s, but teenagers and young people are also at increased risk.

There are about 3,200 cases of bacterial meningitis and related septicaemia each year in the UK¹. The disease causes inflammation of the meninges, the membranes that surround and protect the brain and spinal cord. Most people who have meningitis or related septicaemia (blood poisoning) will recover, but 10% will die and a further 15% will be left with serious, lifelong after-effects, including deafness, epilepsy and limb loss.

Deafness is the most common of the after-effects of meningitis. The disease causes sensori-neural deafness when the infection spreads to the cochlea and damages the hair cells, or when the auditory nerve becomes inflamed during the infectious process.

Meningitis Now's MOSAIC study (Meningococcal Outcomes Study in Adolescents and Children)² looked at the physical, cognitive and psychological outcomes of meningococcal group B disease (Men B), the most common cause of bacterial meningitis and septicaemia. Among the findings it showed that children who had Men B were five times more likely to have significant hearing loss and 2.4% had bilateral cochlear implants.

But the research also demonstrated that children who survive Men B are significantly more likely to also experience a range of other outcomes. These include:

- A borderline low IQ (<85), both verbal and non verbal.
- Deficits across all aspects of memory, both long and short-term.
- Poorer executive function leading to problems with organisation and planning.
- They are five times more likely to experience speech and communication problems.
- A significant risk of anxiety and behavioural disorders.

Regular holistic assessment of children and young people and an understanding of the full potential impact of meningitis will help to ensure that the appropriate timely support is provided for those who require it.

At Meningitis Now we recognise the devastating impact the disease can have on all aspects of life, for the individual, their family and school.

Our vision is to reach out and improve the lives of everyone affected by meningitis and minimise the impact of the disease.

Some of the ways we're able to do this include:

Confidential helpline: We know facing meningitis can feel lonely. Specially trained staff can talk to anyone on aspects of the disease, including after-effects, from 9am to 10pm every day.

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We can help anyone who has suffered from meningitis/meningococcal septicaemia, including family, friends and carers and any professionals working with them.

Home visits: We have Community Support Officers (CSOs) in all the UK regions who are committed to supporting sufferers, whatever their experience and whenever it was. A home visit can provide vital support and a chance to discuss how we can help.

Educational needs: Many families feel that the educational needs of their child following meningitis are not fully understood and can be overlooked. Some benefit from arranging for a CSO to visit their school to discuss meningitis, its impact and resources available to help children after meningitis.

Counselling and emotional support: Counselling can be helpful if you have had meningitis yourself, or if you are close to someone who has had the disease, and can be used by adults, couples together, young people and children. All the counsellors are members of professional bodies and have appropriate skills, experience and insurance. Sessions are available throughout the whole of the UK, are fully funded by Meningitis Now and there are no waiting lists.

Creative and complementary services: Following an experience of meningitis, many children will not want to talk about what has happened to them, but changes in their behaviour, sleeping, eating and interaction with others will suggest that they are experiencing some form of emotional distress. Access to a creative therapy can help children express their feelings in a gentle, supportive environment. We can make a referral to a professional therapist who can use art, play, drama or music to help a child make sense of what has happened. This can also be very helpful for siblings, who may be experiencing the impact of the disease on their own lives.

Family Days: Family Days happen in various locations throughout the UK and throughout the year, and are an opportunity for families with children up to the age of 12 who have been affected by the disease to meet one another in a fun and relaxed environment.

Believe and Achieve weekends: Our popular regional Believe and Achieve weekends are action-packed events for young people aged 11 to 18-years-old who have had meningitis or meningococcal disease.

Financial Support Grants: Perhaps one of the most significant impacts of meningitis can be financial. To counter this we have set up our Financial Support Grants system to provide practical help with things including:

- Therapeutic and re-training activities: such as speech and language therapy, physiotherapy, sign language classes and driving lessons.
- Special aids and equipment: including special beds, wheelchairs, and sensory equipment.

- Computer equipment; including specialist software such as touch screen and special needs educational software.
- Education: if a child has identified special educational needs, and is waiting for an SEN assessment, short-term educational support may be possible.
- Home adaptations: for example, stairlifts and bathroom adaptations.
- Respite care: for those who care for a family member with disabilities caused by meningitis.

For more on how we support families fighting back from meningitis, call our helpline on 0808 80 10 388 or visit www.MeningitisNow.org



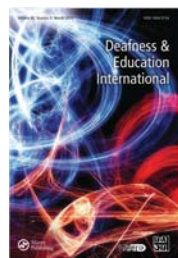
Ffion Haf is Community Support Officer for Meningitis Now in Wales. Cathy Hill is Community Support Officer in the South West region, covering Cornwall, Devon, Somerset, Dorset, Bristol, Bath and North East Somerset and the Scilly Isles.

References:

1. UK estimated average annual number of cases 2001 – 2012
2. MOSAIC study
[http://www.thelancet.com/journals/laneur/article/PIIS1474-4422\(12\)70180-1/fulltext](http://www.thelancet.com/journals/laneur/article/PIIS1474-4422(12)70180-1/fulltext)

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