Impact of Meningitis:

Findings and Recommendations from the Member Survey

Meningitis Research Foundation

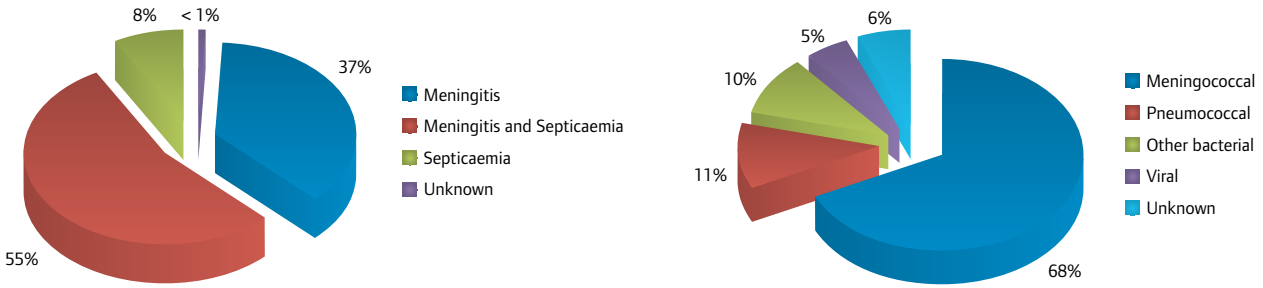
Background, aims and people involved

This summary identifies key findings from the Meningitis Research Foundation (MRF) Impact of Meningitis Member Survey. For the full report please go to **www.meningitis.org/publications**

The survey aimed to gain an overall account of MRF members' experiences of disease, with a particular focus on accessing urgent hospital care and follow-up care, and the long-term impact of the illness on health and well-being.

We received responses to a detailed questionnaire from 809 members who had experienced the diseases between 1988 and 2003 (themselves or a close family member). It was not sent to bereaved members, or those who had been affected within six months of when the questionnaire was sent out. In our survey, those affected had a similar age spectrum to the national averages for the same time period. Figure 1 shows the proportion of those with each disease form and type:

Figure 1: Proportion reporting a) each disease form and b) each disease type



Experience as a patient with meningitis/septicaemia

Figure 2: GP care pathway

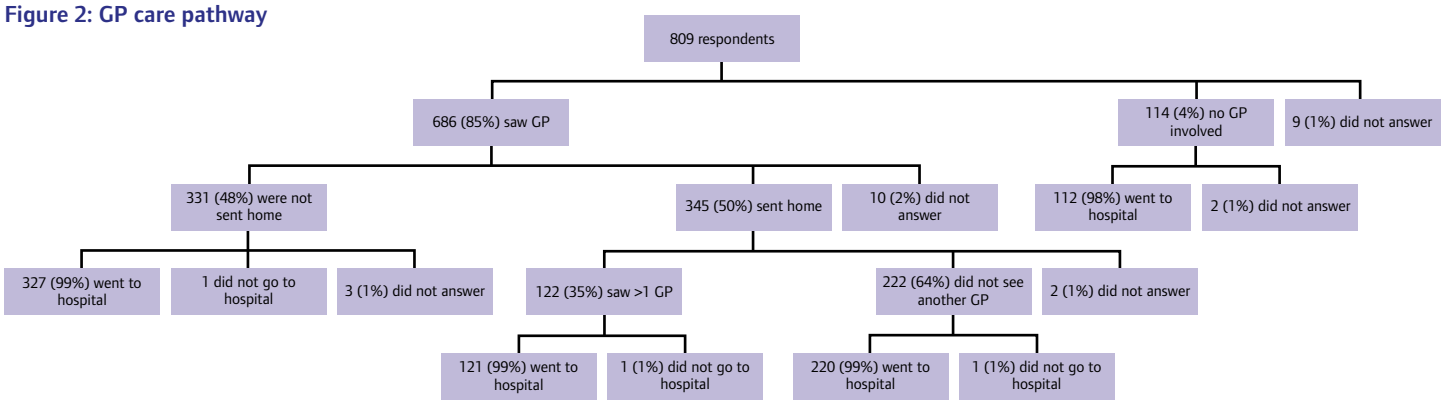
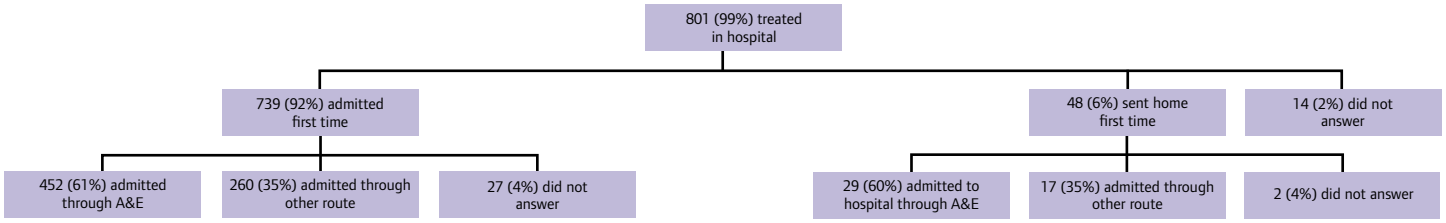


Figure 2 shows how members obtained urgent medical help from their GP. Half of those who went to their GP with meningitis or septicaemia were sent home the first time and this is in line with the findings of a national MRF-funded study of meningococcal disease in children[1]. Those who were sent home first time from the GP were 2.4 times more likely to have pneumococcal infection. In addition, they were 2.7 times more likely to encounter delay at both the GP and hospital, than those people with other infections. More detailed statistical analysis is in the full report.

Pneumococcal meningitis typically has a less dramatic onset than meningococcal disease, and the most visible symptom, the rash, is usually absent. This may explain the higher chances of delayed diagnosis in people with pneumococcal meningitis. In this survey 70% of those with meningococcal disease but only 10% of those with pneumococcal disease had a rash.

Of those sent home from the GP only 4% remembered having the symptoms of meningitis and septicaemia explained to them, which reinforces the need to educate healthcare professionals and the public about the symptoms of meningitis and septicaemia. Since this survey was conducted, studies and guidelines[1,2,3] have highlighted how crucial it is for healthcare professionals to explain to parents how to recognise serious illnesses – including meningitis – in sick children being sent home. This 'safety net' aims to enable parents to seek help again promptly if their child's illness gets worse.

Figure 3: Hospital admittance pathway



(8 participants had viral meningitis without hospital treatment or did not provide information, so were excluded)

Most people were admitted to hospital on their first visit, but delay was more likely in young children. Almost two-thirds (65%) of the 48 not admitted first time were under age five and 31% were under age one. Of those treated in hospital 449 (56%) were treated in intensive care units.

Thirty-eight percent of respondents told a health professional that they suspected meningitis, but fewer than half felt this was acted upon. A number of recent studies and national guidelines[2,4,5] have highlighted the importance of parental perceptions in identifying serious infections, including meningitis and septicaemia, so if their concerns are disregarded, potentially useful diagnostic information is lost.

After effects and after care

The majority (67%) reported short-term after effects and half of the people in our survey had long-term after effects.

The most common short-term after effects included behavioural, emotional and psychological problems (27%), fatigue (16%), headaches (9%), hearing loss (7%), and sleeping problems (5%).

Behavioural, emotional and psychological problems and hearing loss were the most frequently reported long-term after effects (13% and 10% respectively). Fatigue was also reported to be long-term in 6% of cases.

Pneumococcal infection was 2.6 times more likely to cause long-term after effects, nearly three times more likely to cause severe long-term after effects and over two and a half times more likely to cause neurological after effects; compared with other types of meningitis and septicaemia.

Hearing difficulties

Of the 716 people with bacterial meningitis, 25% had no hearing test and of those who did, only 32% remember having a test before or up to one month after discharge.

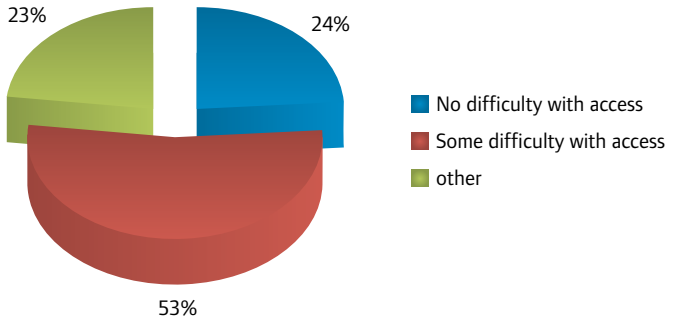
It is well documented[6] that patients recovering from bacterial meningitis need an urgent hearing assessment so that if their hearing loss is too severe to benefit from conventional hearing aids, they can have cochlear implantation without delay. Overgrowth of bone within the inner ear happens rapidly after meningitis, so delays in assessment can reduce the success of cochlear implants.

Forty-seven people required hearing aids, including 12 who had a cochlear implant. Nine of those with a cochlear implant had previously had unsuitable hearing aids fitted.

Speech and language therapy

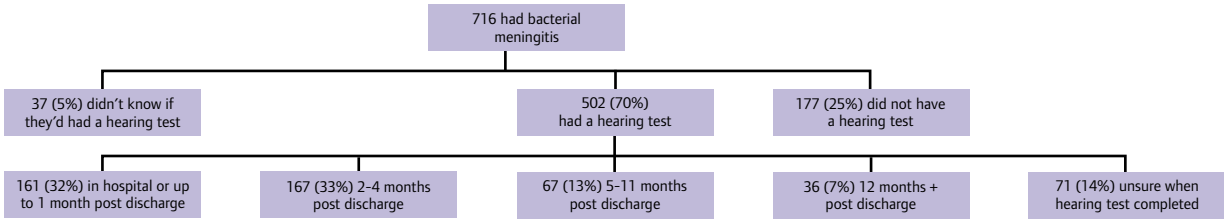
In total 88 people required speech and language therapy. Figure 5 highlights the access difficulties our members experienced. Delayed or insufficient therapy can limit a person's ultimate ability to communicate, and so improving access is vital.

Figure 5: Percentage of those requiring speech/ language therapy with difficulty getting access (either did not start soon enough, not often enough or not long enough, total 88).



'Other' category includes those still having therapy at the time of the survey or who did not answer.

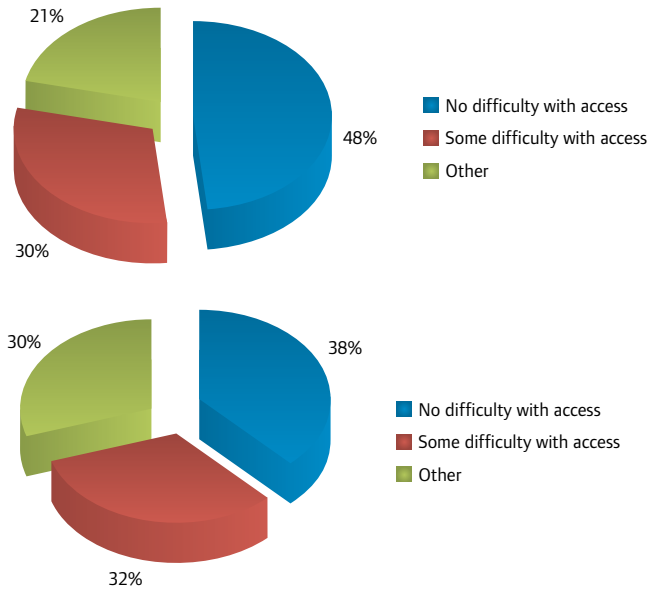
Figure 4: Initial hearing follow up for people after bacterial meningitis



Physiotherapy and occupational therapy

Physiotherapy and occupational therapy often work in conjunction with each other. The occupational therapist is often key for access to physical rehabilitation, equipment for daily living, support for learning disabilities, and financial benefits. It is important that the therapist's assessment of need in these areas is timely, as delay is likely to affect a wide range of aspects of the person's rehabilitation.

Figure 6: Percentage of those requiring a) physiotherapy (total 151) & b) occupational therapy (total 66) who had difficulty with access (either did not start soon enough, not often enough or not long enough).

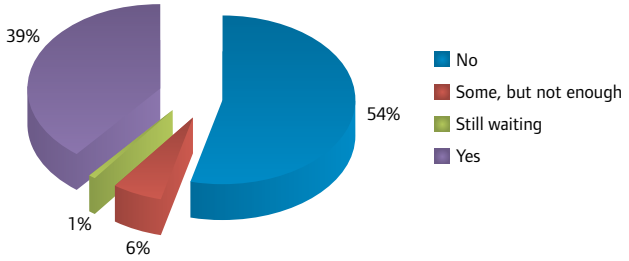


Physiotherapy is crucial for enabling mobility and developing or regaining the ability to carry out everyday tasks. Again delays or inadequacy of provision are likely to affect how recovery progresses. Our survey highlights the need for improvement in access to both areas.

Behavioural, psychological and emotional problems

This was the most frequently reported after effect, 301 members were affected, of whom about one-third (105) reported that the problems were long-term (13% of the total survey). This corroborates previous MRF research documenting psychological problems after meningitis and septicaemia[7,8].

Figure 7: Percentage of people with behavioural, psychological or emotional problems who received support for those difficulties.



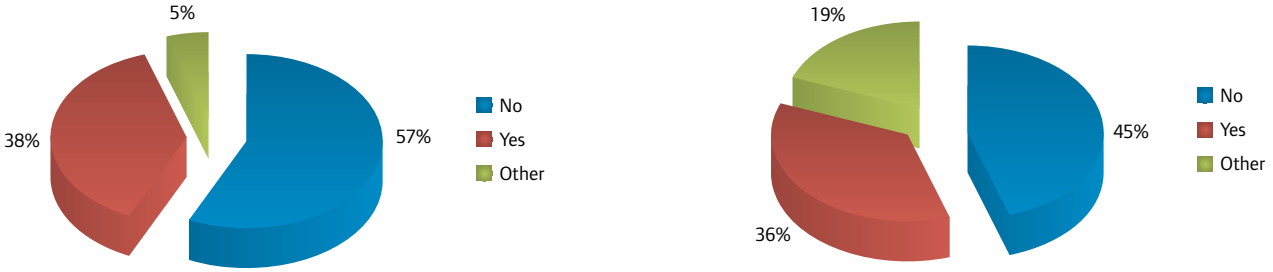
Provision of support for behavioural, psychological and emotional problems was particularly inadequate.

Impact on work, education, finances and family

Seven percent of those in education either at the time of or after the illness (total 455) were given a statement of educational needs. Of the 171 who reported an impact on education, 14% felt that they did not receive enough support. This is in line with the findings of previous MRF-funded studies[8,9].

Long-term after effects had a significant impact on the work and finances of people affected and their families. Nineteen percent of our survey (157) reported an impact on finances and 15 percent (122) reported an impact on a family member's job, sometimes forcing parents to leave jobs in order to become full-time carers. Impact on a family member's job was significantly associated with pneumococcal disease.

Figure 8: Percentage of people reporting an impact on a) education and b) work, if in education at the time or after illness (total 455) or in employment (184) respectively



Conclusions and recommendations

Delays in acute care

In this survey, half of patients with meningitis and septicaemia met with delay when seeking urgent medical help from their GP. **Health professionals involved in recognition and early management of serious illness should receive training to recognise the signs and symptoms of meningitis and septicaemia**.

Meningitis and septicaemia are difficult to detect in the early stages and therefore any ill patient sent home from the GP or hospital should be empowered to get medical help if their illness deteriorates. Health professionals assessing children should take parents' perceptions of their child's illness seriously.

Hearing and bacterial meningitis

In this survey, fewer than a quarter of patients with bacterial meningitis had a hearing test within two months of discharge, despite the well-recognised urgency of this test. **MRF calls for formal audiological testing as soon as possible after bacterial meningitis, preferably before discharge, but within four weeks of being fit to test, in line with the NICE recommendation**[5]. People recovering from meningococcal septicaemia also require hearing testing. Health professionals involved in treating patients with meningitis and septicaemia, and families affected, need to be aware of the importance of prompt hearing testing.

Access to after care and follow up

This survey identified deficiencies in the provision of after care: nearly a third had difficulty accessing physiotherapy and occupational therapy respectively and over half had difficulty accessing speech and language therapy. These therapies are time-critical, and can mean the difference between a child who is able to move and to communicate well enough to take part in mainstream activities and one who is not. **MRF calls for improved access and equality of access throughout the country to speech and language therapy, physiotherapy and occupational therapy after bacterial meningitis and septicaemia.**

In this survey nearly two-thirds of those who required support for psychological problems had difficulty accessing it. **Healthcare professionals involved in the care of patients after meningitis and septicaemia need to be alert to the potential need for early referral to psychiatric services and other sources of support for emotional and behavioural problems, including MRF's befriending service.**

Healthcare professionals discharging patients should inform the GP, and the health visitor or school nurse if the patient is a child, that the person has had meningitis or septicaemia. They should discuss long-term effects of the illness and need for after care with their primary care counterparts and with the patient and/or their family, including potential late effects, especially in young children.

Long-term after effects and impact on work, education and finances

In this survey 14% of people reporting an impact on their child's education said that they did not receive enough educational support. **MRF calls for improved awareness of the need for educational support in children affected by meningitis and septicaemia and for better and more timely access to such support including an early statement.**

Alleviating the burden of meningitis and septicaemia

The impact of meningitis and septicaemia on the work and finances of people affected and their families, demonstrates the far-reaching effects these diseases can have on well-being. MRF aims to improve this outlook by campaigning for early recognition, treatment and better, more timely access to after care and psychological and educational support. However, for diseases that are difficult to diagnose in the early stages, and in which critical illness can ensue within hours, there will always be a limit to the improvements that can be achieved this way. Therefore, we believe prevention is key, and many deadly strains of meningitis are now preventable. **MRF calls for the widest and earliest possible implementation of effective vaccines to provide more comprehensive protection against meningitis.**

This survey illustrates the staggering cost of meningitis and septicaemia to families, the healthcare system and society; and to date, the cost-benefit analyses that underpin the introduction of new vaccines fail to consider the full medical, educational and societal costs of the diseases. There is, therefore, a very real need for more focused quantitative research on the impact of disease on quality of life, to support the evaluation of future vaccines.

Meanwhile, there are deficiencies in the early recognition and treatment of meningitis and septicaemia, and in the discharge process and after care package for people who have had these illnesses. There is a need for healthcare professionals to work together with local authorities and parents, to get the right treatment, support and help as quickly as possible.

Produced by Meningitis Research Foundation[a] in collaboration with University of Bristol Department of Social Medicineb written by L Clark[a,b], C Sunter[a], A Flack[a], S Spencer[a], CL Trotter[b] , M Hickman[b], L Glennie[a] with support from Wyeth Vaccines (now Pfizer) and the Department of Trade and Industry.

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