

# Impact of Meningitis: Findings and Recommendations from the Member Survey

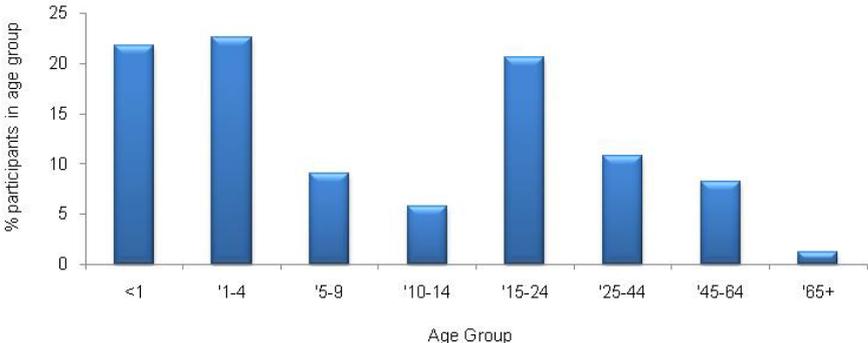
This report is an extended version of the charity’s summary of findings from the member survey which was included with the May issue of Microscope. This report contains extra sections on signs and symptoms, additional information on follow-up care, and includes statistical output. The final recommendations remain the same as those in the summary; however additional discussion points have been included throughout the document.

## Background, aims and people involved

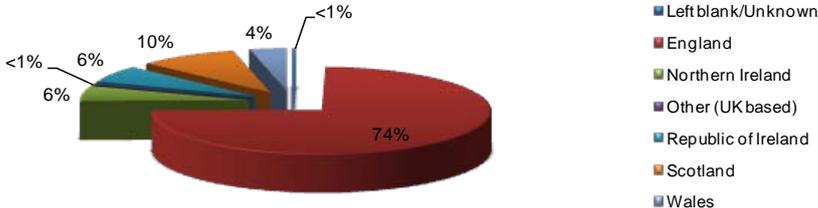
The survey aimed to gain an overall account of MRF member’s experiences, with a particular focus on accessing urgent hospital care and follow up care, and the long-term impact of the illness on health and well-being.

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. In our survey, those affected had a similar age spectrum to the national averages for the same time period (figure 1). Most completed surveys came from England, owing to the larger member base in this part of the UK (figure 2). Figure 3 and table 1 show the proportion of those with each disease form and type:

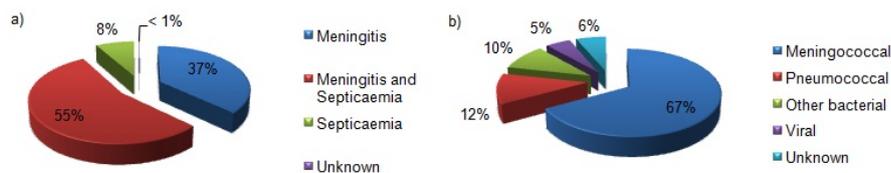
**Figure 1: Age at onset of disease, youngest ‘at birth’, oldest 87 years of age**



**Figure 2: Cases by geographical location**



**Figure 3: Proportion reporting a) each disease form and b) each disease type**



**Table 1: Age-specific frequency and proportion of cases with each disease type**

Causative Agent	<1 year	1-4 years	5-9 years	10-14 years	15-24 years	25-44 years	45-64 years	65+ years	Frequency	%
Meningococcal B	34	67	26	14	66	24	20	2	253	31.3
Meningococcal C	12	41	24	14	48	8	11	1	159	19.7
Meningococcal unknown	27	25	8	14	24	16	10	1	125	15.5
Pneumococcal	39	27	4	1	2	7	10	3	93	11.5
Unknown	11	2	6	3	12	8	5	0	47	5.8
Viral (unknown)	2	4	2	1	6	15	4	1	35	4.3
GBS (Group B Streptococcal)	25	2	0	0	1	1	1	0	30	3.7
Hib (Haemophilus influenzae type B)	8	11	0	0	0	0	1	0	20	2.5
Bacterial unknown	3	2	3	0	4	0	0	2	14	1.7
E.Coli	7	0	0	0	0	0	0	0	7	0.9
Herpes virus	0	0	0	0	0	2	2	0	4	0.5
Other	2	0	0	0	0	0	0	0	2	0.2
Group A Streptococcal	1	0	0	0	0	0	1	0	2	0.2
Listeria	0	1	0	0	0	0	1	0	2	0.2
Meningococcal W135	0	1	0	0	1	0	0	0	2	0.2
Meningococcal Y	1	0	0	0	0	1	0	0	2	0.2
Fungal (Cryptococcal)	0	0	0	0	0	1	0	0	1	0.1
Haemolytic Streptococcal	0	0	0	0	0	1	0	0	1	0.1
Haemophilus influenzae (not type B)	0	0	0	0	0	1	0	0	1	0.1
Klebsiella	1	0	0	0	0	0	0	0	1	0.1
Meningococcal A	0	0	0	0	1	0	0	0	1	0.1
Pasteurella multocida	1	0	0	0	0	0	0	0	1	0.1
Staphylococcal	1	0	0	0	0	0	0	0	1	0.1
Proteus mirabilis	0	0	0	0	1	0	0	0	1	0.1
West Nile virus	0	0	0	0	1	0	0	0	1	0.1
Coxsackie virus	0	0	0	0	0	1	0	0	1	0.1
Enterovirus	1	0	0	0	0	0	0	0	1	0.1
Candida	0	0	0	0	0	1	0	0	1	0.1

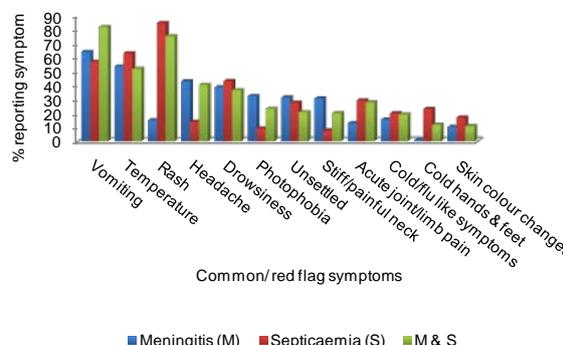
**Signs and symptoms**

The promotion of education and awareness is a large part of Meningitis Research Foundation’s approach to preventing death and disability. Gaining information about the signs and symptoms of these diseases enables the charity to produce accurate information resources for the public and for health professionals. Table 2 shows the most frequently reported symptoms and figure 4 shows how disease form (meningitis or septicaemia) was linked to the symptoms reported.

**Table 2: Symptoms reported in descending order**

Symptom	No. Participants reporting symptom	(%)
Vomiting	566	70.0
Temperature	433	53.5
Rash	433	53.5
Headache	317	39.2
Drowsiness	306	37.8
Photophobia	206	25.5
Unsettled/irritability	205	25.3
Stiff/painful neck	186	23.0
Acute joint & limb pain	181	22.4
Cold/flu-like symptoms	145	17.9
Nausea	143	17.7
Loss of consciousness	140	17.3
Floppy	132	16.3
Confusion	125	15.5
Pale/ mottled skin	90	11.1
Cold hands & feet	80	9.9
Shivering	78	9.6
Diarrhoea	72	8.9
Feeling unwell	72	8.9
Aches	68	8.4
Difficulty standing	61	7.5
Seizures	47	5.8
Rapid breathing	45	5.6
Stiff	45	5.6

**Figure 4: Proportion with each form of the disease reporting ten most common/ red flag symptoms.**



Certain symptoms tended to be associated with a particular form of disease, for example, rash was more likely to be reported if the person affected had septicaemia. The two most common symptoms, however, were very similar to symptoms of viral illnesses that get better without treatment. The fact that the common early symptoms do not help to distinguish meningitis and septicaemia from other illnesses highlights the difficulty of gaining a quick diagnosis and early treatment. Our recommendations reflect this and advocate better training of junior doctors and those involved in assessing patients who may have serious infections. Working with health professionals to improve early detection of these diseases is crucial, but we recognise that prompt diagnosis is not always possible, and so there are limits to the improvements in disease outcome that can be achieved this way. The greatest improvements are likely to be achieved by prevention through vaccination.

## Experience as a patient with meningitis/ septicaemia

We asked members about their experience of healthcare, from the GP surgery through to intensive care. We were interested in when and where delays occurred and whether there were any patterns in those experiencing delay (Participants also gave care satisfaction ratings for each aspect of the care pathway).

**Figure 5: GP care pathway**

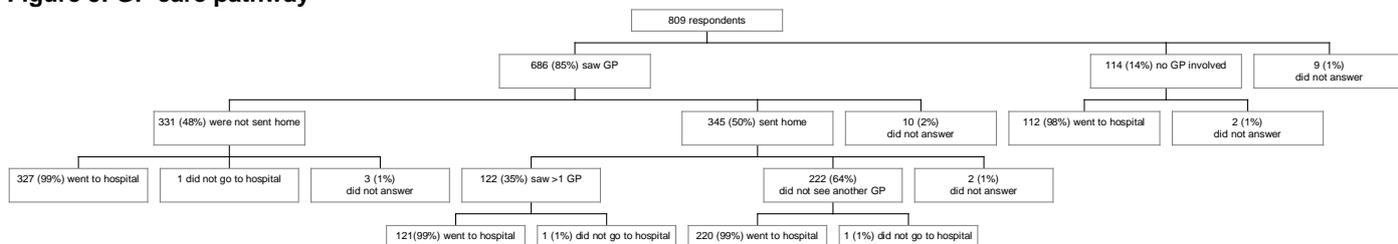


Figure 5 shows how members obtained urgent medical help from their GP. Half of those who went to their GP with meningitis or septicaemia were sent home the first time and this is in line with the findings of a national MRF-funded study of meningococcal disease in children<sup>1</sup>. Those who were 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 the hospital, than those people with other infections. Table 3 shows statistical output:

**Table 3: Association between a) GP delay and b) both GP and Emergency department delay and disease type (\*baseline category). Output from logistic regression controlling for age and disease form.**

a)

Disease category	N	% with GP delay	Odds ratio (95% CI)	p-value
Disease type other than pneumococcal*	716	40.1%	1.0	
Pneumococcal disease type	93	62.4%	2.4 (1.5 to 3.8)	<0.001

b)

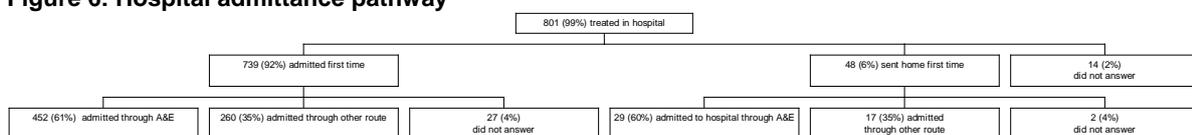
Disease category	N	% with both GP and A&E delay	Odds ratio (95% CI)	p-value
Disease type other than pneumococcal*	716	4.6%	1.0	
Pneumococcal disease type	93	14.0%	2.7 (1.3 to 5.9)	0.01

In the example above a technique called logistic regression was used to ask 'what are the odds of delay in those with pneumococcal disease compared to those with any other disease type?' The 'odds ratio' in table 3 a) is 2.4, this means that those with pneumococcal disease had 2.4 times the chance of experiencing delay than those with other disease types. We can't be sure that the odds are exactly 2.4 times higher – there is uncertainty around our estimate. We can be confident that the odds are at least 1.5 times higher and perhaps as much as 3.8 times higher – that's what 95% CI (confidence interval) means. Finally the p-value tells us how likely it is that this result occurred by chance alone. The p-value here is very small, which means it is likely that there is a true difference between delay experienced in those with pneumococcal disease and those with other diseases.

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<sup>1,2,3</sup> 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 6: 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 5 and 31% were under age 1. Of those treated in hospital 449 (56%) were treated in intensive care units.

We did not find a link between specific symptoms and delay. Although participants with characteristic or red flag<sup>1</sup> symptoms tended to experience fewer delays, this difference was not statistically significant. Our survey did not specifically ascertain which symptoms were present when the patient saw the GP or arrived at hospital, and this may have obscured any potential links between delay and presence of absence of symptoms.

A more detailed MRF-funded clinical study showed that deficiencies in healthcare resulted in a higher death rate in children with meningococcal disease. Since people with bacterial meningitis and septicaemia deteriorate rapidly, delays in diagnosis and treatment can worsen outcome, both in children and adults. The findings from this survey emphasise that delays do occur.

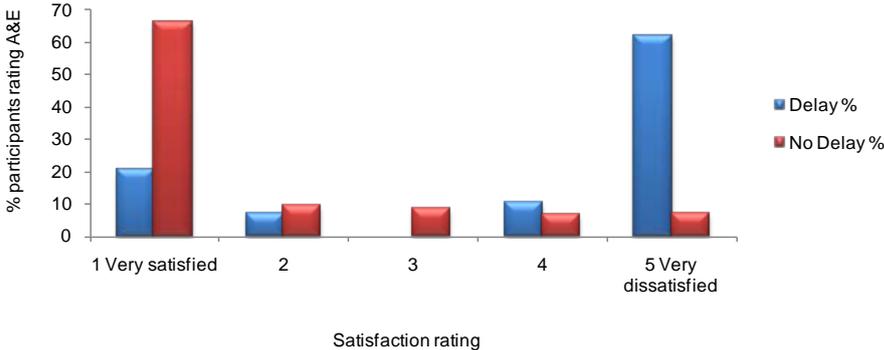
Thirty-eight per cent of respondents told a health professional that they suspected meningitis, but fewer than half felt that this was acted upon. A number of recent studies and national guidelines<sup>2,4,5</sup> have highlighted the importance of parental perceptions in identifying serious infections,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

### Care Satisfaction

We asked members to rate each aspect of the healthcare pathway on a scale from 1-5 (1 being very satisfied and 5 being very dissatisfied). Intensive care had the highest mean satisfaction score (*mean 1.4, 95% CI 1.3-1.5*), followed by general wards (*mean 2.0, 95% CI 1.9-2.1*) then the GP (*mean 2.7, 95% CI 2.6-2.9*) and the poorest rated was the Emergency department (*mean 4.3, 95% CI 4.1-4.5*).

Satisfaction ratings of hospital care were highly dependent on whether or not the patient was admitted first time. Emergency departments were ranked lower if the person was not admitted on the first visit (Figure 7).

**Figure 7: Comparison of Emergency department satisfaction ratings of those admitted first time to hospital and those with delays**



For our members delay in accessing treatment was likely to influence their satisfaction with the care they received.

**After-effects and after care**

National statistics provide information on the number of people who get meningitis and septicaemia and are hospitalised, and the number of deaths. However, when a patient is discharged, there is no information about whether they leave hospital completely recovered or with disability—we do not know what happens to survivors. With no clear picture of the true impact of disease for those affected, the cost of these diseases may be greatly underestimated and after-care may be far from comprehensive. In this section of the survey participants described the after effects they or the person affected had, and gave information about the after-care or therapy required.

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). Eight percent of cases reported memory loss and 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 (Table 4 for statistical output).

**Table 4: Association between reporting a) long-term b) severe long-term and c) neurological after effects and disease type (\*baseline category). Output from logistic regression controlling for age and disease form.**

a)		% with long-term		
Disease category	N	after effects	Odds Ratio (95% CI)	p-value
Disease type other than pneumococcal*	716	48%	1	
Pneumococcal disease type	93	66%	2.6 (1.6 to 4.3)	<0.001

b)		% with severe long-term after		
Disease category	N	effects	Odds Ratio (95% CI)	p-value
Disease type other than pneumococcal*	716	25%	1	
Pneumococcal disease type	93	47%	2.7 (1.6 to 4.3)	<0.001

c)		% with neurological after		
Disease category	N	effects	Odds Ratio (95% CI)	p-value
Disease type other than pneumococcal*	716	25%	1	
Pneumococcal disease type	93	47%	2.6 (1.6 to 4.2)	<0.001

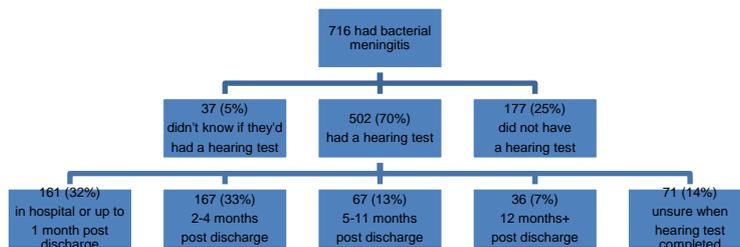
## Hearing and sensory damage

Sensory problems were commonly reported complications resulting from meningitis. In addition to the 10% who reported hearing loss, 30 people (4%) also reported sight problems.

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 1 month after discharge.

*“We were told her hearing was fine. After 3 months at my insistence the hearing was tested again revealing a severe to profound hearing loss.”*

**Figure 8: Initial hearing follow up for people after bacterial meningitis**



It is well-documented<sup>6</sup> 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.

*“Push your audiologist early and hard if you have any doubts. E. had severe Ossification going on and if it hadn't have been for our audiologist we might have missed the chance of an implant.”*

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.

## Cognitive and other neurological damage.

Members also reported diverse long-term severe and often complex neurological disorders. Neurological damage was most often reported as spasms/ gait problems, but also as brain damage, hemiplegia or quadriplegia, cerebral palsy, paralysis, severe complex disorders, developmental delay and intellectual impairment. In total 179 (22%) reported long-term neurological after effects, (the full list can be found in the appendix). For the most severely affected, there were usually multiple problems, with damage affecting hearing, learning ability, and movement, and serious consequences for their quality of life and family well-being.

*“S. has been severely brain damaged. He has quadriplegic cerebral palsy, severe learning difficulties, cortical visual impairment and epilepsy. These are permanent and we are using medications to control them as best as possible....We can't communicate with him as we used to and the sense of loss is great both for us and for his brother...”*

*“E. is severely disabled. She has general shrinkage of the brain, spastic quadriplegia, and severe epilepsy. She is unable to sit, stand or walk, unable to speak or understand language.”*

*“He was left very disabled: severe brain damage, tube fed, double incontinence, confusion, slurred speech, difficulty swallowing, reliant on 24 hour nursing care, short term memory very poor.”*

*“J has severe (profound) brain damage, epilepsy and brain atrophy. She will never walk, talk or be able to care for herself.”*

*“M has been left severely disabled. He cannot walk, so uses a wheelchair, he has no speech. He laughs though and understands everything. He cannot use his hands except for basic pointing. He cannot feed himself, or wash or dress himself. He is doubly incontinent and wears nappies. He cannot open his bowels himself so needs enemas every other night. He has developed a severe curvature of the spine due to spasticity in his body and has to sit in a moulded seat in his wheelchair. He has no sitting balance so needs a chair with supports at home. His right wrist is now contracted inwards and he wears a splint on his left foot to keep ankle straight. He does not sleep very well and his concentration levels are low. He falls asleep in the daytime easily, even when he is being fed.”*

As well as the more severe spectrum of neurological after effects, long-term memory problems (8.3%), concentration problems (3.2%), learning difficulties (3%), and communication problems (2.7%) were reported, which although less severe, limit educational and career attainments.

#### *Scarring and amputations; plastic surgery and prosthetics*

Forty four people reported scarring and 9 reported damage to deeper tissues and muscles. Twenty-two required plastic surgery, and three-quarters of these said the surgery was either successful or partly successful. Most people with amputations (total 27) had lower limb amputations or amputations of digits, Table 5. The healing process was often reported to take an extended length of time and many required follow up care years after the acute phase of disease.

*“Still attend plastic surgery department outpatients for 'patching' when required, and still after 16 years my wife is dressing the open areas on a daily basis.”*

*“The scars on hands and feet have faded over years but are still there. The skin grafts on both feet have not fully recovered after 12 years. Still suffers from pain and infections in feet.”*

*“Where they have taken "split" skin grafts and "full thickness" grafts from my thighs and groin and placed them over my remaining forefeet, although it heals, short term, when I become ambulant again because the skin has not had a chance to become resilient as the rest of the soles of my feet, the skin grafts keep breaking down and small open areas are abraded away, eventually needing repeat skin grafts. To try and combat this a portion of the abdominal rectus muscle was used as a "Free Flap" and was anastomosed to both medial tibial arteries and "stapled" to the forefeet. Then further split skin grafts applied over the "muscle flaps". This has been reasonably successful, but I have no sensation in my forefeet and still the skin grafts break down because I cannot feel when I have done too much.”*

*“I had to change the dressings on my feet at least three times a day for approx 6 months. The blisters or scabs continually bled and clean dressings were necessary.”*

**Table 5: Position of amputation**

Type of Amputation	Frequency
Arm below elbow	1
Leg below knee	5
Both legs below knee	4
Leg above knee	4
Hand	1
Foot/ area of foot	2
Both feet	3
Toes	10
Fingers/ thumbs	7
Fingertips	5
Both hands and legs	2

Of those who had prosthetics (total 15) half said that they were comfortable, 69% reported that they worked properly but 80% said that it required several attempts to obtain an adequate prosthesis.

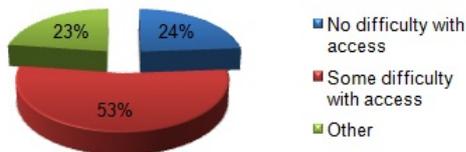
## Pain

Many of the after effects described above are painful conditions, but members also additionally reported long-term pain: arthritis, limb pain, muscle pain and neuropathic pain/numbness/tingling, but the most commonly reported type of pain was headache: 7% reported headache as a long-term condition (4.4% reported severe headache).

## Speech and language therapy

In total 88 people required speech & language therapy. Figure 9 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 9: 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.

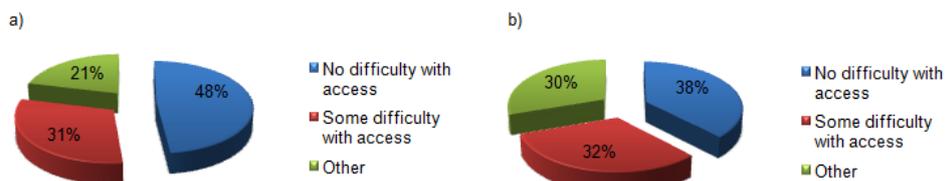
*"Sessions were sporadic. Held once a month with gaps of 3-6 months due to "personnel changes"*

*"Speech therapy is difficult to get. For years there has been a problem over who pays - education and the health service both try to say it is the others responsibility and the children stuck in the middle suffer"*

## 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 10: 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).**



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

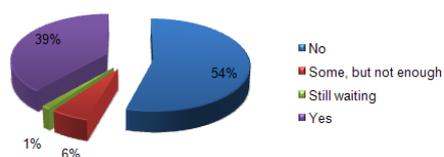
*"Community physio & O.T. very short supply they are hospital based and community care is last on the priority list."*

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<sup>7,8</sup>.

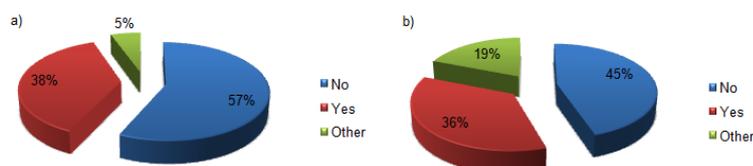


**Figure 11: Percentage of people with behavioural, psychological or emotional problems who received support for those difficulties.**

Provision of support for behavioural, psychological and emotional problems (figure 11) 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<sup>8,9</sup>.



**Figure 12: 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**

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 fifteen 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.

## 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 2 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 4 weeks of being fit to test, in line with the NICE recommendation<sup>5</sup>.** 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 aftercare: 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 aftercare 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 aftercare and psychological & 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<sup>a</sup> in collaboration with University of Bristol Department of Social Medicine<sup>b</sup> written by L Clark<sup>a,b</sup>, C Sunter<sup>a</sup>, A Flack<sup>a</sup>, S Spencer<sup>a</sup>, CL Trotter<sup>b</sup>, M Hickman<sup>b</sup>, L Glennie<sup>a</sup> with support from Wyeth Vaccines (now Pfizer) and the Department of Trade and Industry.

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## Appendices

### Appendix 1: Short-term and long-term after effects as reported.

Short-term after effects	Total	%	Long-term after effects	Total	%
Behavioural, emotional psychological difficulties	216	26.7	Behavioural, emotional psychological difficulties	105	13.0
Fatigue	129	15.9	Hearing loss	77	9.5
Gait difficulties/spasms	97	12.0	Memory loss	67	8.3
Headaches	75	9.3	Fatigue	50	6.2
Hearing loss	59	7.3	Scarring	44	5.4
Memory loss	45	5.6	Gait difficulties/spasms	36	4.4
Mobility problems	40	4.9	Headaches	36	4.4
Sight difficulties	40	4.9	Amputation	27	3.7
Balance difficulties	38	4.7	Depression	28	3.5
Concentration difficulties	37	4.6	Concentration difficulties	26	3.2
Sleeping difficulties	37	4.6	Sight problems	26	3.2
Depression	36	4.4	Balance	24	3.0
Prone to infection	33	4.1	Learning difficulties	24	3.0
Communication difficulties	29	3.6	Prone to infection	24	3.0
Joint problems	29	3.6	Communication difficulties	22	2.7
Limb/muscle pain	22	2.7	Severe headache	21	2.6
Developmental delay	19	2.3	Joint problems	20	2.5
Tissue/muscle damage	18	2.2	Epilepsy	17	2.1
Scarring	17	2.1	Numbness/tingling	17	2.1
Skin problems	17	2.1	Hydroceph/shunt	16	2.0
Medical phobia	16	2.0	Limb/muscle pain	16	2.0
Epilepsy	14	1.7	Other hearing problems	16	2.0
Alopecia	12	1.5	Brain damage	14	1.7
Kidney/bladder problems	12	1.5	Tinnitus	14	1.7
Learning difficulties	11	1.4	Back pain	12	1.5
Other hearing problems	10	1.2	Medical phobia	12	1.5
Back pain	9	1.1	Photophobia	11	1.4
Stomach problems	9	1.1	Sleeping difficulties	11	1.4
Numbness/tingling	8	1.0	Hemi/quadruplegia	10	1.2
Other eye problems	7	0.9	Arthritis	9	1.1
Heart problems	6	0.7	Mobility problems	9	1.1
Hormone disorders	6	0.7	Tissue/muscle damage	9	1.1
Sickly	6	0.7	Hormone disorders	8	1.0
Arthritis	5	0.6	Circulation problems	7	0.9
Hemi/quadruplegia	5	0.6	Other eye problems	7	0.9
Personal assistance needed	5	0.6	Severe speech problems	7	0.9
Circulation problems	4	0.5	Dyslexia	6	0.7
Post traumatic stress disorder	4	0.5	Sickly	6	0.7
Paralysis	4	0.5	Skin problems	6	0.7
Tube fed	4	0.5	Bone disorders	5	0.6
Bowel disorders	3	0.4	Bowel disorders	5	0.6
Hydroceph/shunt	3	0.4	Kidney/bladder problems	5	0.6
Photophobia	3	0.4	Personal assistance needed	5	0.6
Tinnitus	3	0.4	Severe complex disorders	5	0.6
Dyslexia	2	0.2	Alopecia	4	0.5
Intellectual impairment	2	0.2	Other cerebral palsy	4	0.5
Lung problems	2	0.2	Severe kidney/bladder problems	4	0.5
Stroke	2	0.2	Severe Sight problems	4	0.5
Co-ordination difficulties	1	0.1	Skin grafts	4	0.5
Stump pain	1	0.1	Developmental delay	3	0.4
Teeth problems	1	0.1	Heart problems	3	0.4
			Lung problems	3	0.4
			Neuropathy	3	0.4
			Teeth problems	3	0.4
			Attention deficit hyperactivity disorder	2	0.2
			Post traumatic stress disorder	2	0.2
			Severe sight problems	2	0.2
			Stomach problems	2	0.2
			Severe heart problems	2	0.2
			Intellectual impairment	1	0.1
			Paralysis	1	0.1
			Severe hormone disorders	1	0.1
			Tube fed	1	0.1