

Difficulty accessing NHS services

Some children who survive meningitis and septicaemia are left with long term health issues which may require multiple outpatient visits to paediatric specialists, therapists or rehabilitation centres.

Meningitis Research Foundation conducted a survey of families affected to find out how easy it was for parents to access aftercare services for their children and how satisfied they were that the care provided met their child's needs.

Common themes which made it difficult for families to access appropriate support for their children are discussed below:

Navigating the system

Many parents found it difficult to know what to do next when their child had been discharged from hospital.

The meningitis charities produced Your guide and My Journal to help with this. These resources contain detailed information about what to expect during your child's recovery and how to access further support.

Separate supplementary factsheets are also available which provide detailed information about the sort of aftercare that a child can expect if they have been left with permanent after effects from meningitis or septicaemia.

Poorly appreciated link between meningitis and some after effects

Many parents found that the link between meningitis and long-term complications was poorly understood by health, educational and social care professionals and that this could stand in the way of them being able to access services for their children. This is particularly the case for the less visible after effects such as learning and behavioural difficulties.

There is plenty of evidence to show that meningitis and septicaemia in childhood can have lasting physical effects as well as impacting on learning and behavior. It can be useful to share Your guide and any relevant supplementary factsheets with your child's GP or teachers if you feel that they are not taking any concerns that you have about your child seriously.

It can also be very useful to keep detailed records of your child's recovery after meningitis by completing the relevant sections of My Journal. This Journal can be shared with everyone involved in the care of your child and shared with your child's teachers to help them understand how the illness has affected them.

Communication between professionals

Parents who reported poor communication between the different professionals involved in the care of their child felt that the care they received did not adequately support their child's needs.

If you feel you need to relay information from one professional to another or if your child's care is disjointed, you might find it helpful to ask for a joint meeting with some of the key professionals responsible for the care of your child. Many people have found that a multidisciplinary team (MDT) meeting involving the parents, school staff, medical professionals and health visitors enhanced communication and cooperation and is a helpful way to set common goals which facilitate meeting a child's needs.

Appropriateness of support and aftercare

Many parents who were unhappy with the support and aftercare that their child was offered felt that inadequate time and attention was paid to their child's individual needs.

Some issues can be resolved by discussing your concerns with the professionals involved in the treatment and care of your child. Do not be afraid to ask them any questions you have. You may find it useful to write down your questions before your appointment and the continued care and appointments section of My Journal has space for you to jot these down.

Sometimes it is not possible for families to resolve the issues that they have with their child's NHS care and support without seeking further advice or making a formal complaint.

Seeking further advice and making a complaint

The Patient Advice and Liaison Service (PALS)

PALS offers confidential advice, support, and information on health-related matters. The service provides a point of contact for patients, their families, and their carers.

You can find officers from PALS in your local hospital via <http://www.nhs.uk/Service-Search/Patient-advice-and-liaison-services-%28PALS%29/LocationSearch/363>

PALS provides help in many ways. For example, it can:

- help you with health-related questions
- help resolve concerns or problems when you're using the NHS
- tell you how to get more involved in your own healthcare

PALS can give you information about:

- the NHS
- the NHS complaints procedure, including how to get independent help if you want to make a complaint
- support groups outside the NHS

PALS also helps to improve the NHS by listening to and acting on your concerns and suggestions.

Making a complaint

If you're not happy with the care or treatment you've received or you've been refused treatment for a condition, you have the right to complain, have your complaint investigated, and be given a full and prompt reply.

[The NHS Constitution](#) explains your rights when it comes to making a complaint. You have the right to:

- have your complaint dealt with efficiently, and properly investigated
- know the outcome of any investigation into your complaint
- take your complaint to the independent Parliamentary and Health Service Ombudsman if you're not satisfied with the way the NHS has dealt with your complaint
- make a claim for judicial review if you think you've been directly affected by an unlawful act or decision of an NHS body
- receive compensation if you've been harmed

More information about the NHS complaints procedure is available from <https://www.nhs.uk/using-the-nhs/about-the-nhs/how-to-complain-to-the-nhs/>