My Journal

Life after childhood meningitis and septicaemia



Meningitis Now Fern House, Bath Road, Stroud, Gloucestershire GL5 3TJ Tel: 01453 768000 Free helpline: 0808 80 10 388 (UK) Email: info@meningitisnow.org

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Meningitis Research Foundation Newminster House, Baldwin Street, Bristol BS1 1LT Tel: 0333 405 6262 Free helpline: 080 8800 3344 Email: info@meningitis.org

Registered charity number 1091105 (England & Wales), SC037586 (Scotland), 20034368 (Ireland) Company Limited by Guarantee Registered in England Number 4367866

Your details

Photograph

Child's name:

Date of birth:

NHS number:

GP name:

Practice address:

Practice telephone:

Type of meningitis or septicaemia your child had:

Parent's/carer's details:	
Name:	
Contact number – day:	
Contact number – evening:	

It is useful to record the contact details of the discharging hospital in case you need to get in touch with the team who treated your child. If you have been given a discharge letter or notes, it is a good idea to keep them in your folder.

Issues and concerns after discharge

It can take many months to recover from meningitis and septicaemia, although some children are back to their normal activities within a matter of weeks.

Many parents find leaving hospital an anxious time because doctors are no longer on hand to answer questions. If you have any concerns about your child after discharge from hospital, write them down below. Please read page 11 in 'Your guide' to get an idea about common concerns that parents have after discharge. Bring this information with you to your child's 4-6 week review so that you can discuss these notes with the paediatrician.

You know your child best, never be afraid to speak up. If you are concerned for any reason do not wait for the follow-up appointment. You can speak to your child's GP at any time.

In particular, if your child develops a fever, rash or limb pain within two weeks of being discharged from hospital then this needs urgent medical attention.

All health professionals should be aware of the possible late development of after-effects. If you are concerned about your child's recovery or possible complications at any time, speak to your GP or ask to be referred back to the hospital where your child was cared for.

Helplines: Meningitis Now 0808 80 10 388 / Meningitis Research Foundation 080 8800 3344

Notes

Include dates. This will help others understand what has been happening.		

You can download more of these pages online: www.meningitisnow.org/myjournal or www.meningitis.org/After-effects-children

Follow-up care

Every child will be offered a follow-up appointment 4–6 weeks after leaving hospital. This is to discuss how the recovery process is going and any potential complications you might be concerned about.

All children under 16 should have a hearing test as soon as possible or within four weeks of being well enough to test.

If these appointments have not been arranged by the hospital, ask your GP to arrange them for you. It is also a good idea to visit your child's GP, so they can see how your child is getting on and be aware of any concerns or questions you may have.

Some parents are so relieved to get their child home from hospital that they do not want the upset of having to take their child back again for further appointments, but missing the opportunity for follow-up with the hospital can put your child at a disadvantage. Some after-effects can also be subtle and hard to identify, so you may think they have made a complete recovery and not attend, but it is important that any problems are recognised early and treated as soon as possible.

Questions for follow-up

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After-effects

Here you can record any complications and after-effects your child may have as a result of meningitis or septicaemia (some doctors will call these sequelae).

If any after-effects are identified in hospital, the doctors or other health professionals looking after your child will have discussed these with you before discharge. You can complete the below yourself, but it may be beneficial to complete this with the paediatrician at your child's **routine follow-up appointment 4-6 weeks after discharge**.

After-effect or complication your child has:	After-effect or complication your child has:
The impact on day-to-day life:	The impact on day-to-day life:
Treatment or support received/needed:	Treatment or support received/needed:

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After-effects continued

After-effect or complication your child has:	After-effect or complication your child has:
he impact on day-to-day life:	The impact on day-to-day life:
reatment or support received/needed:	Treatment or support received/needed:

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Our family experience

Having a child with meningitis or septicaemia can have a huge impact on family life. The recovery process can take time for everyone. It is often the parents who understandably take longer to adjust after such a traumatic experience, even if their child makes a full recovery.

It is important that all the family receives care and support that meets their needs, including grandparents and extended family. Brothers and sisters, particularly young children, will need extra attention and understanding because they can experience anxiety and feelings of isolation. Parents can feel guilty about dividing their time and attention between their children.

Many families find it useful to write down their account of what happened to their child when they were ill. It can be therapeutic and in the future can help your child to understand what has happened to them, particularly if they were sedated, or too young to remember. Some hospitals encourage families to take photographs; this is a very personal choice, but many families and children have found it useful to look back at the pictures some time later. If children are living with after-effects, the photographs can help explain to them and others what they have been through.

Information about the support available to you and your family can be found online.

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Appointments at a glance



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