After your baby's group B Strep infection

Group B Strep Support

This leaflet provides guidance if your child has been affected by **group B Strep infection**.

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About this booklet

Having a baby who develops group B Strep infection is unexpected and can be traumatic. Most babies make a full recovery, but sadly some will suffer with a long-term disability or even die because of their group B Strep infection.

Your personal circumstances and those of your baby may mean that certain sections of this booklet are more useful than others. Some may be very helpful whilst others may be irrelevant.

Our suggestion would be to start with the sections that are most relevant, and revisit those less applicable later.

Our hope in developing this leaflet is that it will highlight practical information and signpost the support that is available to you.

Proud to partner Group B Strep Support

Our lawyers have been successfully securing settlements for clients and campaigning for access to justice and patient safety for over 30 years.

If your child has been affected by Group B Strep through medical negligence, please contact Emmalene Bushnell on:

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Leigh Day

Key facts about **group B Strep**

- Group B Strep (also known as Strep B or GBS) are bacteria carried by 20-40% of adults that live harmlessly in the bowel and, in women, the vagina. Carrying the bacteria doesn't cause any symptoms, so you can't tell if someone's carrying it without testing.

- Group B Strep can cause infection in newborn babies - approximately 1 in every 1,000 babies born in the UK develops group B Strep infection.

- Group B Strep infections usually presents as meningitis, sepsis and/or pneumonia. They are considered a medical emergency, and need to be treated immediately by health professionals.

- Most babies will make a full recovery from their group B Strep infection, but even with treatment, approximately one in every 20 of these sick babies die, and one in every 10 of the surviving babies recoverwith a long-term disability.

- **Your baby's group B Strep infection is not your fault.** Women are sometimes told that 'you passed GBS to your baby' which can make women feel guilty. We don't yet know why one baby exposed to GBS will develop an infection, and another baby exposed to GBS will not.

- Group B Strep infection is usually treated with intravenous (through a vein) antibiotic therapy and intensive care. Some babies will need the expert medical attention of intensive care and ventilatory support, as provided in Neonatal or Paediatric intensive care units.

- There is no evidence that group B Strep infection leaves survivors more likely to catch other illnesses such as coughs, colds, colic or develop allergies.

What is **group B Strep** infection?

Group B Strep is the most common cause of severe infection in newborn babies and can cause sepsis ("bloodstream infection" or "blood poisoning"), pneumonia (lung infection) and meningitis (inflammation of the fluid and linings of the brain).

Group B Strep infection occurs most often in babies shortly before, during or immediately after birth. After the first 6 days of life, group B Strep infection is uncommon and after age 3 months it is very rare indeed.

GBS infection is considered a medical emergency, and needs to be treated immediately by healthcare professionals.

Approximately one in every 1,000 babies born each year in the UK develops group B Strep infection.

Most babies will make a full recovery from their group B Strep infection. Sadly, approximately one in every 20 babies who develop group B Strep infection die, and around one in every 10 of the survivors have a long-term disability.

Your baby's group B Strep infection is not your fault

When a baby develops a group B Strep infection, particularly newborns, sometimes mothers are told 'you passed it to your baby'. This can make mums feel responsible, as though it is their fault. **This is NOT the case.**

20-40% of adults carry group B Strep without any problems. The bacteria live quite harmlessly in our bowel and, in women, in the vagina. Many babies born to women who are carrying the bacteria become colonised themselves. A small proportion of babies – for reasons that we don't currently understand – are susceptible to group B Strep and, when exposed to it, develop infection rather than being able to cope with it.

That is not the fault of the mother (or father) in any way, and there is absolutely no reason for any parent to feel guilty about their baby developing a group B Strep infection.

Understanding what happened to your baby

If your baby has been affected by group B Strep, it is natural to have questions, and to want a better understanding of what has happened.

Looking after your wellbeing

Your baby developing a group B Strep infection can be a scary and traumatic experience. Things may feel out of control, and you may feel isolated and confused, resulting in distress not only to you but also to those who are close to you. Your health professionals are the first line for medical help and support, as is your GP. They can direct you to specialised support should you or your family need it.

It's important to remember that there is not one "right" way to cope with your baby's group B Strep infection. Everyone is different and each of us will need to find a way that works for us and our families. However, there are people who can help. As well as your family and friends, there are health professionals and charities available to support you. Do reach out to them.

Information at **www.gbss.org.uk/OtherOrganisations** includes signposting to counselling services for you and your family, including children, together with information about support groups, charities and places of spiritual or religious comfort.

For many parents, understanding what happened is very important. As a first step, your baby's medical records may help fill the gaps in your knowledge about what happened, and when. You are legally entitled to view or obtain a copy of your own and your baby's medical records.

In order to obtain these records, you should contact either the medical records department within the hospital or alternatively, contact the relevant patient support service who would be able to assist obtaining these. We would also recommend taking a copy of your antenatal notes before handing these to the Trust at the end of your pregnancy.

You will probably find it helpful to review them with your healthcare professional so that they can explain what everything means, particularly the medical terminology and abbreviations.

There are different support services available across the UK nations. Speak with your hospital to understand what is available locally.

Meetings with your health team

Your hospital may invite you to meet with an obstetrician (pregnancy specialist), midwife and/or paediatrician/neonatologist, ask your hospital to signpost you to the local patient support service.

Take someone you trust to meetings; they can support you, help you get all the answers you need, and take notes to remind you what was said. Alternatively you can ask for the hospital to minute the meeting or you may want to ask if you can record the meeting. You should not record a meeting without all parties' consent. You will be entitled to a copy of the recording or minutes made.

Don't be afraid to repeat your questions, or ask for clarification. Medical professionals respect the opinions of parents and will want to answer your questions fully.

NHS staff have a "duty of candour" to their patients. This means doctors, nurses and midwives have a duty to be open and honest with patients when things go wrong and the patient or their child suffers harm or distress as a result. It also means that doctors, nurses and midwives should always report when mistakes are made that have, or could have, compromised patient safety.

It's a good idea to plan for the meeting with your health professionals. We recommend you make a list of questions you want answered. For example:

- **What happened to my baby, and should anything have been done differently?**
- **Did you test for group B Strep during the pregnancy?**
- **Were you aware that I carry group B Strep?**
- **Did I receive antibiotics during the labour?**
- **Is my baby likely to have any long-term issues following their group B Strep infection?**
- **If I get pregnant again, what can be done to protect a future baby from group B Strep infection?**

Further options

If, after meeting with the obstetrician and/or the neonatologist/ paediatrician, you do not feel that you have been given the full facts, you can ask for an independent professional to review what happened. You can ask for a report from a doctor from another hospital. This request should be made in writing to the Chief Executive of your hospital trust, whose contact details will be on the hospital website, or can be obtained from the local patient support service.

If you remain unhappy about the care you or your baby received, you may decide to make a complaint to the hospital or to explore other options.

irwinmitchell

With specialist experience supporting families affected by Group B Strep, we're here to offer legal guidance and support for you and your child.

0800 023 2233

irwinmitchell.com

Group B Strep Support

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Continuing care and support for your baby

It is natural for you to be more concerned about your baby's health than you might otherwise have been had they not developed a group B Strep infection.

After you've taken your baby home

There is a small chance – estimated to be around 1-3% - that a baby who has had one group B Strep infection may develop another. So if you are concerned about the health of your baby, it's important that you seek medical advice. You are not wasting anyone's time or being a nuisance if you raise concerns with your health professionals – they would much rather see a healthy baby than be unable to diagnose an illness.

Golden rule with young babies:

"If in doubt, check it out…" and mention group B Strep when you do.

When continuing care is needed for your baby

While most babies will make a full recovery from their group B Strep infection with no long-term consequences, approximately one in every 10 babies who survive will have with long-term problems.

On some occasions, it is immediately clear that a baby has sustained long-term health issues as a result of their group B Strep infection. Sometimes, however, the signs may be subtle and only become apparent after a number of years. Problems can be temporary, and may disappear completely as the child gets older, or they may be permanent. In all situations, health professionals are there to support your child and you, the parents. An important part of this care is helping you to understand your child's development.

Your health professionals are the first line of support for you and your baby.

Your health professionals will be able to advise you about your child's health. If your child has a disability, there are organisations that can offer help and support.

- You can request a social services assessment which will help determine what extra support may be available for you and your child.

- Local Child Development Centres offer a multi-disciplinary assessment for children, from birth until they start school at 4 years of age, who may have a delay in their development or other special needs.

- The NHS webpage 'Social care and support guide', provides advice on caring for a disabled child and signposts a range of additional resources offering practical help and financial support.

- Children and young people (aged under 18) with complex health needs may be eligible for NHS continuing care funding. This is different from NHS continuing healthcare which is for eligible adults.

- As a child with special educational needs grows up, they may benefit from an Education, Health and Care Plan (EHCP) to help ensure that their educational needs are met at Local Authority expense. ECHP models differ in England, Wales, Scotland and Northern Ireland. However, they could include provision for specialist, residential or independent school placements and also consider needs, such as, therapies and equipment. An EHCP may be secured from birth up to age 25, following assessment by a local authority. These are issued following assessment by a local authority.

Speaking with other families affected by group B Strep

You might find it helpful to talk with another family who has experienced something similar. You might want to talk with another mum, or another dad. It can help to know that you are not alone, and they may understand in a way that others simply can't.

You may also want to ask practical questions of others who are, or who have been, in a similar situation. For example about coping day-to-day with a child affected by group B Strep, or seeking financial support, or what to consider when choosing a nursery or school as the child grows up.

Group B Strep Support can put you in touch with other families happy to share their experiences with you. Please get in touch with us on **info@gbss.org.uk** if you would like to reach out to other families in this way.

TOZERS

Experts in Group B Strep claims – Here for you every step of the way

With unmatched experience in Group B Strep claims, our dedicated legal team provides expert support to families affected by GBS, guiding you through the legal process with compassion and care.

As long-standing partners of Group B Strep Support, we're committed to helping you seek the justice and answers you deserve.

tozers.co.uk | enquiries@tozers.co.uk | 01392 207 020

When a baby has died

The death of a baby is a tragedy and one of the most traumatic things that can happen to any parent. It usually comes as a total shock and is hard for the parents, the siblings, and the wider family and friends, both in the immediate aftermath and for many years to come.

Grief and loss

There are several widely recognised stages of grief and loss, including:

- **Denial and isolation - particularly in the early days after your baby has died, including shock and numbness.**
- **Anger – as the shock starts to wear off, parents will often feel angry that their baby has died and angry with others (strangers, health professionals, partners, inanimate objects).**
- **Bargaining – the 'if onlys'. If only we'd known that…. If only we'd done… If only…**
- **Depression – often accompanied by feelings of despair and deep sadness. Parents can be withdrawn and exhausted, realising that nothing can be done to change the situation.**
- **Acceptance – accepting that the world is different, and moving into a new 'normal'. Grief never ends, but the searing pain recedes and becomes more manageable and, slowly, parents and families start to live again.**

Presenting these stages in a list is misleading though. Although you'll probably experience all of these feelings, it's unlikely to be a smooth path from one to another – it's more likely to be a roller-coaster that turns, over time, into more gently undulating hills.

For many people, understanding the reason for a loved one's death helps them begin to come to terms with their loss.

Post-mortems

Sometimes the reasons why a baby has died are not clear, and a post-mortem (also known as an autopsy) is undertaken to try to determine the cause of death. Post-mortems can give much needed answers to questions that have been unanswered previously, but even they can't always find the reason. They can, and usually do, however provide useful information to better understand what happened.

Post-mortems come in two formats. A hospital post-mortem is carried out only when the precise cause of death is already known, and helps to confirm and identify the extent of that cause. This can only be performed if the next of kin consents. By contrast, a Coroner's post-mortem is performed to identify the cause of death and will be carried out by law, whether a family agrees to or opposes it.

If your baby has died and a post-mortem is to be carried out, hospital bereavement officers can offer you support and advice. They also act as the main point of contact between you and the staff carrying out the post-mortem.

Memories

Many parents will find creating memories of their baby helpful – not only at the time, but also in the years to come. Some parents find it helpful to have photos of their baby around their home. Others like to create a memory box, including photos, and also perhaps hand/foot prints, a lock of hair, the baby's hospital tag, a scan photo, baby clothes, or notes of your and others' thoughts about the baby or the pregnancy. All this can help you and your family to remember your baby and can, over time, help you come to terms with your loss.

Some parents find it helpful to fundraise for a cause, as a way of doing something positive and channelling their energy into helping others. This can help people deal with a part of their grief, and it can be comforting to know that money raised in your baby's memory will help others.

If you would like to fundraise in memory of a loved one, visit **www.gbss.org.uk/InMemory**

Talking about your loss

Talking and sharing your feelings with others really can help. Some people find that relying on the support of family and friends is the best way for them, others find speaking with someone outside immediate family and friends is more helpful.

You might find it helpful to talk with another family who has experienced something similar. You might want to talk with another mum, or another dad. It can help to know that you are not alone and they may understand in a way that others simply can't. You may also want to ask practical questions of others who are or who have been in a comparable situation.

Group B Strep Support can put you in touch with other families happy to share their experiences with you. Please get in touch with us on **0330 120 0796** or **info@gbss.org.uk** if you would like to reach out to other families in this way.

Do consider bereavement counselling – it can be very important for mums, dads and siblings. Hospitals have specialist bereavement and information services that offer support, as well as information and the ability to refer to appropriate community support agencies. They will be able to help you with practical issues and the next steps. The midwife, health visitor and GP will also be able to help with support and signposting.

Please do ask for support if you need help.

Another pregnancy

If you decide to have another baby, the memories of your previous experiences plus anxiety about the health of your unborn baby can make it a challenging time.

Please remember that the chance of group B Strep affecting another baby is small. It is important that you tell your midwife, at booking, your complete obstetric history, including how group B Strep has impacted you and your baby. It is important group B Strep is flagged up from the outset so that you and your health professionals can ensure the potential risks presented by group B Strep are taken into account and, between you, ensure your care addresses and minimises them.

Even if you have told them at the outset, when you are admitted into hospital for the birth of your child, it is really important that you inform them again of your group B Strep history. Following the birth of your child, you should also ask them to confirm that you received antibiotics during the labour.

If you have any questions or concerns about your or your baby's health during pregnancy, do speak with your midwife or obstetrician. They will be keen to address your concerns.

Group B Strep Support can provide you with general information about group B Strep and what the latest national guidance is. We can lend a listening ear or put you in touch with other families who have had more children. We don't, however, offer you medical advice – for that you need to see your health professionals.

Please do not be concerned, there are thousands of healthy babies born after an older sibling developed group B Strep infection.

Making a complaint or taking legal action

It may be that nothing could have been done to change what happened to your baby. However, sometimes mistakes are made that result in babies developing group B Strep infection unnecessarily, or those infections not being identified or treated promptly.

Where errors do occur, it is often a system rather than an individual at fault - making a complaint or taking legal action can sometimes help to ensure that such failures are addressed, and the same mistakes are not made again.

Making a complaint

If you are unhappy with the care you or your baby received, then you are entitled to make a formal complaint. Your hospital will have a complaints procedure and the NHS website provides some useful information. You may find it helpful to talk to someone about the complaints procedure before making a complaint.

Patient support services can offer confidential advice, support and information on health-related matters. They provide a point of contact for patients, their families and their carers. You can also seek advice from third parties, for example, your local Citizens Advice Bureau or Action against Medical Accidents (AvMA) at any point.

Address your letter of complaint directly to the Chief Executive of the Hospital or Trust.

To be most effective, in your letter:

- Include details of what happened and when, plus the names and positions of those involved
- Explain why you are unhappy
- List the specific questions you would like answered
- Describe what you want to happen as a result of your complaint (eg, an apology, an explanation, a specific action, etc)
- Ask for a full investigation to be carried out
- Request a copy of any Serious Incident Report or Root Cause Analysis Report (this may be prepared by the maternity unit when a child is unexpectedly born with, or develops, GBS infection in the neonatal period)
- Ask for a response in accordance with the NHS Complaints Procedure
- What happened to you and your baby may be referred to the Maternity & Newborn Safety Investigations Special Health Authority this is an independent organisation that may be asked to look into the care received. The hospital should inform you if this is the case and provide you with information about the process. You will then receive a copy of the report once it is prepared. The report is not aimed at attributing blame or liability to individuals or organisations
- If a serious injury has occurred to your baby, the case may automatically be referred to NHS Resolution and you will be informed that your care is being investigated under the Early Notification Scheme (ENS). You should be advised to contact a lawyer at this stage, but if you are not then you should still do so. See below for details about contacting a law firm

You should receive an acknowledgement within a week, with a timeline of when you can expect a response. If the response is delayed for any reason, you should be kept informed.

Taking legal action

If the treatment you or your baby received was negligent, causing you or your baby either injury or harm, you may be able to make a claim for compensation.

Medical negligence claims are not a case of 'punishing' the health professionals and a successful claim won't necessarily result in an apology, a change in medical policy or the health professional being disciplined.

However, if care fell below a reasonable standard and damage was caused, legal action may result in a financial settlement to compensate for that damage. This can help secure appropriate care and support for babies left with permanent and lifelong disability.

To pursue a legal claim successfully, two conditions need to be met:

- The medical treatment provided fell well below an acceptable and reasonable standard, and
- The harm or loss caused was as a direct result of that negligence or was materially contributed to by the negligence.

Choosing a law firm

Medical negligence proceedings are complex and stressful for parents. You may have to go over the detail of what happened many times. Legal action may be both expensive and time consuming, taking many years to complete, although cases can be concluded quickly if the hospital accepts early on that there were mistakes.

It is therefore vital to make sure when considering whether to go down the legal route that you seek advice from expert lawyers with experience in group B Strep cases. At the very least you should contact a specialist clinical negligence practitioner who holds accreditation with either the Law Society, AvMA or APIL. They will be able to advise you on the funding options available to you and your family to ensure that there is no financial risk to you.

There are relatively few specialists in the field so if you think you have a case, or would like to see if you have the foundations for a case, we recommend you contact two or more of the experienced solicitors on our Legal Panel for an initial discussion.

The Group B Strep Support Legal Panel consists of a range of law firms, each of which has successfully dealt with clinical negligence cases relating to group B Strep infection. See page 24 for more information about the members of the Group B Strep Support Legal Panel.

Before contacting a law firm, however, do get together as much information as you can. The lawyer may need this to make a realistic assessment as to whether you might have a case. They should be able to make a preliminary assessment of your case with no charge, to enable you to decide whether to proceed.

Experience and a good track record are very important, as is finding someone you trust, and can develop a good working relationship with - clinical negligence claims are hard emotionally and may take many years.

If you think you may need legal advice it is wise to get help sooner rather than later, so that you can be clear about your options going forward.

If you would like further information, please contact us or one of our preferred legal providers listed at **www.gbss.org.uk/LegalPanel**.

Please note, Group B Strep Support receives no referral fees from any law firm. And, naturally, any contact you have with any of these firms is completely confidential between you and the firm.

How you can help

Group B Strep Support is the only UK charity dedicated to eradicating group B Strep infections in babies. We provide up-to-date, evidence based information on group B Strep to families and health professionals, and support affected families. We rely on public support to continue our vital work.

Help us raise awareness

Parents who haven't been touched by group B Strep often haven't heard of it, or the life-changing impact it can have on families. We ask our supporters to share information about group B Strep on social media, wear a pin badge, distribute information locally and write to their MP. Each July we hold a Group B Strep Awareness Month and we and our supporters work hard to make more families and health professionals aware of group B Strep.

www.gbss.org.uk/AwarenessMonth

Fundraise for us

There are lots of ways you can raise money to support our vital work, from fun runs to bake sales to more challenging running or walking events. Some parents find it helpful to fundraise in memory of their baby or a loved one.

www.gbss.org.uk/fundraising

Join a local fundraising group

We are looking for volunteers to join local fundraising groups. This is a great way to support fundraising activities and to be put in touch with people in your local area who have been affected by group B Strep.

Email **info@gbss.org.uk** for more information.

Get your Corporate involved

If your organisation is looking to support charity work, whether with one-off donations, a long-term relationship or to support employee fundraising, we can find an opportunity to meet their needs.

www.gbss.org.uk/corporate-support

Donate

Every year we talk to hundreds of families affected by group B Strep on our helplines, by phone, on social media, in online forums and by email. You can help us continue this vital work by making a one-off or regular donation.

www.gbss.org.uk/donate

Volunteer

We are always looking for volunteers to support our office staff; with admin, fundraising or graphic design. Or you might have other skills to offer, or be interested in becoming one of our Volunteer Ambassadors.

www.gbss.org.uk/get-involved/volunteer/

We always need people to help support our fundraisers at a variety of events, from the London Marathon to the local Fun Run. If you could help us with photography or vocal support please get in touch.

Email **info@gbss.org.uk** for more information.

Share your story

If you would like to help us raise awareness of group B Strep by sharing your story online or with the media then please let us know. You can read families' stories on our website at **www.gbss.org.uk/info-support/support/your-gbss-stories/**

GBSS Legal Panel

All the members of our Legal Panel hold accreditation with the Law Society, AvMA and/or APIL, as well as having successfully dealt with clinical negligence cases relating to group B Strep infection.

We are extremely grateful to our Legal Panel who have contributed to the production and publication of this handbook, and for the services they provide our supporters. The Legal Panel in this handbook provide financial and gift-in-kind support to Group B Strep Support.

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This leaflet was updated in 2023. The information in this leaflet was correct at time of writing. The information is for educational and awareness purposes, and should not be taken as medical advice. If you need medical advice, please contact your GP, midwife or other healthcare professional.

If you would like to provide feedback on this leaflet, or have any questions, please email us at info@gbss.org.uk or contact us on 0330 120 0796.