

# Going home after birth trauma



This leaflet is prepared for the situation where you and your baby have suffered birth trauma and you are preparing to go home together. You may be wondering what might happen now and this leaflet will provide some guidance of where you can get legal help and support around what happens next. We also suggest some sources of non-legal support. We explain the process from the viewpoint of a fictional family, Ali, Stefan and their son Joey.

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## Dealing with how you feel as parents

Ali experienced birth trauma when her baby boy, Joey, was born in a poor condition at 37 weeks, and required resuscitation and medical support for a hypoxic ischaemic brain injury. Ali and Stefan have been told that Joey has suffered a brain injury, but it is too early to know how this will affect his future development. Their world has become very medicalised and everything they expected from their pregnancy has been upended.

Ali and Stefan have struggled to come to terms with what happened as well as think about what the future holds; they have had a deeply distressing time. They have built a support network of family and friends around them to talk with about how they are feeling and to provide them with help and support. However, not all people have understood what they are going through, or the world they are now immersed in.

Many parents will receive support from their hospital's neonatal palliative care nurse, and Ali and Stefan had that support, so that when they started to plan going home, the nurse told them about any local organisations that might be able to give them extra support with both counselling and help when they got home.

Families whose babies suffered Hypoxic ischaemic encephalopathy (HIE) can independently contact organisations such as PEEPS HIE Charity. They give you lots of information about what to expect going home and where you can get support. The Charity BLISS is another charity that provides advice and support to families of premature or sick babies. They offer a wide range of free services including a video call support service.

When parents have suffered birth trauma and need a safe place to talk that through they may want to speak to an organisation that can help with that independently of the hospital where the trauma happened. Ali and Stefan felt that they needed to

speak to a professional about what they had been through. They were advised to reach out to their GP, midwife or health visitor, who could refer them to a specialist in birth trauma. They were also advised that needing support is very common among those that have experienced birth trauma and they wouldn't be judged. Ali and Stefan were also recommended to join support groups in their local area or online. They contacted a charity, Petals, for support.

There are many other charities and organisations that offer support and advice around struggling with your feelings after trauma and grief (see below or scan the QR code).

## Staying near your baby after you are discharged

Usually mums are discharged before their babies, and the hospital should put you in touch with someone who can help you access parent accommodation in or close to the hospital. In Ali and Stefan's case, the hospital where Joey is being treated has a charity funded Ronald McDonald House where they were advised they could stay so they could be close to him after Ali was discharged. They were also advised that they could seek ongoing support from their local community hospice team. Ali and Stefan were told that if they were religious the hospital had had people who could come and see them and provide additional support. Another family they met at the Ronald McDonald House told them that they were getting a lot of support from the hospital team.

## Understanding what happened - debriefs and making a complaint

Ali and Stefan want to understand what happened and requested a 'debrief' with the hospital to understand what happened. They spoke to their

dedicated Neonatal palliative care nurse (but they could also have spoken to their midwife or health visitor) to arrange this. They also asked her if they could have a copy of Ali's maternity records and Joe's neonatal records and if she would go through the notes with them to explain them.

The debrief meeting took place with a member of the obstetric and midwifery team. In that meeting Ali and Stefan were told about what had happened in their care. The team told them because of Joey's condition at his birth, the MNSI, a national maternity and newborn safety investigation programme, will investigate and produce a report about the care, which would be shared with the family.

This was obviously very hard for Ali and Stefan to hear.

Whatever Ali and Stefan are told at the debrief meeting, and whether they have to deal with the prospect of an investigation, their priority will remain the health and wellbeing of their son. They will still be focusing on his daily needs and thinking about what happens next.

Other specialist organisations provide a range of support and information, including counselling services. For more detailed information, please scan the QR code.



contact For families with disabled children



## What happens next?

The next weeks and sometimes months will be spent planning for Joey going home, and Ali and Stefan will be working with their local community care team to work out what changes, if any, need to be made to their home so that Joey can go home with them. They may need to have some training in certain care needs he has, for instance in how to feed him if he has particular feeding needs. Some children need daily physiotherapy and parents become incredible experts at learning how to deliver exactly the care and support their children need. For Ali, Stefan and Joey, it will be about working with their care team at the hospital and their local community paediatric team, and local authority social care team to make sure that everything is in place for Joey.

It is really important to remember, especially during times that feel overwhelming, to take everything step by step and day by day.



## Once you are home

Depending on your child's condition you will have had referrals made to appropriate consultants for ongoing outpatient care. Joey for instance will be under a Paediatric Neurologist and a community paediatrician. Ali and Stefan will also have a health visitor and Joey's GP and if they have any concerns about Joey at any time they can speak with these healthcare professionals for assistance. There should also be referrals to therapist, such as physiotherapists and Speech and Language therapists, although waiting lists are often long. Any of Joey's doctors could refer him to other doctors for further assessments and investigations and support if required.

It is often said that having a child can be expensive, but if your child has extra healthcare needs the extra costs are much greater. Ali and Stefan found that the costs of the extra support needed was adding

up as Joey started to grow and needed specialist equipment.

Instead of having to pay for all of this equipment themselves, Ali and Stefan can ask their local Authority to fund it. Local Authorities have a duty to provide any non-medical care services to disabled children. This includes supplying aids, equipment and/or adaptations to support their child's development, supporting them with care at home as well as holiday play schemes, portage and respite services. However, it can be difficult to get the funding agreed and there are delays.



There are also some charities such as HIE PEEPs and Dame Vera Lynn that offer some equipment grants. It is always worth looking into whether there is a charity that will fund an extra piece of equipment for your child.

Ali and Stefan can also claim some state benefits for Joey, such as Disability Living Allowance (DLA) and Personal Independence Payments (PIP) and/or carers allowance for themselves. Ali and Stefan will need a supporting letter from one of Joey's doctors confirming why he is in need of DLA for extra care.

Every child has a right to education, but those who need extra support can face additional difficulties getting the education they are entitled to. Ali and Stefan have been told Joey will never fully recover from his injuries and that means he will have special



educational needs and disabilities (SEND). Whilst they do not have to think about that for his early years, once he goes to nursery, the nursery will want to make special educational provision for him, as they get extra funding for him that way.

They will also support Ali and Stefan in requesting an Education, Health and Care (EHC) needs assessment which is carried out by local authorities to decide if their child needs an EHC plan. They can find more information on the government website, as well as charities such as Cerebra, Contact and Mencap.

## Working and caring for your child

After you have a child who needs a lot of extra care parents often have to make major life style changes. That particularly applies to working hours and the jobs they can do. Ali and Stefan decide that after Ali's maternity leave she will go back to work because she earns more than Stefan, and he will ask his job for a flexible working role. Ali will also ask for flexible working so that between them they can provide Joey with all the care he needs, and so that they can still spend time together. Not all employers are sympathetic to these requests and they may need to ask for some advice about their rights. Working Families is a national charity that gives free advice on these issues and Ali and Stefan make sure they check what their rights are before they make their requests for changes at work.

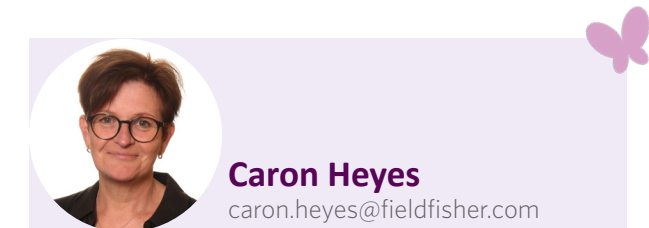
Finally - if you are reading this leaflet you are undoubtedly at the start of an unexpected journey that no one and nothing can prepare you for. We hope that the information here is of some use. If you scan the QR code below you will be taken to a webpage with more information and links to other organisations that can assist.

If you do have questions about the care you received during your pregnancy or birth or anything in this leaflet please contact us on our **free helpline 0800 047 2791**.

## How can I get further information and advice?

Fieldfisher is an award winning, leading firm of medical negligence specialists, recognised for going the extra mile for our clients. To get more advice about your own circumstances, or to assist you in supporting a family you are caring for, please contact one of key contacts Caron Heyes or Christina Gardiner, or contact us on our **free helpline 0800 047 2791** or email us on **maternitylaw@fieldfisher.com**.

*Simply fantastic in dealing with my medical negligence claim, listened to my thoughts about the situation. Legal knowledge and instinct are amazing, always professional, positive and unbelievably supportive during sad and challenging times.*



**Caron Heyes**  
caron.heyesh@fieldfisher.com

**Caron Heyes** is a Director in the medical negligence team and has worked in the medical negligence sector for many years specialising in bringing claims for adults and children injured during the antenatal, birth and neonatal period.



**Christina Gardiner**  
christina.gardiner@fieldfisher.com

**Christina Gardiner** is a Senior Associate Solicitor and runs a varied caseload, including complex, high value cases involving birth injury. She works with medical related charitable organisations AvMa and sits on the board of trustees for the Open Hands charity.