

nova

foundation

Together through babyloss

A guidebook for
recently
bereaved
parents

We at Nova Foundation are deeply sorry for your loss. We realise that you will feel shocked, numb and in disbelief as to what has happened, and overwhelmed by how much you have to think about and deal with in the upcoming months, but especially the next few days.

Everyone's experience is unique to them. While we at Nova Foundation will never understand exactly what you are going through as individuals, as babyloss parents we have a greater understanding as to how you will be feeling than most people.

What has happened is against the natural order of things. It is overwhelming, frightening and exhausting. While this is never the situation you wanted, this guide has been designed to support you and prepare you for the birth of your baby.

We understand that the information contained in this document is a lot to take in. What has happened to you is overwhelming. Go through the information at your own pace. If at any point this feels too much take a break, rest and return to it another time.

This document will guide you through what to expect in the next few weeks, as well as outline how to look after yourself, especially when it may be the last thing you will feel like doing.

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Birth Options for babyloss

When being given the devastating news, the Doctor will likely advise that you have two options – to be induced or to let nature take its course.

Natural will mean no medication to induce birth, but with no prediction of when birth may happen. If you are induced you will be given an initial set of tablets orally, and then asked to return 24/48 hours later for the remainder of the tablets, some of which will be given orally, some vaginally.

These tablets turbo charge the hormones and kick start the birth process.

Most hospitals will expect you to return for a hospital birth. Induction for a natural birth will happen after a scan locates the placenta. If this and everything else is straightforward you will have a vaginal birth, if not you will be referred for a caesarean birth, which your doctor will advise you on.

The first thing to think about is, if you are not referred for a caesarean, is whether you want a natural or induced birth.

You can take as long as you need to make the best decision for you. We know what an impossibly hard decision this is.

What to take to hospital

It can be hard to know what to take to hospital through the shock.

The following list of items to take to the hospital has been made by babyloss parents, which helped them to make memories with their baby.

The hospital will also have baby clothes (if you need them) and likely have memory boxes, these often contain knitted teddies, should there not be time to get these items.

The midwives will likely offer to make foot and handprints of baby. You can always ask a friend or relative to fetch you items to bring to you.

Items to bring with you

- Camera/camera phone
- A polaroid camera to take pictures to hold immediately
- Two teddys, one for us to keep and one for baby to keep
- Three sets of clothes, one for the baby to be in to be changed out of for us to keep with the baby's scent, one for baby to be changed into, one spare
- Two blankets to wrap baby in, one for us to take home
- Phone chargers/camera charger
- Food – hospital food is horrible, and usually the food is for patient only, meaning the birth partner may not get any meals. Bring along fruit, snacks and, if the hospital has a microwave you can use, microwave meals if this is something that you might want.
- You can ask for all the scan pictures from your notes, should your notes not be electronic
- Change of clothes for you
- Toiletries
- Contact lenses/glasses

Memory Making

- Take your time - The staff at the hospital will likely be extremely sympathetic. You can spend as long as you want with your baby. There is no rush
- Photo taking - Birth is exhausting. You may feel like you want to wait to take pictures of your baby or hold your baby. You may not feel like you can bear to take pictures of your baby.

Those pictures will be the most precious photos that you will have. Take as many pictures as soon after birth if possible, ask the midwife to take them if you cannot bear to.

- More photos- take as many photos as you wish.
- Your baby may look different to how you expected, but that is ok. If you are worried about seeing your baby ask the midwife to have a look.

The baby may be very delicate, which is normal, and may also change appearance overnight, not drastically but enough that it may be worth taking photos as soon as they are born.

- You can request a cuddle cot for baby to keep baby cooler for longer.
- If you want, you can take your baby for a walk.
- If you feel that it will help you, you can invite family and friends to spend time with the baby too.

It can be hard for friends and family to know how to best support you. Nova Foundation have created a guide for family and friends, which they may find helpful, and which may help them support you better.

We know this all seems heartbreakingly impossible, but promise you will be able to do this.

Making the space your own

You do not have to give birth in a hospital nighty. You can wear what you like to give birth in (or not wear anything at all), although bare in mind you may not want to keep it afterwards. Wear whatever feels most comfortable.

Just because these are not the circumstances you would have ever chosen, does not mean you cannot make the space feel like your own if you have the energy and inclination to do so.

If there is a cushion, or any other comforting or grounding objects you would like to bring from home it may feel comforting to bring them.

Returning for birth

The hospital will give you a number to ring when you want to come in for an induction. You do not have to give birth at the hospital you were told the news at. If you would prefer to use another hospital which you feel would provide a better level of care call up their triage department or contact your GP for a referral.

For a natural birth you will go to hospital once your waters have broken and for a caesarean you will be provided with a date to return. Whatever birth you have, your care team will be kind and compassionate and put you at the focus of your care. They will do all they can to assist and comfort you. You are not alone in this, as much as it may feel like it.

Time

Birth can take a long time and it is probable that a large part of your time there will be waiting. It may feel like no one is telling you anything, but most likely it is because until you are needing pain relief or giving birth, there is nothing much to update you on, as frustrating as this can be.

Due to the nature of your birth, you probably will not be able to have a water birth. You may be told that you cannot move around, but you can move around as much as you like. Do what feels right and comfortable for you.

Once you have given birth you will be offered tablets to help stop breastmilk from being produced.

The birth partner can play an active role in being your advocate and contacting the hospital, and if they do not feel the level of care is what you deserve to speak to staff regarding this.

The chance is your care when you go into hospital for birth will be much better than your care inbetween leaving hospital after finding out the terrible news and returning for the first set of induction tablets.

When to go through the birth plan

You will meet with a consultant when you go into hospital to give birth. You can outline your wishes to them below so that they can work to ensure that they can support you as much as possible.

You can also share this plan with your midwife. It is likely that, due to how long birth takes, you will have a day midwife and an evening one. While your care team will be extremely compassionate and understanding, this plan helps you to reiterate your needs to your team.

I wish to be treated with dignity and kindness, and want to minimise anxiety by creating a safe space with professionals that understand and are sympathetic to my circumstances.

Please amend the following to suit you best. This plan is for you, we have a plan without explanations designed to be given to your care team which is at the bottom of this guide and can also be downloaded on our resouces page.

1. My name is

2. My Child's Name

The language that people use can help you feel more comforted. Instead of technical language, if you have a name or nickname for the baby/babies, or your surname, you can share this with your care team
I want to refer to my baby/ babies
as.....

3. Father/ Birth Partner

Please feel free to remove the term birth partner and directly replace it with your partners name. Some hospitals only allow one birth partner, please check with your hospital if you would like to bring more than one person

My birth partner/s is/are called who is/are
my..... and

I would like my birth partner to be with me during labour yes/no

If I require a caesarean section I would like my birth partner to be with me yes/no

I would like my birth partner to be present and actively included in all conversations regarding all options regarding pain relief, delivery etc
Yes/No

I would like my birth partner to have somewhere to sleep and to be offered food the same time that I am

How the birth partner can feel more involved

The stillbirth of a baby is traumatic for both partners. This is a helpless situation for both parents. It is fair to say that the birth partner would do anything they could to swap places with the mother.

There are lots of ways that birth partners can support Mums. You may feel like you are not doing anything but by supporting your partner you are doing so much. Make sure that you also get support from someone.

Be an advocate

Chance is you know your partner better than anyone. Be an advocate for them. If you feel that information is not being explained clearly enough by health professionals, ask them to clarify. If, for example, you know that the birth partner does not want certain people in the room, keep them away.

Oxytocin

The love hormone, which helps reduce pain and is released when we feel comforted. Offer Mum a back massage or a hand massage. Gently stroke her arm if she wants that. Hold her. Make her feel loved.

Make Mum feel safe

You can make the room feel safe for Mum. Is there anything you can bring from home or do to make her feel more comfortable

You may only have a chair to rest in. Check with the hospital what space there is for you to stretch out in, whether the room has a bed, or a foam birth mattress. You will feel exhausted and need to sleep at some point.

Look after your own mental health

Speak to someone. Whether it is a friend who will just listen and be there, or a health professional, do not keep it in. You may feel like you have to be strong for Mum, or that men shouldn't cry. You have endured a traumatic loss, you deserve to be treated as you wish your baby's Mum to be treated. Please look at our pages regarding support when the time is right for you.

4. My hospital care team

Your support team will likely be a midwife (probably one during the day and one in the evening, or even two midwives). You may be offered a student midwife, who will be able to spend more time with you than the regular midwife, and is often a brilliant and helpful resource.

Some people may find it a reassuring comfort having someone else who is with them the whole time, some people may not want anyone else in the room they do not know. It is completely up to you and if you do not want a student in the room, or change your mind halfway through, then the midwife will have to honour your wishes.

You may also receive (and can request) a visit from the bereavement midwife. She will outline what support is available once you leave hospital and provide you with a support booklet of local resources and, if the hospital has them, a memory box.

Different hospitals provide different levels of bereavement support. The bereavement midwife will also advise of registering the birth if post 24 weeks and funerary care.

I want to minimise the number of people coming into the room, and do not want anyone entering the room unless they fully understand that I am pregnant after a loss so that then I do not have to repeat my situation.

I do/do not want a student midwife in the room.

I wish/do not wish to see the bereavement midwife

Feeling like you may poo

Please be aware that it is quite natural to feel like you need to poo during the later stages of labour. It may just be that you need a poo, that you want to get out of the space you are in and feel in a smaller safer space, or that your body wants you to be upright rather than lying down just because it feels better.

Be mindful that if you go to the loo in the later stages of labour, have a midwife be outside the door as you may give birth. This was my advice from a midwife and then it happened, but because I was made aware I felt in control, it was fine. Do not be afraid if you need to poo.

5. Pain Relief

During labour you will likely be offered paracetamol, gas and air, diamorphine or an epidural, although there are more methods of pain relief which we have outlined below.

The midwives will make your pain relief options available to you. If you receive pethidine or diamorphine, this may be accompanied by an anti-nausea injection.

During labour I would like the following pain relief, and would like to have explained to me clearly the side effects, of each pain relief if and when I decide to use them.

- Bath/Shower
- Hypnobirthing techniques (with/without my birth partner)
- Breathing techniques
- Massage (self/with birth partner)
- TENS Machine (I would like to use a TENS machine as soon as possible/I will use a TENS machine when I feel I need it most)
- Gas and Air
- Pethidine/Diamorphine
- Epidural
- Other

Spending time with baby after the birth

Just because your baby is not alive does not mean you cannot care for them, cuddle them or say goodbye.

As the hospital staff will explain, if your baby died some time before birth they may look different.

This is nothing to be scared of. If for whatever reason you feel apprehensive or scared to see your baby, you can always ask the midwife to take a look first.

The baby may become more fragile overnight, but the midwives will swaddle baby so that you can hold baby if you choose.

You can spend as much time with the baby as you want. You can spend time with the baby and then sleep and see them again when you wake. The midwife will ask you if you would like prints made of their feet and hands.

- I wish to hold my baby as soon as possible after birth
- I want my baby to have their hand and footprints taken
- I want the midwife to take photos of myself and my partner soon after birth
- I wish to have the baby dressed in the clothes I have bought in
- I want to spend as much time with the baby as possible
- I wish to receive a memory box if the hospital has one
- I would like the midwife to tell me what the baby looks like
- I would like the following items to stay my child/children

Any other comments

Visitors

The hospital will let you have visitors to see you, your partner and the baby. It is important that you as the parents put yourself first. If you do not want visitors, are feeling pressurised into having visitors or feel that the people visiting will make you feel worse then you should not have them visit you.

You can refer visitors to our resources of how family and friends can best support you here, and you can also ask the midwife if she can meet visitors and explain to them how best to support you.

I wish to have

.....
.....visit us

If possible I would like the midwife to meet with visitors before they come into the room and explain to them how I may be feeling, and helpful things for them to say and not say

Aftercare

You will likely be given drugs to prevent milk production way before birth starts. If not then you can request this.

- Often leaving hospital can be worse than the actual anticipation of birth. Make sure the health professionals support you by finding out what support resources are available to you and your partner before leaving hospital.

The bereavement midwife will liaise with the funeral home. More information regarding funerals is available below.

- I wish to be given medication that stops breast milk production
- I wish to have explained to me what therapeutic support is provided either by the hospital or in the local authority, and be guided as to how I can receive this support as quickly as possible
- I would like support with funeral arrangements
- If possible, when leaving the hospital, I would like to not use the lift and exits that are the same as the maternity ward. I would like someone to explain alternative routes out of the ward.

Placenta

Your placenta will be sent away to be tested. It is up to you to consent to this, but consenting will give a better reason as to why this happened.

Change in hormones

When you give birth your hormone levels drop. For the first two weeks after birth this is known as the blues, and is expected. This is then combined with grief and trauma, meaning that, while both parents will feel exhausted, for Mum in particular the hormones will be adding to this.

Hormone levels will gradually return to normal over 6-8 weeks. You will feel a storm of emotions. Be patient and kind to yourself.

The next day

The consultant will come and talk to you both. They will go over next steps for finding out why this happened, which will include going over a post mortem.

Let the consultant/bereavement midwife know if you, for whatever reason, wish to have a burial or cremation in the next few days. It is up to you whether you want a post mortem. You can ask the hospital if they can undertake a post mortem with a scan if for religious or any other reason you do not want a traditional post mortem.

Usually the post mortem has to be signed and agreed by the mother, but not always. If you as the Mum want a post mortem, but find it too much to agree too, the baby's father/birth partner can also sign this off.

The consultant or midwife should again go over care options and organisations that may help on leaving hospital and give you your aftercare options, most of which will be external to the hospital.

The consultant will then give you a check, which will probably involve gently pressing on your belly. This is not usually an internal check. You will have your bloods taken, and a vaginal swab (which may be done after birth) and a urine test.

You will probably be informed of the dates of the consultants clinic to go over findings. It is likely that the same consultant you speak to will be the same person who runs the clinic you will be invited back to.

There are sometimes delays in getting the results back, but you will be informed if this is the case.

Your midwife will give you some sanitary towels (the night time ones) as you will produce lochia.

Lochia

Lochia is discharge after birth, much like a period. It lasts 4-6 weeks. During this time it is important to use pads not tampons, and avoid baths until the bleeding stops. Much like a very long period it will start off bright before turning brown. It will be heavy (night time sanitary towels will be needed initially) for the first few days.

Clots

At the hospital they will tell you to get in touch if you produce large clots.

A large clot is anything bigger than the size of a plum.

You may produce clots, and some of these may dislodge after say, coughing or if you brush your tongue and wretch.

Clots are to be expected but do call your midwife if you get any plum size ones so they can check you over and give you the relevant treatment.

Leaving hospital

This will be the hardest walk you will ever have to make. Be as kind to yourselves as possible. Take all the time you need to do it. You may want to get a taxi or ask someone to take you home. Do whatever is kindest for yourselves.

Being at home

You will be feeling numb and exhausted. Give yourself as much space and time you need. If you do not feel up for visitors do not see any. It may feel hard to watch tv with adverts with babies on.

It may feel horrible to see pregnant women, families with prams or babies. It is natural to feel upset or even angry at these. Do what you can to create a safe space for yourselves at home.

While the upcoming days, weeks, months will feel impossible, you are safe at home now.

A community midwife should visit you for at least the first week after you return home. Depending on the hospital some teams are better than others. Contact your GP or bereavement midwife, to chase. The community midwife should then call you to arrange when they can visit.

Telling others

You will feel absolutely exhausted and on autopilot. Partners may feel like they have to be the one to tell others. You can always text people and then ask key people to tell others. People often do not know what to say and while their intent is with love in their shock the delivery can be unhelpful.

It will be heartbreaking to write a text along the lines of 'it breaks my heart to tell you this but our baby died. We have just come back from hospital and need some time alone/ it would help us if you did...'

You can send your friends and family the link here to our support books so they have a better understanding of what to say and how to support you.

The below information outlines what practical things you can do and expect in the first month. We have additional guides on grief, bereavement and trauma to provide you with more in depth support.

Creating a support network for yourself

The people around you want to help you. You can largely divide these people into emotional supporters and practical supporters.

The emotional will be people that will provide comfort, make you feel better, listen, and give you space to cry, be quiet, talk, whatever, uninterrupted.

The practical supporters love you just as much but may not be as helpful in making you feel emotionally better. What they are good at is doing. These are the people that will be good at the telling others on your behalf what has happened to you, cleaning your home when it feels too much, cooking you dinner, going to the shops to buy you whatever.

Partners need this just as much.

Choose those people that will help. As harsh as it sounds those people that will make you feel worse do not need to be in your space right now.

If people do feel make you worse, refer them to our section for family and friends and if people continue to be unhelpful take a break from them for a while. You may find that people you did not expect to be supportive are in the mosy suprising, loving way. The focus now is on you.

The S Word

You may receive countless messages telling people you are so strong. Strong is an overused word generally used by people that really think that without realising the full impact that describing someone as strong has on someone that feels anything but.

Strong can an unnecessary level on which to compare yourself to which can leave you feeling worse. Much worse. It is also other peoples perception of the word. Whatever strong means, you do not need to be it.

You have experienced one of the most catastrophic, traumatic things anyone could experience. Strong does not even do justice to what you are SURVIVING through. Do not let other people's overuse of the word make you feel worse. Either self correct and replace the word strong with survivor, or any other word you like.

People may say you are doing well. People think that because you are not in a heap on the floor not moving for years that that is doing well. And if you were in a heap that would be understandable because what happened is terrible.

You will likely have some kind of physical ache (which we go into more detail in our trauma and grief sections, handbook and app), and forget everything because grief is exhausting. You may wish you don't wake up in the morning or wish you were with your baby. This is normal too. The difference is when you act on these thoughts.

You, or your partner, need to seek immediate support from your GP if you do have suicidal impulses, or if you do not get out of bed, shower or eat for several days straight. Apart from this most other reactions to grief are 'normal' even though they feel anything but normal.

Self care

Looking after yourself will be the last thing you will feel like doing. You may feel like you do not deserve to self care. You do. Your baby would not want you to be neglecting yourself. Whether it is having a nice hot shower, eating yummy food, making sure you are hydrated, sleeping for as long as you need and just treating yourself as you would a friend, do it.

One tiny act of self kindness a day.

Our workbook will help you to plan your days and look after yourself. Take as much time as you need off work. Do not let others feel like you need to do anything (with the exception of if they think you should see a doctor).

Saying Goodbye

The whole process of babyloss is cruel. From the finding out, birth, the adjusting to 'life' afterwards, and planning your precious child's funeral. No parent should ever have to do this. There has not been a word invented in the English language to describe a parent who has lost a child – it is a pain beyond words.

In Sanskrit there is one word – Vilomah, which means against the natural order of things.

Which is exactly what babyloss is. Which is why then having to plan their funeral, balancing the exhaustion of grief against the want to do one last thing for your child is incomprehensible. But this is something, if you want to do, you can, and whilst sad it can feel incredibly healing.

It can feel incredibly overwhelming organising a funeral, not just for your child, but for your child who you never got the chance to develop their interests or see their personality.

You may feel unsure of what music to play or things they may have liked. You are still their parents. Whatever you choose and pick for your baby will be perfect.

We speak elsewhere about the word strong. You are better than strong, you are a hero because heroes do things they are scared to do. You have already done so much for your baby.

It can feel overwhelming planning all this. Make sure you take regular rests and self-care breaks and if things feel too overwhelming take a break. Friends and family will be happy to help if you there is anything you need them to help out with.

The practicalities

If your baby was born post 24 weeks then you legally have to register the death, and have a cremation or burial. You do not have to have a funeral, but many parents feel that this is one last chance to do something for their baby. It is completely up to you.

You will need to take the death certificate to the registry office in your Local Authority. The bereavement midwife or the funeral director will be able to tell you your nearest one though you can check online.

In the UK funerals for children under 18 are free. Most funeral homes offer free funerals for babies and small children. This includes the hire of the car and the casket. The funeral director will collect the baby from the hospital, and will wash and return clothes they are in should you want baby to be buried in a new set of clothes.

Most celebrants will offer their fee either free or reduced. The funeral directors can suggest a celebrant they work with, although you may wish to find your own.

The funeral director will advise on costs of burial plot. In some cemeteries and local authorities this is free for children. They, and the bereavement midwife, can also advise on organisations that can help with these costs.

The funeral director will also work with the cemetery to organise the date of the burial. If you require the funeral to take place quickly due to religious or any other reason please tell the director and the midwife. The cost of the headstone will be separate, but there will usually be a wooden memorial plaque erected.

They will ask you for anything you may want your baby to be buried or cremated with. These can be teddies, story books, football shirts, dolls etc. If you have any teddy's from the hospital you may wish for one to stay with your baby.

We understand that this is a very distressing thing to have to think about. Take a break from planning if you need to. The celebrant (and funeral director) will ask in advance what readings, if any, you may have. They will have some that they can suggest. They may ask you if you want to play music and if so what tracks.

The funeral

This is a goodbye ceremony for you, your family and friends. It can just be the two of you, or you may one wake, or have different wakes. It is completely up to you what you do. It can, however, feel very comforting and empowering to plan a goodbye ceremony for your baby.

The below are things that other parents have done which may help you think about what you might like to do during a time when this is not what you want to be thinking about

- Butterfly release
- Playing songs at the funeral
- Asking guests to wear bright colours
- Having celebration of life events in different cities (particularly if the parents are not from the city they live in)
- Asking guests to bring a small keepsake gift for the baby for you to keep at home
- Taking flowers from the grave site and drying them at home

You will think of your own memorials to celebrate the life of your baby. Whatever you decide will be the the right thing for you and your family.

They will ask you for anything you may want your baby to be buried or cremated with. These can be teddies, story books, football shirts, dolls etc. If you have any teddy's from the hospital you may wish for one to stay with your baby.

The planning of your goodbye can take up a lot of focus, and once it has passed you may feel like you do not have much to focus on, and that is when you are with your grief and loss.

Nova Foundations online resouces, downloadable guides and app will help provide you with comfort, support and guidance during this strange, scary and new time, helping you understand your emotions and adjust back to life, albeit a new and different one. We also signpost to other babyloss providers on our 'Where to Find Support Page'.

However you need to be supported, you are not alone.

I want to ensure that I, my baby and birth partner are treated with respect, dignity and kindness at all times by creating a safe space with professionals that understand and are sympathetic to my circumstances.

About Us

- My name is _____
- I want to refer to my baby/babies as _____
- My birth partner is called _____ who is my _____
- I would like them to be with me during labour
- If I require a caesarean section I would like my birth partner to be with me
- I would like my birth partner to be present and actively included in all conversations regarding all options regarding pain relief, delivery etc
- I want to ensure there is somewhere for my birth partner to sleep
- I would like my birth partner to be offered food when I am _____

My hospital care team

- I want to minimise the number of people coming into the room, and do not want anyone entering the room unless they fully understand our situation. This includes doctors, midwives, cleaners, catering staff etc
- I do/do not want a student midwife in the room, and understand that if I change my mind can ask the student midwife to leave
- I wish/do not wish to see the bereavement midwife

Pain Relief

- During labour I would like the to have explained to me different forms of pain relief available and the side effects if and when I decide to use them.

Memory making and spending time with baby

- I wish for my birth partner and I to hold our baby as soon as possible after birth
- I want my baby to have their hand and footprints taken
- I want the midwife to take photos of myself and my partner soon after birth
- I wish to have the baby dressed in the clothes I have bought in
- I want to spend as much time with the baby as possible
- I wish to receive a memory box if the hospital has one
- I would like the midwife to tell me what the baby looks like
- I would like the following items to stay my with child/children
- Any other comments

Visitors

- I wish/do not wish to have visitors see our family
- If possible, I would like a midwife to meet with visitors before they see us and explain helpful things to say and not say

Aftercare

- I wish to be given medication that stops breast milk production
- I wish to have explained to me what therapeutic/bereavement support is provided either by the hospital or in the local authority, and be guided as to how I can receive this support as quickly as possible
- I would like support with funeral arrangements
- If possible, when leaving the hospital, I would like to not use the lift and exits that are the same as the maternity ward. I would like someone to explain alternative routes out of the ward.

Notes

Notes