

Parenting with vision impairment

R N I B

See differently



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Foreword

Hi,

My name is Ben and I have sight loss. I am a proud parent of Adam. The prospect of becoming a parent for the first time is a daunting one; I've been there and know how you are feeling. But I can honestly say that being a father to my son is the most rewarding thing I have ever done.

But, being a Dad with sight loss can present unique challenges and I hope this document – with its wide range of tips and ideas – will give you some reassurance and useful advice. I also hope that it will help you know that others have been there and appreciate the worries and concerns you may have.

Personally, the best advice I ever received was from my mum who told me: "Do what feels natural. People will try and tell you how to do things but trust your instinct, it's there for a reason".

But, there's much more for you to find here.

And, RNIB is always there for you if you need support. Do not hesitate to contact the Children, Young People and Families (CYPF) team through its Helpline on **0303 123 9999** if you need any advice or assistance.

Yours,

**Ben,
VI parent**



Parenting with vision impairment

Pregnancy to one year old

“Parenting, regardless of eyesight, is often a voyage of discovery. You may well surprise yourself.”

No matter who you are, having a baby can be one of the greatest, most exciting and most rewarding challenges of your life. Every family has their own challenges and triumphs. While raising children can raise some specific issues for people with vision impairment (VI), everyone experiences highs, lows and sleepless nights.

This guide has been produced by a group of blind and partially sighted parents who share their experiences of having children. It features their ideas, hints, tips and advice and we hope it will empower and encourage new blind and partially sighted parents as well as the professionals who support them.



How to find out if you are pregnant

Pregnancy tests are not always accessible to women with a visual impairment.

It can be an exciting, personal and emotional time and one you may not want to share with other people. There are ways in which you can find out if you are pregnant, whether you want to keep it private or share it with someone.

- You can go to your local GP. They will do a test for you. (Some doctors may require you to wait a few weeks before they will do the test.)
- Speak to your local pharmacy. Staff can read your pregnancy test to you.
- Ask a friend or family member to read the result.

If you wish to find out the result privately you can use technology to help.

Clear Blue pregnancy tests has now linked up with the **Be My Eyes** app (www.bemyeyes.com) enabling women to find out the result of their pregnancy test in a safe place and without fear of judgement.

Through the specialised help section of the app, you can access a Clear Blue-trained advisor who will be able to tell you your pregnancy or fertility test result. All advisors are trained. As well as telling you your result, they will be able to answer any questions you may have. Digital tests are recommended as the result stays for 24 hours. However a line test can be read but it only is valid for 10 minutes. After this time the result is invalid.

Other apps that can be used to read a pregnancy test include:

Seeing AI app (www.bemyeyes.com) which uses Artificial Intelligence to describe, people, text and objects.

- **Tap Tap See** app (<https://taptapseeapp.com>) will take a picture of something, describe what it is and read the label.

Sharing the good news

Sharing the exciting news of your pregnancy can be met with different responses. We hope that this is a really positive moment. Parents told us that there were often questions they had to face, which sometimes seemed negative. For instance:

- How are you going to cope?
- How are you going to change a nappy?
- Are you able to look after a baby?

People asking these questions may not intend to be critical, though it is easy to feel that they are. You may feel defensive, or less able to ask for advice about caring for your new baby if you haven't had a positive response.

Facing others' questions could give you an opportunity to challenge perceptions, but also to show that you may share some worries, are nervous, but are keen to find solutions. Be honest and remember you have nothing to prove. People know how hard it is to be a parent.

Remember you are entitled to the advice and support that all new parents need.

"I have three children and I get occasional comments... that are encouraging and keep me going really! Children, that saw me pregnant, used to ask me: "Can your child then also not see?"

Inherited eye conditions

Many parents tell us they thought about their own eye condition as they were considering their own family plans and found it useful to get advice and information.

If you have an eye condition which is genetically inherited (can be passed between generations of a family), you can get advice from a genetic counsellor in order to understand the possible implications for your baby.

Genetic counselling allows you to find out what the chances are of passing on any genetic condition you have to your new baby.

If this is something you would find helpful you can be referred to a genetic counsellor. Your GP can make this referral. If your baby or child has a vision impairment we can provide advice and support about all aspects of their growth, development and education. Please reach one of our Family Support Officers through the Helpline at **0303 123 9999** or email us at **cypf@rnib.org.uk**

"I have a genetic condition and my partner is blind but her condition is not genetic. Our son was born fully sighted and as far as they can tell, doesn't have a trace of the eye condition. We were given a 50 per cent chance that he would inherit my condition."

Preparing for the birth

Try to ensure this time is as calm and stress free as possible. Ensure you are organised and have asked questions about anything you are unsure of.

- Ask for a tour of the maternity department to visit the main areas, delivery suite, post-natal ward, toilets, nurse's station, café etc. Most hospitals do group tours. Feel free to ask for an individual tour; this will allow you to ask questions and to move around the room if you want to.
- You may also want to ask about any equipment, buzzers or machines with unfamiliar sounds.
- Allow staff to guide you if necessary. Ask if you need help.
- Ask staff to be descriptive when going to scans. If you can get a print or digital copy of a scan photo, you can share it with friends and family. They can also describe what they can see to you.

“Even if you can't see the detail on a scan it's still an important moment. Don't be afraid to ask questions...”

- Hospitals will accommodate your guide dog if you need to take them into hospital with you. You will have to ensure plans are in place to make sure the dog's needs are met. If you have any concerns contact **Guide Dogs** (www.guidedogs.org.uk) for guidance.
- Getting to the hospital can be expensive if you are using taxis. Community transport may be available in your area – ask your midwife.
- (If ordering a taxi be clear on what you need. Tell them if you have a guide dog, push chair, hospital bags etc.)

Pack your own hospital bag then you will know what and where you have put things. It is helpful to be organised as it will reduce stress when you are in the hospital.

“My wife was furious when I couldn't find her chocolate bars while she was in labour. I should have learnt what was in all the pockets. We seemed to have taken the kitchen sink with us in that bag!”

- Ask if it is possible to have an individual room. This will allow you to make sure that everything is left where you put it. You may also want or need to do things differently from others, so you will feel less self-conscious. It may also be possible for your partner to stay over to offer you extra support.
- When you have had your new baby, it is a busy and exhausting time. There can be many people coming to see you to do routine checks that you and your baby are OK. Ask a member of staff to write a note by your bed asking people to introduce themselves and their role when they come to speak to you.

Feeding: breast or bottle

Feeding is a special time for you and your baby. Make sure you feel comfortable with what you decide to do. Don't feel pressured into breast or bottle feeding.

Breast feeding is very tactile and learning how to do it relies heavily on feel and positioning. You can ask for someone to check initially that the baby is latched on. Babies feed very often, so just by repeating the process you will soon feel familiar with it and be able to tell if all is going well. It is a completely new skill for both you and your baby so give yourselves time to get the technique right. Ask your midwife or health visitor to spend time with you so that you and your baby get off to the right start. You can try different positions and techniques to find out the most successful for you and your baby.

If you encounter problems or feeding is painful, ask for advice. You can access ongoing support from your health visitor, the baby clinic or a local breastfeeding café. It is common for many women to need support with breastfeeding in the first few weeks and months.

Some mums choose to express breast milk using a pump and store it to be given as a feed later. This can enable you to share the feeding duties with a partner. You will need to sterilise and prepare equipment as you would for bottle feeds.

Bottle feeding will allow you and your partner to share the feeding.

Create a bottle zone by using a tray to put everything on. If the bottle is knocked over, the mess will stay contained in the tray and be easier to clear up.

- Ensure everything is sterilised correctly. You can sterilise bottles in a dish washer or by using a dedicated sterilising machine.

Technology can help. You can get bottle preparation machines that will make a bottle that is suitable to give to a baby straight away without waiting for it to cool. They are becoming increasingly popular but are not recommended by the medical profession. Machines cannot substitute for your own care and attention in preparing feeds for your baby.

Use **talking scales** (<https://shop.rnib.org.uk/talking-kitchen-scale.html>) to measure water for bottles. (One ml of water is equal to a gram in weight.)

Talking kitchen scales are available from the RNIB Shop. Place the bottle then zero the scale before pouring water. A small funnel may help with getting the water in the bottle.

You can also use a syringe with tactile markings which could be made using tacti-mark, or bumpons, which are available from the **RNIB Shop** (shop.rnib.org.uk).

Some parents find plastic containers that are the correct size to measure powdered milk and water. You may need to ask a sighted person to assist you in setting up your kit.

However you choose to make up your bottles, always ensure you test the temperature before giving it to your baby. You can do this by tipping a small drop on to your wrist. If you are in any doubt leave it to cool a little longer.



Changing nappies

“You will touch poo at some point!”

Changing nappies is a messy business no matter who you are. Make sure you are organised and have plenty of towels, flannels and wipes around to minimise the mess.

You can practise on a doll. It won't move or fidget, but you will get used to knowing what you need close by: wipes, cream, nappy, clean clothes, nappy bag.

Change your baby in a place which is safe and where they cannot fall down when they are able to roll. You may find this easiest on a changing mat on the floor so that your baby is safe if you need to reach for other things. If you are using a changing table, make sure you always keep one hand on your baby so that you are aware of your baby's movements and any of their attempts to escape.

There is a tag on the back of a disposable nappy. When you pull the tag there is a sticky strip that can be wrapped around the dirty nappy to stop it from opening to make it easy to dispose of.

Ensure you clean your baby thoroughly. If you are still concerned, a bath and change of clothes will ensure your baby is clean. It is common that you may need to clean your baby higher up their back or tummy than the nappy reaches, so get used to cleaning the whole of their lower body and tops of their legs as a part of your routine.

If changing a boy, use a flannel or absorbent tissue to place over him while you position the nappy. This could help prevent you getting sprinkled!

Many babies get nappy rash at some time. Use a barrier cream every time you change the baby to ensure you don't miss the nappy rash. The rash is usually raised so it can be felt.

Make sure everything you need is within your reach, not the reach of the baby.

If your nappies keep leaking check you have the correct size nappy.

Give your baby something to play with, to keep them distracted.

If you have any concerns, ask a sighted person to check. This will help you to build confidence to let you know you are doing it right.

Bathing

"Organisation... is the best policy!"

Bathing your new baby can be a worrying thought for all parents. However, following a few simple tips can make this daunting experience a little less scary.

Have everything you need to hand. (Flannel, soap, towel, jug.)

Start small. When bathing a newborn you can use a clean washing up bowl. Develop your confidence and then move into a bigger bath.

Test the temperature of the water; bath thermometers are available but are often very visual. If in doubt use your elbow. (If your elbow doesn't feel too hot or too cold, it is suitable for your baby.) Don't use your hand to test the water as this is less sensitive to the right temperature for your baby.

Apron baby towels allow you to wear the towel as an apron while bathing the baby. This prevents you from having to straighten the towel while trying to hold the baby.

Using a thin flannel allows you to be aware of where you are washing the baby and will help you to feel where their eyes and ears are. Eyes and ears need to be washed delicately.

Give your baby a running commentary of what you are doing; this will keep you focused on the task in hand.

One way to hold a baby in the bath is to lie them on their back, resting their head on your forearm, and with the same arm reach through and gently hold the top of your baby's arm (the one that is furthest away from you). This will stop them from being able to roll over, gives you a free hand to wash them, and will help you to make sure that their head is always above the water.

As your baby grows and is able to sit, keep your hand on the baby's back, by their shoulders while they are in the water. This allows you to know what they are doing and where they are.

- You can buy baby baths with bum bumps in which help to prevent baby from slipping.
- There are also several different supports that can be put in the bath to help support your baby.
- Your baby should never be left in the bath unsupported by you even if using an aid.

Weaning

“Just accept this is going to get messy!”

At around six months, your baby will be ready to start to eat more solid foods. There are different methods of how you can do this.

Neither of the methods are the only correct way, choose whatever suits you and your baby.

One method is to puree foods and introduce them to your baby by spoon feeding them.

“I tried solid food too early when my first baby was growing up and knew it was easier to wait that little longer to introduce baby to solids with my 2nd and 3rd [children], to avoid a bit of mess.”

Pureeing food

When you are spoon feeding, rest your hand on the baby's shoulder to gauge which way they are facing.

Use your thumb to work out if their mouth is open and if so, how far. Practice makes perfect.

When pureeing food, you can use ice cube trays to make portions which can be defrosted at a later date. Make sure you label them otherwise it could be baby food roulette. The RNIB Shop has various labelling options.

High contrast equipment will help you to identify what you need.

Using bowls and cups with rubber suckers on the bottom can be helpful.

Stick with it! “It can take 10 attempts before your baby gets used to different tastes and textures.” (NHS 2019)

With food that contain allergens such as gluten, hen's eggs, fish and peanuts, introduce them one at a time and in very small amounts, just in case of an allergic reaction.

For guidance about allergic reactions visit the NHS website: [nhs.uk/conditions/allergies](https://www.nhs.uk/conditions/allergies) ([nhs.uk/conditions/allergies](https://www.nhs.uk/conditions/allergies)).

If you are ever in doubt **call 111** for advice.

Baby-led weaning

Baby-led weaning is a method that allows your baby to feed themselves. Introduce them to finger foods that they can pick up and try.

- Place a mat under the highchair to make cleaning up easier.
- Cut food into manageable small-sized pieces for your child. Your child will be holding the food and trying to chew one end of it.
- Always make sure small round foods such as tomatoes and grapes are cut into small pieces lengthways – from the stem end – then into quarters. Also make sure boiled or steamed vegetables such as carrots are cut into small pieces. These size pieces can be swallowed easily and won't get stuck in the child's throat.
- This maybe a good time to shut the guide dog out of the room as they might eat any dropped food making it more difficult to know how much actually went in your child and how much on the floor.
- As with pureeing food if you are introducing allergens, make sure you do so one at a time.
- You can try a mixture of both feeding your baby with purees or baby-led weaning on more solid foods.
- Whatever your method of weaning, make sure you always supervise your baby when they are eating.

How do I know if my baby is choking?

While your baby is learning to eat solid food, they are getting used to chewing and swallowing.

What is the difference between my baby choking and gagging?

Signs that your baby is gagging

- Their eyes may water.
- They will push their tongue out.
- May bring up food because of retching.

If this happens your baby is getting used to new tastes and textures. It can be a normal sensory reaction to trying new foods.

You need to be aware of the signs that your baby is choking and make sure that you are prepared if this situation ever arises.

Signs that your baby is choking

- They struggle or are unable to breathe.
- Gaspings or wheezing.
- Can't make a noise or cry out.
- Go limp or unconscious.

This NHS guidance explains what to do if your baby is choking: [nhs.uk/conditions/pregnancy-and-baby/helping-choking-baby/](https://www.nhs.uk/conditions/pregnancy-and-baby/helping-choking-baby/)

Teething

There are multi-sensory signs that your baby is teething. You will get to know your baby well so trust your instinct.

- Your baby may seem more upset and unsettled than usual.
- They may be dribbling excessively.
- Putting things in their mouth, sucking and chewing on them.
- Their cheek(s) may feel very warm and flushed.
- They may hold their ear.

By the time you can feel or see new teeth in a baby's mouth, the hard part is usually over so be aware that they may demonstrate teething behaviours for some time before teeth come through their gums.

You can purchase several items at pharmacies which will help to ease the pain for the child.

If you are in doubt about whether your baby is teething or whether they are unwell speak to your health visitor, GP or call 111 to get professional advice.

Crawling and walking

During your child's first year they may be starting to crawl across the floor and getting ready to walk. You need to be sure that you are aware of where your baby is at all times to keep you and your baby safe.

There are things you can do to ensure this:

- Attach bells to their arms and legs so that you know where they are.
- Make a safe space; this can be done with play pens or travel cots.
- Use noisy toys so you know what baby is doing.
- Remember all babies fall over, that is normal.
- Make sure that visitors keep doors or stair gates closed so that you know how far your baby can travel.



Illness

If you are concerned about your child's health always ask for advice. Your local GP or Pharmacist will be happy to advise you. If you are unable to get out **call NHS 111**, they will be able to advise what to do.

- Keep medicine in the box it comes in; it will have braille on the packaging.
- Put labels on the bottle with what is in it and the dose your child should have.
- Use a syringe and bung to give medicine. (These can be bought from your local pharmacy and come in a range of different sizes.)
- Get someone to use a knife and score a mark on the syringe so you know how much medicine to give.
- Use a medicine dummy – this allows you to put the correct dose into the teat and ensure the baby gets the full amount.
- Use medicine sachets so you know you are giving the correct amount of medicine.
- Look into local paediatric first aid courses.
- Look out for a raised temperature; you will get to know when your baby feels too hot. If you want further reassurance you can buy audible thermometers which make a sound if the temperature is too high.



Hazards in the home

When you find out you are having a baby start to think about what you can do to make your house as safe as possible. It is much easier to plan and put things in place before your baby arrives. Imagine your house from your baby's own height. Some parents suggest crawling around it yourself to find out where the hazards are.

When purchasing any safety equipment make sure that the instructions are followed, and items are installed correctly. You may need to get support from a sighted family member or get a professional to fit the items.

- Use safety gates to prevent your child from accessing the stairs (There are several gates on the market so ensure you are purchasing one that fits your stairs and is easy for you to operate. If you are unsure, ask.) Use a safety gate to prevent your child from having access to rooms that may be dangerous such as the kitchen. You can install bells on the gates so that you know if they are being moved when they shouldn't be.
- Make sure cupboards have locks on to prevent access to breakables, dangerous liquids, medicines etc.
- Use corner covers on any items that have sharp pointy corners.
- Make sure breakable items are out of reach of your child or that your child cannot reach and pull at anything that would fall on them. Ornaments on shelves, or tables with overhanging tablecloths can present a risk.
- Place knives, scissors and any other sharp items, up high out of reach of the child or in a lockable drawer.

Getting out and about

It can be daunting for any parent going out with their baby especially for the first time. However getting a change of scene can be helpful especially if the first weeks with your baby feel very new and tiring. It can help to make sure that you are prepared. There are items available that can make this easier.

- Take time choosing a pushchair. Make sure you go somewhere that will allow you to feel the pushchair and practise putting it up and down. How heavy is it? Can you manoeuvre it with ease?
- Pull buggies allow you to pull the buggy behind you, so you can continue to use your cane.
- There are several back packs and slings on the market so make sure you choose the best one for you. Seek advice if you are unsure or try different styles in a sling library if one is available – your health visitor can advise you.
- Get to know your car seat. Feel comfortable securing it into a car. This seat will protect your baby and it is very important that it is fitted into the car correctly and that your baby is positioned and strapped in correctly.
- Always carry your own travel change mat; often a portable one comes with a changing bag. When you are out and about and changing your baby, you want to make sure that they are changed on a clean surface.
- Keep some antibacterial wipes with you so if you are in doubt you can wipe any surface clean. (Make sure these wipes are clearly labelled so they don't get confused with baby wipes.)

Useful contacts

Blind Parents UK

01905 886252

blindparents.uk

Guide Dogs adult helpline

0345 143 0229

guidedogs.org.uk

VI parents and carers together

Facebook group

bit.ly/3nr7DzD

RNIB Children, Young People and Families (CYPF) team

0303 123 9999

cypf@rnib.org.uk

RNIB VI parents Talk and Support telephone group

Groups run during term time only,
on a Monday at 1.30pm, please
call **0303 123 9999** or visit

rnib.org.uk/talkandsupport

Sight Advice FAQ

sightadvicefaq.org.uk

NHS: 111

NHS Emergency: 999

RNIB depends on public support to deliver its life changing services, support and information to people affected by sight loss. To find out more about supporting or fundraising for RNIB, please visit: rnib.org.uk/donations-and-fundraising

RNIB

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