

Self-Care for the NICU Parent



Self-Care is not selfish



www.inha.ie



Congratulations on the birth of your precious baby!

We know that the neonatal intensive care unit (NICU) is not a place you ever thought you would be. You may experience many emotions over the coming days, weeks or months including shock, fear, anger, anxiety, sadness, loss and, as confusing as it may be, maybe even happiness.

During your time in the neonatal unit, you may hear about the developmental challenges that your baby could face. You will experience milestones and setbacks. Celebrate the milestones, no matter how small. Mourn the setbacks. It is okay to feel bad.

Try not to worry or stress about what the future might hold that you forget to cherish the moments you have right now. Find ways to live in the moments. Look for love over fear, and let it be your strength. Your baby, so tiny and fragile, will show you just how strong a person can be. The neonatal unit may seem like a rough place at first, full of struggle, but it can teach you how beautiful and precious life truly is.

This booklet has been developed to support families with babies who begin life being cared for in the neonatal unit and help them safeguard and protect their mental wellbeing as they embark upon their journey as NICU parents.



NICU *Emotions*

NICU Parents often feel that they have to put on a brave face when they might be struggling themselves, and this can be especially true when your baby is in neonatal care.

Feeling Overwhelmed

Having a baby is always a big change to your life, whether this is your first baby or you have other children.

But spending time in a neonatal unit is something most parents do not expect. It can also follow a sudden, difficult, or sometimes traumatic birth.

Feeling overwhelmed can be very common for parents on the unit. Often people describe feelings like:

- Anger
- Sadness
- Shock
- Confusion
- Guilt
- Helplessness
- Being out of control of your situation
- Not really knowing how you're feeling
- You might also feel less able to focus on practical things which might still need doing, like organising childcare for other children, paying bills, or planning meals.
- You might feel a mixture of different emotions at the same time, which could feel confusing and difficult too.
- Not knowing what might happen next can also add to this feeling.
- You might be spending a lot of time on the unit, or finding it hard to sleep. These changes in your regular pattern could make you feel like life has been turned upside down.
- You may feel worried about going back to work, finances, travel, or caring for other children.



These unexpected challenges can add more pressure on the everyday things that make up your life. The environment of the neonatal unit can make these feelings worse for you. Having no natural light for prolonged periods, and living in a small and quiet space can have an impact on how you face challenges.

Feeling Anxious

Having an unwell baby can leave you feeling out of control of your situation. Often parents have lots of questions about why this has happened to them, what will happen next and what they can do. The unknown can be very worrying for parents, especially when their baby is vulnerable.

Hospitals can make many people anxious. This could be because you have experienced something difficult or traumatic in a hospital before (either with yourself or other family members).

Or you may feel anxious because there are lots of staff who you might not know, and the environment can feel unfamiliar.

You might also feel fearful of what might happen, and sometimes expect the worst for your baby.

Not knowing how to get involved with caring for your baby can also make you feel anxious. We often hear that parents feel very anxious when they take their baby home. It might feel scary to be faced with being alone with your baby, and you might be worried that they will become ill at home.

It is common to feel anxious during difficult times, but sometimes it can have a bigger impact on your day to day life, or can last longer than you might have expected. If you feel this might be happening for you, it is important to get support.

Spending time on a neonatal unit might make it harder to face mental health issues you have struggled with before. If you've suffered with anxiety in the past, you could find that being in the neonatal unit brings back those feelings. You might find it helpful to go back to the support you've used before, or to talk to someone new about what you're feeling now.



Feeling Grief - even if your baby survived

Feeling grief doesn't only happen to parents whose baby has died. Having a baby in neonatal care can mean losing or letting go of ideas and plans you had.

You might have imagined the birth you wanted, or the first few moments or days with your new baby. Often, these ideas can have been imagined by parents for years before their baby was born.

Being forced to let go of those plans can leave parents feeling a sense of grief, for moments they will never get back. Parents often say they feel guilty for feeling this if their baby has survived.

How you feel and process what has happened to you might be different to how others face these challenges. Feeling this way is completely understandable and very common.

Fear or Worry

You may be fearful and ask yourself *"Will my child survive?"* or *"Will my child be normal?"* You may worry about how life will change while your baby is in the neonatal unit and ask *"Can I really do this?"* and *"What will life be like?"*

You may worry they will not be able to take care of your tiny baby or feel that you do not understand all of the equipment or medical words you hear from your baby's care providers. It can be hard to be a NICU parent and you may fear being judged or that friends or family do not understand what you are going through.

Sadness

Sadness is quite common for families in the NICU and can come and go. Sometimes this can result in crying spells, but not for everyone. "Baby blues" is the feeling of being overwhelmed, sad and unmotivated to take care of daily tasks within the first few weeks after giving birth.

These feelings may last longer for others and are more severe, progressing to what is known as post-partum depression (PPD). PPD can be more common for NICU parents due to the extra stress. Make sure you talk to a health care provider if you are having these feelings.



Anger

You may feel frustrated or angry about not having a birth that you had planned or home-coming. Anger can also come from feeling a lack of control about the situation. You may find yourself getting angry with your loved ones or with medical staff. Sometimes this may be due to overall frustration and less about a specific issue.

Self-blame or Guilt

It can be hard to accept when things do not go as planned or when there might not be a good explanation why something has happened. It is common for parents to blame themselves. Learning how to let go of guilt and forgive yourself can help you be more emotionally present and focus on building a relationship with your baby.

Relief and Gratitude

You may have had a difficult and high risk pregnancy or a rough birth experience. It can be a relief that your baby has arrived and settled into the NICU.

Loss

You may feel that you have missed out on milestones, like having a third trimester or bringing your baby home right away after the birth. It's ok to miss being pregnant and all of the sensations and feelings that come with it. You may also be grieving over the loss of what you pictured for your family by not having a "typical" child if the child was born with challenges.



Jealousy

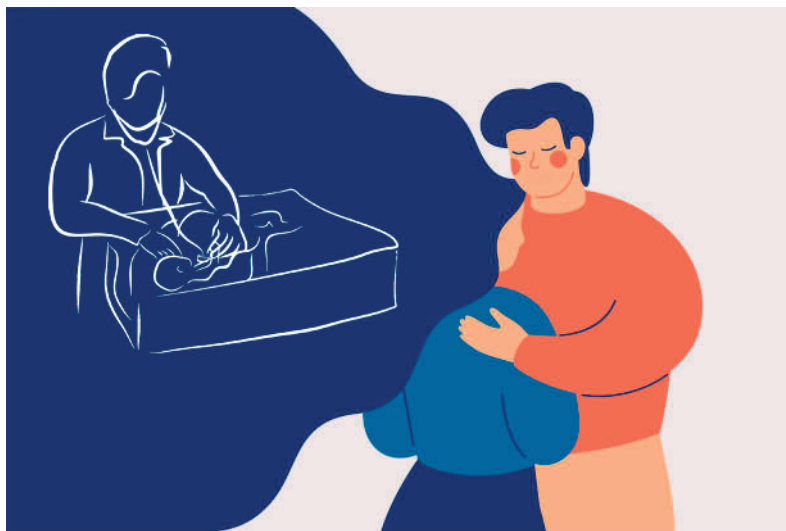
This is a common feeling, especially when other friends or family members may be pregnant or having healthy babies, or when fellow NICU babies may go home before yours.

Numbness or Avoidance

You may want to mentally shut down or not visit your baby because you feel overloaded. Taking small steps and having short visits with your baby may help with this. However, if it continues or becomes a problem, let the medical staff know as it can be a sign of traumatic stress.

Vulnerability

It is hard to be separated from your baby, not have control of what is going on and trust the medical team in taking care of him/her.



When to talk to a Healthcare Provider

While negative emotions are common, if they continue and interfere with your daily routines, this may be a sign of a bigger problem.

Since the NICU is very stressful, NICU parents are at a higher risk of having depression, anxiety or traumatic stress symptoms. It is very important to let someone know if you are struggling and are having any negative emotions or reactions that do not go away.

Sometimes it can be hard to ask for help, especially when you might be used to dealing with problems all on your own. There is no shame in getting help during tough times.

Some support staff that are available to help are:

- Social Workers
- Chaplains
- Psychologists
- Nurses
- Doctors

It is very important for you to reach out to your unit's support staff if you experience any of the following:

- Problems bonding with your baby
- Frequent crying spells
- Emotional numbness or feeling disconnected from reality
- Feeling unable to manage your responsibilities
- Not sleeping for many nights in a row
- Trouble getting out of bed and starting the day
- Thoughts of wanting to harm yourself, or someone else, or end your own life (suicide)



Resources for Dads

Fathers with babies admitted to the NICU generally have unique needs that are different from those of the baby's mother.

- Dads are sometimes the first parent to see their new born in the NICU because Mum may be too sick to come to the NICU or may still be admitted to the birth hospital. This can be a scary and overwhelming situation to walk into as a new parent.
- Dads may be on their own when first arriving and may have to speak with the medical team and relay important news about the baby to their partner. Many times this can be the start of a stressful and terrifying journey where dads may feel like they have to hold back their own fears so they can support Mum and the rest of the family.

The environment of the NICU can be intimidating with the sight of babies connected to equipment by tubes and wires surrounded by medical staff.

- It is perfectly normal and fine to feel scared, sad, anxious and confused.
- It is okay to feel helpless, angry, and sad when having a child admitted to the NICU.

Dads often feel that they have to be *“big and strong”* and hide their negative emotions. They feel that they have to support their partner and child, often at the cost of their own health. This is understandable, but in order to best help their family, Dads must also put some effort into taking care of themselves. It can also be common to feel helpless in the NICU, like things are not under their control. This can be tough for Dads who are used to being the *“fix it”* guy.



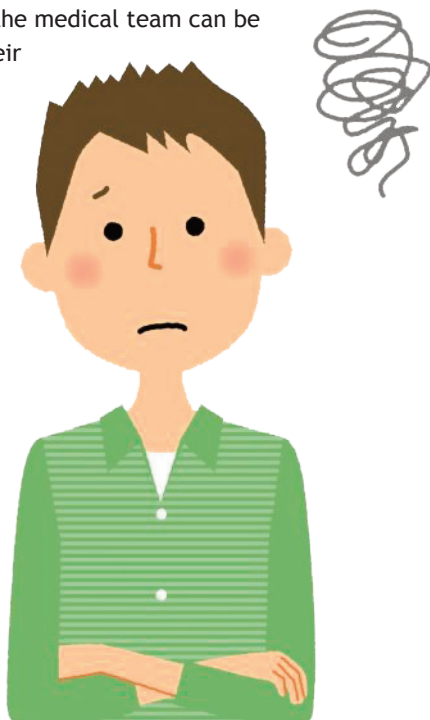
- Building trust with the baby's care team and finding ways they can help care for their baby can be valuable.
- Asking others for support or help is one of the most important ways to practice self-care but can often be the hardest for men. It can be hard to admit that they are scared or confused or that they feel angry and do not know what to do about it.
- Taking a chance and finding someone in their life, whether it be a partner, family member or friend that they can confide in, makes a big difference. ***Do not hesitate*** to ask when you need help or want someone to talk to!

You Are An Important Part of Your Baby's Team!

While the bond between Mum and baby is special and important, the bond between Dad and baby is equally as important. Dads need to be involved with the care of their baby at the same level as Mum.

- Feeding, bathing, and kangaroo care are important parts of bonding for dads and their babies.
- Some men report feeling scared about holding such a tiny, fragile baby. Remember that these are normal feelings and it will get easier with practice.
- When Dads are present on the neonatal unit it is imperative that they be invited and supported to participate in their babies care.
- Again, do not be afraid to ask for help.

Some Dads report feeling “*left out*” or “*invisible*” during their baby's time in the neonatal unit, as much of the attention of the medical team can be focused on Mum. Dads are just as important as their partner when it comes to the care of their child. Often Dads are balancing jobs and childcare for siblings at home which is a really important part of supporting their partner and baby.



Coping Strategies

Parenting in the NICU is hard and you may not always be at your best. Sometimes, parents can feel like lashing out at their family or friends or even staff at the hospital. It is important to discuss these concerns, find a solution, and deal with the anger in order to free up more time and energy to take good care of your baby and yourself.

For some families, visiting the NICU can be hard due to having other children at home, jobs, and other responsibilities. Sometimes, parents may feel so poorly that they are unable to come visit. While visiting, parents may also feel they cannot leave the bedside and need to be with their baby every moment. While it is important for families to be with their babies as often as they can, it is also important that you are taking care of your needs too!

Staying Healthy

- Parents need to eat regularly, even if just small meals or snacks every few hours.
- Parents need to drink plenty of water to stay healthy.
- Getting rest when you can is also key to feeling better throughout this process.
- Rest and food/drink are very important for mothers who are providing breastmilk.
- Taking care of your own health so you do not get sick also can help protect your baby from illness. Also, you do not want to miss out on spending time with your baby if you get sick.



- Give yourself permission to cry and feel overwhelmed. You may worry that you will never be able to pull yourself back together, but you will.
- Be kind to yourself and lower your expectations. You just had a baby and life changes a lot. With home tasks, get comfortable with aiming for “good enough” and be okay if things may not get done perfectly or on time.
- Get into a routine. Find a way to balance work, home and visiting the hospital. Your baby needs you, but it is also important to have time to yourself, with your partner and with your other children. Also, take time to do things you enjoy. These restful breaks will help you find the strength to keep going.
- Connect with other NICU parents. They share many of your feelings and struggles.
- Keep a journal. Expressing your feelings on paper can help you cope with your emotional changes. A journal also strengthens your hope and patience by reminding you how far you and your baby have come.
- Vent your frustrations. If your baby has a setback, this may create some fear or anxiety. Please talk to the medical team about your concerns to help you understand and prepare for the next steps. Talking with your friends/family or support staff (i.e., social worker, chaplain) may also help.
- Cultivate gratitude. Research has shown that focusing on good things that happen during the day can help create feelings of gratitude which has been shown to increase happiness. By writing down the good things that you noticed during each day shifts our focus to hope and optimism. This can help us get through tough times.



- Get moving. Take a short walk around the hospital campus a couple of times a day. Exercise is good for your body, mind, and spirit. If you are able, try to find exercises you enjoy like yoga, running, dancing, strength training, biking, etc.
- Celebrate when you can. When your baby makes progress, it is okay to be happy.
- Accept the support of others. Let people know how they can best help you.
- Accept that you and your partner will react differently. Share your experiences and listen to how the other person feels so that you both can feel supported.
- Spend time with your baby. Taking care of your baby can help you bond and feel closer to them. Learning more about how you can be involved with your baby can help increase your sense of control.
- Mindfulness. A way of thinking which involves a state of active, open attention on the present. This is also known as being “*in the moment*.” This means a moment-by-moment awareness of our thoughts, feelings, bodily sensations, and surrounding environment. This awareness is met with internal acceptance. Paying attention to our thoughts and feelings without judging them. Not dwelling on the past or anticipating the future.
- Meditation. One strategy to calm the mind and body is to take a few minutes to sit quietly with eyes closed. Focus on taking deep breaths. This is a strategy to help calm the mind and body. This practice is well-known to have physical and mental health benefits.



How to use your Social Support

It is important to reach out to friends and family members you love and trust. This is a time when it may “*take a village*” to get through your NICU stay.

It can be nice to have family and friends be involved in your NICU journey, but also hard some days. There are times when you might want to be alone with your baby or at home resting. It is okay to set new limits around your time as you heal from the birth and balance time at the hospital.

Hopefully, your family will understand that you are adjusting to becoming a parent and this takes time and space. Change can be hard and it may take a while for the people in your life to adjust too.

Keep in mind that they mean well and just want to be there for you. Your support people may not know how to best support you and may need more direction. Giving them specific tasks or jobs may help them know how to best help you.

Some ideas for family and friends who want to support you

- Childcare and transportation of siblings
- Transportation for parents to/from hospital
- Household chores, such as cleaning, dishwashing, laundry, etc.
- Pet care, like walking the dog, feeding pets, etc.
- Bring in mail, taking out trash, etc.



- Set up nursery room at home
- Provide lawn care, gardening, etc.
- Cook a meal
- Offer to run errands for the family
- Provide gift cards or cash for petrol, snacks, meals, baby supplies, etc.
- Send a note or text/email message of encouragement

While you may feel like your friends and family do not understand, it is important not to isolate yourself from them. This will not be helpful long-term for your mood or coping process. You will need your family and friends again.



Relationship Care

You and your partner may have been together a relatively short time, together for years, or perhaps are no longer together. Perhaps you are first-time parents or have already experienced raising other children.

The two of you may have planned every detail of becoming parents or have been unexpectedly surprised to learn you had a baby on the way. Every set of NICU parents has their own unique story and ways of relating, but all will experience stress during their baby's NICU experience.

Many parents come to find that they experience and process emotions in very different ways because every individual is different, and that is okay. You may have different comfort levels with being at the hospital. You may have different opportunities to be at the bedside depending on demands outside the hospital, such as juggling work and childcare.

While you may notice the differences and the additional stress, it is important to try to respect and support each other no matter the differences. You may find that the NICU experience brings you and your partner closer together.

Here are some ways you can work to support your relationship

- Keep each other updated about medical information you may receive, and work as a team to make decisions for your baby.
- Support each other by dividing necessary tasks and establishing a daily routine. This can be very helpful during the period new mothers need to physically recover from childbirth.



- Take time to take care of your relationship by making time to talk to each other, and take occasional breaks to do activities together.
- Asking for help from outside supports, such as family and friends, can also help you make time to focus on caring for each other during a difficult time.
- If dealing with the NICU stay is straining your relationship, think about getting help by talking to counselling professionals either individually or together. Your unit's social worker may be able to give information about possible referrals.



Siblings can also be affected by the early arrival of a new baby and may struggle to understand why the he/she has to remain in hospital after the birth.

Normal reactions for siblings include:

- Feeling mad, sad, or scared
- Feeling confused about why their brother or sister is in the hospital and why parents or caregivers are away from home
- Feeling afraid that they might also get sick
- Feeling left out or abandoned
- Feeling jealous about attention and/or gifts that their brother or sister is getting
- Worrying about being away from parents or caregivers
- Worrying about their brother or sister
- Not wanting to go to school
- Irritability or getting mad easily

How to help siblings

- Be honest with your other children about what is happening to their brother or sister in the hospital, in ways your children can understand.
- Try and help siblings keep up with normal routines and activities as much as possible, such as going to school, seeing their friends, and participating in sports and other activities
- Talk with siblings about a schedule for when parents or other caregivers are away from home



- Plan for making sure someone is always with them to provide care
- Make sure siblings know how to get in touch with parents and caregivers when they are away from home
- Reassure siblings that they did not do anything to cause their brother or sister's illness or cause them to be in the hospital
- Let siblings visit, call, write, or draw a picture for a brother or sister who is in the hospital
- Show siblings that it is okay to be upset and give them a chance to talk about their emotions
- Plan special time just for siblings, even if it is brief
- Help siblings figure out what to say when people ask about their brother or sister
- Let them be kids! Sometimes parents and caregivers need to rely on siblings for help around the house when their brother or sister is sick or in the hospital, but try to avoid having them take on the role of a parent. If possible, reach out to neighbours, friends, and family for help with practical needs.

Signs it might be helpful for a sibling to talk with a psychologist or other mental health provider for some extra support:

- Feeling sad or worried for a long time and this gets in the way of things like school, friendships, or other activities
- Refusing to go to school or getting in trouble at school
- Having a hard time focusing at school
- Not wanting to be with friends
- Not wanting to do activities he or she used to enjoy
- Continuing to be overly clingy and fearful of separation from parent

If you have questions about how to connect with help for siblings, please speak with the neonatal unit social worker.



Having a baby who is unwell can leave you feeling very low. Spending a lot of time in hospital and not knowing what will happen next can leave parents feeling very sad, overwhelmed and exhausted.

Depression can come in many forms, and can affect people in many different ways. You could, for example, feel very low for a period of time where you are struggling to cope with life on the unit, or when something in particular has happened.

This is a very common way to react to having an unwell baby, especially if you are also recovering from the birth.

Depression, however, is where this feeling doesn't pass with time, and begins to get in the way of other parts of your life. It could be that you feel like you can't cope with parts of daily life, your mood has changed, or you're behaving in a different way.

What is Postnatal Depression?

There is another type of depression called postnatal Depression, or PND. This is when depression starts after having a baby.

Parents who have a baby in a neonatal unit are more likely to suffer from postnatal depression.

It is usual for Mums to feel down after just having a baby. This is because the birth and first few days of a new baby coming into your life is a big adjustment to parents' lives. You often have less sleep and can feel overwhelmed by the change to your routine. This period of feeling low is often called the '*baby blues*'.

But postnatal depression lasts for longer than this and has a bigger impact on you.



Can partners also suffer from depression?

Whilst only Mums who have given birth can be officially diagnosed with postnatal depression, studies show that partners can develop depression after the birth of their baby too.

If you do think you are suffering from depression, it is important that you get help and support. Staff on the unit can help you talk about what options might help for you.

What is post-traumatic stress disorder (PTSD)?

When something happens to you which is hard to process and has a big impact on your life, it can feel very traumatic. You might find that you feel numb, find it hard to sleep, or find it hard to talk about what you've been through.

You might have some more intense feelings, like thinking you are living your experience again.

You may have vivid nightmares, or feel very anxious a lot of the time. It might be difficult to face the places or situations which you link with that trauma.

These symptoms can be very common for many parents on the neonatal unit, and are a normal reaction to a traumatic experience. Feeling these symptoms for a short amount of time is common, and won't usually be given a name or diagnosis. If you do talk to a professional about how you are feeling, they might call short periods of these feelings acute stress disorder, or ASD.

PTSD however is a condition which can be diagnosed from four to six weeks after the trauma you've experienced, if particular symptoms are not going away.

Some of these reactions to trauma are very common and can pass in short periods of time. PTSD is only diagnosed in people where those feelings are lasting for longer and having a bigger impact on their lives.

Speaking with your GP about your symptoms will help you to find the support that is right for you.



Who suffers from PTSD?

Parents who have a baby in a neonatal unit can suffer from symptoms of trauma or PTSD if they've had a difficult or traumatic birth. For example, giving birth unexpectedly much earlier than usual, or needing emergency procedures during or after birth.

These symptoms can also come about as a result of something very distressing that happens after your baby is born, i.e. if your baby requires surgery, needs to be resuscitated, is very unwell, or you are separated from them.

Being in hospital can also feel traumatic and very worrying for parents, especially if you are based in a hospital far away from your home.

Experiencing trauma can come from many different situations - what causes this response will be different for different people. If you feel you are experiencing trauma, whatever you have been through, it's important to get support.

It's not just Mums who have given birth who can suffer from symptoms of trauma or PTSD. Partners can also suffer with symptoms, especially if they've seen their partner go through a traumatic birth, or they've faced very difficult and upsetting situations on the unit.

When does PTSD happen?

Symptoms of trauma can happen quite soon after a traumatic experience - for example soon after your baby has been born. PTSD can be diagnosed from four to six weeks after the traumatic experience, if particular symptoms are not going away.

Sometimes, symptoms of PTSD can start later on, months or even years after what has happened to you. It is not unusual for symptoms to appear post discharge home from the neonatal unit or after a big milestone like a first birthday.

If you are experiencing symptoms of trauma which are not going away or are getting worse, and you think you might be struggling with PTSD, it is important that you get help and support. Staff on the unit, or your GP, can help you talk about what options might help you.



What is birth trauma?

Researchers are learning more about trauma, how it affects parents and what causes it. It is well known that birth and things that can go wrong during birth can be a big cause of trauma in parents giving birth and partners watching this.

If you are experiencing symptoms of trauma after your baby has been born, speak to your GP about treatment options.



Seeking Help

It may be that following some of the tips in this booklet will help you to face your challenges in a way which works for you, and helps you feel more able to come to terms with what's happened.

But sometimes people will be suffering from bigger changes to their mental health which need the support of a health professional. This can feel incredibly scary, and can make many parents worry that they will be seen as unfit or unable to care for their child.

Struggling with your emotional well-being or mental health does not automatically mean that you are not able to care for your baby. Health professionals know the importance of keeping families together, for parents and children.

If you feel that you or someone close to you needs help from a health professional, there are different options available to you.

Getting help ON the unit

If you are still on the neonatal unit, you can talk to one of the nurses if you feel comfortable doing so. They see you every day, and are aware of the stresses parents face and how important it is to support you too. They will be able to give you details of any counselling or psychological support available for you on the unit.



Some units will have psychotherapists, psychologists and/or psychiatrists available for you to talk to. Some of these roles can overlap, and many professionals might have experience in more than one field.

Psychotherapists can work with you to face and manage things you are finding difficult, such as anxiety.

Psychologists can suggest therapies and ways of approaching difficulties which might help you.

Psychiatrists are doctors who focus on difficulties with mental health, and can prescribe medication if needed.

Getting help OUTSIDE the unit

If support on the unit isn't available or right for you, you might want to make an appointment with your GP. They'll be able to talk through what you're experiencing, and suggest options which might help you, such as therapies, treatments or medication.

Will medication affect breastfeeding?

Many breastfeeding mums worry that being put on any medication might mean they're not able to breastfeed or express. If you are feeding your baby this way, talk to your health care professional and they will help find the best medication for you.



Post-Natal Depression Ireland

Tel: 021-492-2083

www.pnd.ie



Postnatal Depression Ireland

providing support & friendship to those suffering from Postnatal Depression

Aware

Tel: 1890-303-302

www.aware.ie



Parentline

Tel: 01 873 3500 or lo-call 1890 927 277

www.parentline.ie



Nurture Health

Tel: 085-8619585

www.nurturehealth.ie



www.inha.ie



Irish Neonatal Health Alliance



@irishneonatal



ineonatal



irishneonatalhealthalliance



Irish
**Neonatal
Health
Alliance**

INHA, 26 Oak Glen View, Southern Cross, Bray, Co. Wicklow.

The INHA is a registered charity under Section 39 of the Charities Act 2009 - RCN 20100100, CHY21984.