Powitalnik

the Gentle Welcome Guide
for Parents Facing Their Child's Diagnosis

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Dear Parent,

You have recently learned that your child may face particular health challenges. This may be one of the most difficult experiences of your life.

The difficulties may be the result of your child's premature birth or complications during labour and delivery. They may be caused by genetic factors beyond anyone's control. And sometimes, doctors can't yet explain the reasons behind the challenges your child is facing.

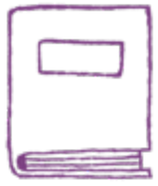
Perhaps the news about your child's special needs has come as a complete surprise. Or maybe you have known about the diagnosis for some time already.

You may feel joy at the birth of your child and look to the future with hope. Or you may feel as though your world has fallen apart.

Whatever your situation, you are now at a turning point in your life. And we want to be here with you. We want you to know that you do not have to face these new challenges on your own.

The aim of this “Welcome Guide” is to give you access to:

1. Psychological first aid, helping you work through the emotions that come with a diagnosis.



2. Clear information about your rights and the steps you can take to make use of them.

3. Practical tools for coping with stress and anxiety in difficult situations.

4. A safe space to learn how to care for yourself and for your relationships with your loved ones.

We hope that this guide will be a source of support you need right now. At any moment, you can share your needs and experiences with us – or simply let us know that you are reading our guide.

Just email us at: **kontakt@powitalnik.pl** and we will be there for you.

Warmly,
Mudita Association

A warm welcome

Dear Parents,

if you are reading this Guide, you are probably at the beginning of a journey that many others have made before. We do not yet know where this path will lead, but we hope to walk it together with you.

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The first days together

The birth of a child is a turning point in any family's life. It can be a time of great joy, but just as often it brings feelings of uncertainty, fear, and worry about what life with a new baby will be like. This may happen whether you are welcoming your first child or your fifth.

When it turns out that your newborn faces serious health challenges, all of these feelings can be much stronger, and the difficulties ahead of you can feel overwhelming.

If life after birth is very different from what you imagined, it is natural to feel surprised, disappointed, or even frightened. You may experience an array of difficult emotions – anger, fear, sadness, or grief – and it is important not to push them away. Every feeling matters. Every feeling may be useful. They are part of the process of adjusting to a new reality.

The first weeks after a baby is born bring change to every part of family life. **The biggest changes – hormonal, physical, and emotional – happen to the mother (but fathers also go through their own journey as they welcome their child into the world!)**. After birth, a woman's body experiences a sudden drop in the hormones progesterone and oestrogen, which had helped sustain the pregnancy. This hormonal shift, together with the challenges of a new role, is what causes the so-called "baby blues" – feelings of sadness, low mood, and anxiety after giving birth. Did you know that up to 80% of mothers experience this, even if only for a short time? Added to this, tiredness, lack of sleep, feeding difficulties, or problems with milk coming in can make you feel drained or even wish you could run away – despite the joy of having your baby here. These feelings can be even more intense if your child is facing health challenges.

Everything you are feeling right now is completely natural. However, if sadness and anxiety last for more than two weeks, your mood continues to get worse, or you notice worrying signs – such as feeling indifferent to your baby's needs or being unable to manage daily tasks – it is important to seek help from a professional, such as a psychologist or psychiatrist. These may be symptoms of postnatal depression, which is an illness that requires proper treatment.

It is estimated that about 15% of mothers experience postnatal depression.

When risk factors are present, such as health complications in the newborn, this number can rise to as much as 30%.

Postnatal depression, though less common, can also affect fathers.

In this very challenging time, pay close attention to how you are feeling. If you notice any concerning symptoms, reach out for professional support.

Worries about the future

You may be wondering what the future will look like for your child. You might have many fears. Perhaps your baby is not even with you right now, and you are waiting for the moment when you can finally hold them in your arms. This separation can be very hard.

You might be asking when you will be able to go home. You may be longing for that moment – or you may be afraid of it. After all, here in the ward there are so many specialists watching over you. What will it be like when they are no longer there?

Perhaps you are facing the hardest questions of all – will my child live? Will it be possible to ease their suffering? You have every right to ask yourself and others these questions. You have every right to feel sad or frustrated that you can't have all the answers right now.

What will the next few days be like? And the years to come? The truth is, in these earliest days of a baby's life, we rarely know. From our experience, the development of children who have had a difficult start around birth can be very different. Some children who receive a serious diagnosis at birth go on to develop much like their peers. Others face more challenges along the way.

Remember that medicine is advancing at an incredible pace. Conditions that not long ago were considered untreatable can now be managed successfully. That is why it is best not to look too far ahead. Instead, try to be in the present moment. Remember – your child is not only someone they will become in the future. Healthy or ill, fully able or with disabilities… They are already here. Take time to look at them calmly. You may notice something that fills you with wonder and makes you want to smile with pride. You may also feel the weight of loss and want to cry. Let yourself do that.

As more tests are done, you will usually receive recommendations for further medical consultations or rehabilitation to follow after leaving the hospital. These recommendations are, of course, important. But what your baby needs most is tenderness. **Remember that you are, above all, parents – not therapists. And your little one is, above all, a child – not a patient**. Give yourselves time to get to know each other and to build your bond. Whatever happens, your relationship will be the most important foundation on which you build your future together. Your child may need many hours of treatments, therapy, and exercises. But more than anything, they need your love and acceptance. In this, you will always remain the best specialists for your child.

Although there are many unknowns ahead, there are some things you can take care of right now. **Most importantly, make use of the support available to you**. You will need it to get through the coming days of tests and diagnoses, through conversations, examinations, and decisions – through moments of happiness and moments of doubt. In many hospital wards, it is possible to arrange a meeting with a psychologist. We encourage you to take this opportunity. Such a conversation can give you a safe space to let out all your emotions – to cry, to release tension, and to gather strength for the days ahead.

Staying in hospital

When your child has health challenges, it often means stepping into a world of clinics and hospitals you may have never known to exist before. During this time, you may hear many medical terms that sound unfamiliar. You may have to make decisions about tests or procedures you have never even heard of before. All of this can be stressful.

You will probably have many conversations with doctors. Some of these talks may be difficult, unsatisfying, or leave you feeling uncertain and confused. **Remember – as your child's legal guardian, you have the right to full information about their health, explained in a way you can understand.**

- A good way to make sure you have understood a piece of information is to repeat it back in your own words and ask if you got it right. When emotions are running high, it is easy to misinterpret what we hear, especially if it is given too quickly.
- You do not have to ask every question right away. You can always go back to the doctor later if new doubts or concerns arise.
- It is helpful to write down the information you get from doctors, nurses, or midwives. You can look back at your notes later, on your own or during another meeting with the medical team.

Medical staff should treat you and your child with respect, care, and empathy. However, it is common for stress, workload, or fear of responsibility to get in the way. Sometimes, staff simply have not been trained in how to communicate well with parents. This is usually not out of bad intentions, but because they may not realise how much their words can affect you.

What can you do if this happens? Often, an honest conversation helps – agreeing together on the way information will be shared that works for both sides. In the end, everyone wants the same thing: the health and wellbeing of the smallest patients and their families.

If you feel that the behaviour of medical staff clearly violated your or your child's dignity, do not hesitate to report it to the proper authorities. You can call the free national Patient Information Helpline at 800-190-590 and speak to staff from the Office of the Patient Rights Ombudsman. The helpline is open Monday to Friday, from 8:00 to 20:00.

Separation from your child

Your child's treatment plan will always be tailored to their individual needs. Some children require intensive therapy, which can sometimes limit physical contact with you for a while. As a parent, your natural instinct is to hold and comfort your baby. Sometimes, though, weeks can pass before parents are able to hold their child.

In hospital units where the focus is on saving the lives of very sick children, there are many rules. These rules can be hard to understand, and in such a difficult situation, they may even feel unfair. It is important to know the reasons behind these rules. Do not be afraid to ask questions if something does not make sense to you. The doctor caring for your baby should explain everything.

Even if your baby can't be touched, ask the staff about safe ways to let them know you are there.

Every form of closeness matters and has a positive effect – both on you and on your baby.

Feeding your baby

Breastfeeding isn't always easy, especially when your baby is unwell.

Sometimes, even during intensive medical care, you can keep your milk supply going. Offering your baby your milk in those moments can give you a sense of strength and closeness – and it can be healing for both of you.

But sometimes, stress leaves a mother without the energy for this effort. Your body knows what is best for you and will not take on a challenge it can't meet. If breastfeeding is not possible, try to accept this and remember that there are many ways to provide your baby with nourishment.

Depending on your baby's health and abilities, they may be fed intravenously, through a feeding tube, with a bottle, or with milk from a Human Milk Bank. This milk is carefully tested and comes from donors, and is an emergency supply for situations when the mother's own milk is not available or there is not enough of it. If you choose to feed your baby your own milk, you can get help from lactation consultants, available in many hospitals. They can guide you in choosing the right breast pump, keeping yourself comfortable during milk engorgement, and establishing milk supply in line with your baby's needs.

I want you to know, dear Mum, that whatever your own "milk journey" looks like, you are giving your precious baby as much as you can.

Will everything be "okay"?

Parents who are facing their child's diagnosis often hear well-meant words from family, friends, or medical staff: "It's going to be okay." For many, this feels like their child's serious condition – and their own fears – are being dismissed.

I admit, though, that I too sometimes want to say those simple words. Not because I believe your child's development will definitely be typical or that all your problems will disappear – I don't know that. I trust it's going to be okay because, whatever your future looks like, you will find a way to live with it and you will still experience joy.

I believe it's going to be okay because, on the path you have found yourself walking, you will meet many wonderful people – including other parents, like me – who will stand beside you in hard moments.

Although it may seem impossible right now, this time will pass, and you will live through it. In this race – with time, with medicine, with your own sense of helplessness – there is really only one goal: to love. To give your child love, no matter how long they are with you, what abilities they will have, or what kind of future awaits them.

We are here to walk that road with you.

With a warm embrace

Emilia Więcek
Midwife, mother of four children, including seven-year-old Kazik with cerebral palsy

"I used to get very upset when people around me told me I had to be strong. When I cried, when I wanted to share my doubts or simply say how I felt, I was always told I had to be strong for my son – brave, not crying, never giving up, a heroic mum.

Looking back, I think what I missed most was space for my tears – permission to shout, to be angry, to feel rage and frustration. A chance to express all those negative emotions that are completely normal in such a situation."

"At the beginning, it's important to be patient and persistent. First, remember to take care of yourself so that you have the strength to keep going. Second, if one doctor says things look bad, it doesn't mean it will always be that way. And third, trust your instincts – they will tell you if you are in the right hands."

"You have the right to receive medical information in a way you can understand. A doctor is not a god and has no right to dismiss you. Doctors are required to follow laws and procedures – they are not doing you a favour.

There are excellent doctors out there – stick with them and appreciate the good specialists. Those working in the public system are often paid very little. If serious mistakes are made, you have the right to make a formal complaint."

"Your child is simply a child. Nothing more, nothing less. Your child is not their disability, their genetic condition, or their illness. None of these can impact their humanity."

"What matters most? To love as deeply as you can."

Psychological first aid

Learning that your child has health challenges can bring up a mix of strong and difficult emotions. It’s worth taking a calm look at them and seeing what they might be telling you.

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The arrival of a baby born prematurely, or facing a serious illness or disability, is something almost no one is prepared for. You do not know what the future will look like, how to arrange family life so there is space for new challenges and responsibilities, or how to talk to your loved ones about what is happening. Sometimes you can't even tell what you might think or feel. You wonder what is "normal" and what is not. Depending on your past experiences, beliefs, and resources, you may cope with this demanding time in different ways.

That's why we invite you to take a gentle and compassionate look at the emotions that may arise after receiving a diagnosis, and at the different ways of expressing them. We will also give you a few ideas on how to care for yourself and your relationships in this turning point in life.

First emotions

In the first days after learning about your child's health challenges, you may feel a whole range of emotions. You might feel joy and pride, but also sadness, anger, fear, or disbelief. You might be filled with happiness and hope – or you might feel fear and a desire to run away. You might want to disappear, or turn back time by a few days or months. You may even feel a number of these emotions at the same time.

Sadness Often appears when you have made a great effort but lost something – or someone – important. When you are sad, you often have less energy to act. It can also be harder to feel pleasure or satisfaction. Sadness helps your body save energy for the new challenges ahead. It is also an emotion that brings the most compassion from others, by helping to show those around you that you need support.

Anger Shows up when your most important needs are not being met. It makes your heart beat faster and your muscles tense, preparing you to fight for what matters – your child's wellbeing, a moment of sleep, or someone's presence.

Fear Signals that you feel threatened. It tells you that you may need more time, more information, or more support from others to face what is happening.

Allow yourself to feel every emotion that comes, and try to understand the message it carries. Treat yourself with the same gentleness you would offer someone close to you in such a demanding situation. Remember that the emotions you feel now will not stay with you forever – they will shift, calm down, and eventually pass.

Every emotion you are feeling right now is normal – and it is helping you adjust to the new situation you are in.

Remember that caring for yourself is essential if you are to care for your loved ones.

Don’t hesitate to ask for help – and to accept it. Say yes when someone offers to bring you a warm meal. Ask a friend or family member to stay with your baby, or to be on call, so you can get some rest.

With the support of others, you will have more strength to face the challenges that may come your way.

Grieving the future you hoped for

When you learn that your child is facing serious health challenges, you might feel a sense of grief. This is a natural emotional response to losing the future you once imagined.

This grief concerns the plans, hopes, and pictures you once had. You may have imagined what your child would be like, how they would be part of your family, and the things you would do together. Now, you may feel that none of this will happen.

Of course, you can’t predict what the future will actually bring, or whether your fears will come true. But right now, you are feeling a sense of loss – and this is a completely natural experience, shared by many other parents.

Just like any grief, losing the expected image of your child or family can include the following stages:

1. **Denial – shock**

- In the first moments after a perceived loss, many people feel shocked. They may block out the truth of what has happened and deny that there is a problem.

- Some people withdraw from others and feel frozen – unable to move or feel anything. Others, in contrast, may experience a burst of energy caused by adrenaline. They may throw themselves into countless activities to distract themselves from the difficult reality. For example, they might consult an endless list of specialists, hoping that one of them will finally say what they want to hear.

- Shock can also trigger many physical reactions. Some people may have trouble sleeping or lose their appetite, while others may sleep more than usual or feel constantly hungry. Each body reacts differently to unexpected challenges.

- Thoughts that may appear at this stage include: “The doctors must be wrong; I need to find another specialist”, “I need to renovate the kitchen now. I’ll think about what the doctors said later”, “I keep forgetting about the diagnosis, and it feels strange.”

2. Anger – looking for someone to blame

- When it becomes impossible to continue denying the facts, you may feel anger or even rage. You do not want to follow the scenario that has been handed to you, so you begin a fight with reality. The human brain, when faced with a challenge, triggers a natural “fight or flight” response.

- Since physical escape is usually not possible, you may instead burst out in anger and look for someone to blame – often turning against yourself or your loved ones. Sometimes, the parents argue more frequently with each other during this phase, blaming one another for the situation. They may also try to find culprits outside the family – doctors, employers, or their own parents. Some people treat the child’s illness or disability itself as an enemy and declare war on it, focusing on finding the perfect therapy that will restore the child’s full health and abilities.

- Thoughts that may appear at this stage include: “It’s because I ate fish during my pregnancy.”, “It’s my boss’s fault for giving me too much work”, “Everyone in my family was healthy. The fault lies with my partner”, “I didn’t want to have a child, and this is the consequence.”

3. Bargaining

- At this stage, you hold on to every possible source of hope. You become resourceful, full of energy to act and to change things.

- Many people become open to any suggestion for treatment, even those that go against medical knowledge or are discouraged by specialists – just to get a promise that their child’s condition will improve. Others may take on excessive responsibilities, such as hours of therapy each day, following a strict diet while breastfeeding, or keeping the home perfectly clean, believing that doing so will improve the family’s situation.

- Thoughts that may appear at this stage include: “We’ll find the best hospital and they will fix everything”, “If I do five hours of rehabilitation with my child every day, everything will go back to normal”, “If my partner spends all their time calling experts, we will surely find an effective treatment.”

4. Depression – disorganisation

- When the steps you take do not bring the results you hoped for, the next necessary stage of grief arrives – a time of deep pain and emotional disorganisation.

- Many people withdraw from social relationships and from their usual activities. This can be due to low energy and the need for rest after the intense effort of the earlier stages.

- At this stage, some symptoms of depression may appear: a sense of helplessness, negative thoughts about oneself and the world, and overwhelming fear about the future.

- Thoughts that may arise during this period include: “We won’t manage”, “It would be better if we died”, “This is the end of the world.”

5. Acceptance – reorganisation

- Accepting what is happening is the beginning of healing. You face the truth about your situation and can once again take control of your life. Acceptance is also the starting point for creating a new version of yourself.

- By embracing the change that has taken place in your life, you can find new sources of meaning, strength, and security. You may notice possibilities that once seemed out of reach. You may recognise people around you with similar experiences, ready to offer help. If some of your earlier relationships did not survive the crisis, you can form new connections and build other support networks.

- Thoughts that may appear in this stage include: “I have people around me I can rely on, who will help us through this time”, “It’s just an illness. Our world has not ended”, “My child has many wonderful qualities beyond their disability.”

Acceptance usually comes only after you’ve given yourself time to move through the earlier stages. The grieving process can take months or even years. Acceptance is called the last stage, but it’s not final. You may return to earlier stages at different points in your parenting journey. This often happens at important moments – such as your child starting school or facing new challenges related to their needs. Every life includes periods of peace, growth, and crisis. Knowing this can help you keep hope, even if you find yourself feeling anger or sadness again.

Remember, the grieving process looks different for everyone. Not everyone will go through all the stages described here. Some stages may last longer or shorter, and their intensity may vary. Your own story will depend, among other things, on the resources you have: your social support networks, access to professional help, your temperament, and your situation before your child was born.

If you feel that a stage of grief is lasting too long, or is especially hard for you, it’s worth seeking help from a professional – a psychologist or psychiatrist.

Depression

Sometimes, the natural stage of grief that brings sadness and low energy can, over time, turn into full depression that needs medical support. It can be hard to tell when ordinary sadness ends and a serious illness begins, requiring treatment.

A key sign is how intense your distress is and how long it lasts.

Possible symptoms of depression may include:

- mood changes during the day (often feeling worse in the morning and a bit better in the evening)
- anxiety, constant tension, and ongoing worry
- lack of energy, feeling permanently tired
- loss of interest in things you used to enjoy
- no sense of satisfaction or pleasure in life
- low self-esteem, lack of confidence in yourself
- sense of guilt
- problems with memory and concentration, slowed-down thinking
- difficulty making decisions
- withdrawing from friends and loved ones
- loss of appetite or increased appetite (leading to weight loss or weight gain)
- trouble sleeping or sleeping too much, waking up often at night
- being overly sensitive to sensory stimuli
- difficulty with daily tasks, including caring for your child
- monotone voice, reduced facial expressions
- doing things mechanically, as if on “autopilot”
- reduced sex drive.

Some people experience what is called masked depression. This is a type of depression in which symptoms appear that are not usually linked with low mood.

Common “masks” of depression include:

- chronic pain in different parts of the body
- tingling sensations
- changes in the menstrual cycle
- nausea
- restless legs syndrome
- dizziness
- panic attacks, shortness of breath
- vision problems
- angry outbursts
- compulsive behaviours (e.g. overeating)
- tendency to take risks.

If you notice these or similar symptoms that make your daily life harder and last for a long time, we encourage you to speak with a psychiatrist. Remember – today, there are many effective ways to treat depression. You do not have to live with it.

Where to find help:

Crisis Helpline
Run by the Institute of Health Psychology of the Polish Psychological Association
https://116sos.pl/
Tel. 116 123

GO TO THE WEBSITE

Sources of strength

Your thoughts and the emotions you feel now do not define the future – – for you or for your child. Just as a cough or fever are normal signs of a common cold, even the hardest feelings are a natural part of a life crisis.

You do not need to hold on to what you are feeling right now, or feel guilty if your emotions are different from what you would like them to be (or from what others expect of you). Feelings such as anger, joy, sadness, and disappointment come and go. Let them.

All your feelings are real and valid – but in a crisis, it is easy to feel alone or to believe you do not have what it takes to face new challenges. Often, this is not the truth. The skills, talents, and knowledge you had before your child was born are still your strengths – and they can help you face today's difficulties.

However, your resources are likely stretched thin right now. One way to understand this is through a metaphor: imagine that every person carries inside them a cup filled with a special mixture of strength – enough to get them through each day.

This "mixture" is made up of many different needs being met:

biological – enough sleep, being well-fed, being free from pain,

emotional – feeling safe, peaceful, or joyfully excited,

sensory – a comfortable room temperature, no excessive noise, a pleasant view and smell,

intellectual – getting the amount of information you need to satisfy your curiosity, without being overwhelmed by too much,

social – supportive relationships with others, touch from loved ones, and time for conversation,

self-acceptance – a sense of your own strength, worth, and ability to make a difference.

It is easy to see that when a child is diagnosed, almost all the ingredients in your “cup of strength” can run low. It can be hard to get enough sleep, keep up with relationships, or feel positive emotions in the middle of a crisis.

For your health and wellbeing, it is important to keep refilling your cup of strength – even in this demanding situation. As much as possible, take care of your needs, starting with the simplest (like drinking water or going to the toilet), and moving on to more complex ones.

It may sound like an over-simplification, but when we are fed, rested and surrounded by beauty, we have more resources to face the challenges ahead.

Make time for activities that help you feel better. Take care of both your body and your mind – remember to eat well, move your body, take breaks, and enjoy small pleasures like reading or a long bath.

Find moments for activities that boost your mood by increasing your body’s natural “feel-good” chemicals:

- Social connection (oxytocin)
- Physical touch with someone close (oxytocin)
- Massage (oxytocin)
- Sunlight and time in nature (serotonin)
- Meditation (serotonin)
- Physical activity and sport (serotonin)
- Celebrating small successes (dopamine)
- A varied diet rich in vitamins and minerals – especially wholegrain bread, nuts, vegetables and raw fruit.

Caring for yourself is not selfish – it is an act of responsibility that gives you the strength to live and to care for others.

Support networks

To function well, you need to feel that in the face of new challenges you are not alone and can always count on help from those around you. The more extensive your family’s support network, the greater the chances of effectively managing the difficulties you face. **Research shows that the amount of support received from others has a significant, positive impact on parents’ satisfaction with their new role and their sense of competence.**

Sources of support can include:

- **close relationships:** partner, family, friends;
- **social environment:** neighbours, colleagues, religious community;
- **professional psychological help:** psychologists, psychiatrists, psychotherapists, therapy groups;
- **state institutions:** healthcare, social services, schools and preschools;
- **non-governmental organisations active in the relevant area:** associations, foundations, informal activist groups;
- **peer support groups for people in a similar situation,** e.g. Facebook groups for parents of children with disabilities, children born prematurely, or children with a specific condition.

Taking a little time to map this out could reveal more options than you expect. Keep in mind that just finding the right contacts and resources can take time and energy, so if you can, ask friends or relatives to help you build your network. Together, you could put together a list of useful contacts – specialists, institutions, and organisations – that could offer help, information, and experience, both in daily life and in times of crisis. This list could be as simple as a private Facebook group or a shared chat thread.

When facing major challenges and intense emotions, you may feel that your surroundings are not offering the kind of support you expect. Often, this is not due to ill will, but rather to a lack of understanding of your needs and how to respond to them. Naturally, you can't control what your family, friends, or doctors are able to offer you. However, the more clearly and confidently you express what you need, the greater the likelihood you will receive it.

Your newborn baby

The way parenthood – especially motherhood – is often portrayed in the media and popular culture suggests that the moment your baby is born will be filled with overwhelming joy and instant love. In this picture-perfect version, parents step into their new role with ease, and simply having the baby is seen as the ultimate reward for all the pain and effort.

Real life can feel very different. The birth of a child can bring a mix of emotions – from excitement and fulfilment to uncertainty, resentment, or even the wish to run away and go back to your old life. None of these feelings mean anything is "wrong" with you – they are a natural response to a huge change and the challenges it brings.

Science shows that in the first weeks after birth, both mothers' and fathers' (!) brains are flooded with hormones. Some of them help you pick up on your baby's needs and give you extra stamina, while others can leave you exhausted or emotionally unsettled. It is normal to swing between joy and fear, confidence and self-doubt, unconditional love and moments of detachment. Hearing that your baby may have health problems can put even more strain on your mind and body, making those ups and downs all the more intense.

Still, your baby's diagnosis does not define who they are. Above all else, they are a tiny human who needs to feel safe, loved, fed, and rested. You may not be able to change their health, but – and this might surprise you – that is not the thing they need most from you.

The most important thing for any child's development is to feel loved and accepted.

What will help your child most in facing the challenges of their health condition is knowing they are loved and accepted.

- Every child – even one living with a serious illness or disability – has unique qualities that go beyond their diagnosis.
- Try to notice and value these qualities.
- Think about how you can let your child feel your love (even if you can't yet hold them).
- What do you want them to know right now? Could you write a letter, record a short video for the future, or make an audio story they can listen to when you're not there?

Older siblings

If you have older children, it is natural to wonder how they will cope with the arrival – and diagnosis – of a younger sibling. Like adults, children need to feel they are not facing their challenges alone. **In fact, research suggests that their emotional struggles often come less from the situation itself and more from feeling isolated in it.**

Make it a priority to spend a few minutes each day in relaxed conversation or spontaneous play with your older child(ren). Give them your undivided attention, letting them feel, even briefly, that they are at the centre of your world. These small moments can make a big difference in how they adjust to the new reality.

Older siblings have a lot to navigate. They need to find their new place in the family and may also be dealing with a mix of emotions – worry about their sibling's health, concern for you, or frustration that they are not getting as much time together as before.

- Let them express whatever they are feeling, even if it is hard to hear.
- Create a safe space where they can talk openly or show you what is on their mind.
- Share age-appropriate stories from your own life about situations when you felt similar emotions.
- Keep these stories encouraging rather than heavy – the aim is to show them that their feelings are normal, not to hand them over your own worries.

- Explain to your older child, in a way that makes sense for their age, what is going on with their younger sibling – for example, that you might be away from home more or visiting doctors more often. Reassure them that their sibling is safe, cared for by doctors, and surrounded by love.

It is normal if you find it hard to talk about things you are still processing yourself, or if the diagnosis isn't yet clear and you don't want to give too much detail. In those moments, keep it simple and honest. You might say: **"Your brother/sister might have some health problems. That makes me feel sad and tired sometimes, but we are doing everything we can to help. They are part of our family, and we always look after each other."**

Keep reminding your older child how much they mean to you: **"No matter what is happening, I love you just as much as ever. What you're going through matters to me. You can always tell me what you need or how you feel. I still want time with just you, and I'll do my best to make that happen. It's okay to have hard feelings – and I want to hear about them."**

- If they ask for your attention when you are in the middle of something important, agree on a time you can be together – and make sure you stick to it.

- Small, predictable rituals can also help, like reading a bedtime story (even over the phone from the hospital), leaving little notes for them to find, or giving them a warm hug before you leave the house.

- If you can, aim for at least an hour each day where your attention is fully on your older child – just the two of you. But don't beat yourself up if that's not always possible or if you simply don't have the energy right now.

It can take time to figure out a new daily routine. Let your child's preschool or school know about your family's situation and ask for understanding if your child shows strong emotions or unusual behaviour. At the same time, protect your family's privacy – you can ask teachers not to share what you've told them with others, including your child's peers.

If you are unsure how best to support your child, consider talking to professionals or other parents who have been through something similar. Children's books can also be a great starting point for conversations about topics like illness, disability, sadness, or anger.

Research shows that simply having a sibling with special needs doesn't, by itself, harm a child's wellbeing. In fact, children in such a situation often develop a stronger sense of trust in their family, a clearer understanding of the help available in difficult times, and a deeper bond with their loved ones.

If you and those close to you make sure your older child feels unconditionally loved and seen, their sibling's illness won't take away from their happy childhood.

Your relationship as a couple

Learning that your child has special needs can put a serious strain on a relationship. Some couples navigate this experience relatively smoothly. Others face a deep crisis, which they may emerge from stronger and more connected. Some relationships, however, do not survive. If keeping your partnership strong matters to you, it's worth giving it attention during this demanding time.

First, try to see your partner as more than just a co-parent focused on caregiving, scheduling, or therapy.

Just as your child's medical challenges do not define their worth, these challenges do not have to define your romantic relationship. Amid daily tasks, hard decisions, and painful moments, make an effort to notice again the person you once fell in love with – the man who drew you in, the woman who captured your attention – and show them that the love and fascination are still there.

Second, try to understand what your partner is feeling and thinking right now. If one of you is still in denial about the diagnosis while the other has already accepted it, disagreements and tensions can arise. Good communication skills, awareness of the common emotional reactions to a crisis (including the grieving process), and outside help – such as from a psychologist, sex therapist, or couples counsellor – can all make a difference.

It is not often discussed, but some couples actually report greater satisfaction in their relationship after their child is born and diagnosed with special needs.

Research shows this can happen, and certain factors seem to make it more likely:

- finding shared goals and a sense of meaning,
- noticing and valuing each other's efforts,
- communicating with empathy – speaking from your own perspective ("I feel upset when…") rather than blaming ("You are…"),
- making time just for the two of you,
- keeping up small rituals you enjoy together,
- caring for physical affection, intimacy, and your sexual connection.

We hope the information above helps you navigate the emotions that can come with your child's arrival. In the next sections of the "Welcome Guide", you will find practical tips and exercises to put this knowledge into practice for yourself and your family.

- The chapter "Stress relief toolkit" offers techniques for easing strong tension and anxiety.

- The worksheets provide ideas for caring for yourself, supporting siblings, and nurturing your relationship with your partner.

- The booklet "Notes for Family and Friends" gives your friends and family practical advice on how to be there for you in the months ahead.

Remember, accepting help isn't a weakness – it can make challenges easier to face and leave you with more strength for the road ahead.

Olga Ślepowrońska
psychologist

"Hearing my daughter's diagnosis was both heartbreaking and a relief – at least I finally knew what we were dealing with."

"When the diagnosis came, my whole world collapsed. What did I feel? Shock and disbelief. A deep sense of unfairness. I had no idea what lay ahead. To me, disability felt like the end of the life I had known."

"We got the diagnosis on the third day after birth. It was a shock – we felt like we were in some kind of film. Waiting for the genetic test results was one of the hardest parts."

"I felt so much sorrow that this was the fate he had been given. I was afraid he wouldn't survive."

"Getting the diagnosis confirmed was a relief – we finally knew what steps to take."

"The diagnosis was both an ending and a beginning. Looking back now, I'm grateful for that moment and glad we learned the cause of our son's problems. Yes, it was an incredibly hard moment – one of the hardest days of my life. Thousands of thoughts raced through my mind: tears, grief, doubts, thoughts like 'I'm not cut out for this, I can't do it,' and even 'I wish I didn't know'... and so on."

"It was a huge shock, and I couldn't believe it. I kept hoping there had been a mistake, especially since the first test came back fine. Then came the grief, sadness, despair, emptiness – a kind of mourning for the healthy child I had thought I had. Everything felt overwhelming, from pumping milk to leaving the house and making it to the hospital. At first there was shock, tears, despair, and collapse. Later came defiance, a fighting spirit, and stubbornness"

"If I could speak to myself back then, I'd say: give yourself time to feel what you're feeling. Cry it out. Let yourself grieve. Don't blame yourself – even though that's the hardest part for me. Try to look after yourself and your family so you don't miss too many precious moments with your other child. And I'd tell myself: 'I'm proud of you."

"For me, it's important not to fall for pseudoscientific 'therapies' – they'll only waste time and money that could be spent on something more meaningful or enjoyable. And yes, you can vaccinate your child without worry. If the doctor doesn't recommend it, there's no need for any special diets. I know this is hard right now – that's a normal stage. If you can, look for support from a therapist. And if it ever gets too much, don't be afraid to see a psychiatrist – because if it's depression, it can be treated effectively."

"Let's not forget that we are the parents – not doctors, offices, physiotherapists, teachers, psychologists, or speech therapists. We are mum or dad, and we can't lose sight of that. Let's play, hug, rock, laugh, and do all the things we would do with a healthy child."

Stress relief toolkit

Facing a child’s illness naturally stirs up a storm of difficult emotions. Sometimes these feelings can become so intense that it feels impossible to cope.

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The exercises below are designed as a kind of emotional first aid – something to reach for in moments of high stress, anxiety, or anger, whether triggered by your current situation or other challenges you may be facing.

Here's a selection of simple exercises to help you ease stress and work through the emotions you might be feeling right now. You don't need to try them all at once – choose the ones that feel most helpful and suited to your needs.

If you find that a particular practice works well for you, make it a regular part of your routine.

A moment to breathe

Your breath is one of the simplest tools you have to steady yourself. It's always with you, and when you learn to use it well, it can help you feel calmer, more focused, and more in control – whether you're dealing with an everyday challenge or a real crisis.

Here are a few things worth knowing before you start:

- Breathing through your nose is healthiest – it filters, warms, and moistens the air and naturally encourages your diaphragm to work as it should.
- When you are stressed, your breathing often becomes fast and shallow, your muscles tense, and your body gears up as if in the face of danger.
- When tension becomes chronic, "stress breathing" can turn into a daily habit – quick and shallow, draining your energy, exhausting your body, and intensifying stress.
- Slowing your breath down and letting it deepen signals to your body that you're safe. It helps your nervous system settle and gives your body a chance to recover.
- Paying attention to your breathing is a simple way to clear your head and manage your emotions.

1. Rescue exercise

Adapted from the Buteyko breathing method.

If you feel so stressed or angry that it's hard to function – or you sense a panic attack coming on – this exercise can be a quick lifeline.

It's a simple cycle of holding your breath briefly, then returning to normal breathing. After you exhale, pause your breath for three seconds, then breathe normally for ten seconds. You can use a watch or your phone's stopwatch.

1. Sit in a comfortable position with your back straight, as if you're gently lifting the top of your head toward the ceiling.
2. Breathe in and out through your nose at a normal pace.
3. After the exhale, pinch your nose shut with your fingers and hold your breath for 3 seconds.
4. Release your nose and breathe normally through it for the next 10 seconds.
5. Repeat: inhale and exhale normally, hold for 3 seconds, then return to normal breathing for 10 seconds.

Keep going until you feel calmer. If 3 seconds feels too easy, you can stretch the hold to 4 or even 5 seconds – but no more.

2. Diaphragmatic breathing (360° breath)

This type of breathing sends air deep into the lower part of your lungs, around your lower ribs, where blood flow is richest. Here, your diaphragm – the main breathing muscle – does most of the work. It's a proven way to calm the stress response while safely oxygenating your body.

1. Sit comfortably with your back straight and your shoulders relaxed.
2. Breathe slowly and evenly.
3. If you can, make your exhale slightly longer than your inhale.
4. Rest your hands on your lower ribs to feel the movement.
5. As you inhale, notice your lower ribcage gently expanding outward and to the sides.
6. As you exhale, feel it draw back in.
7. Let your breath move in all directions – front, sides, and back – like a soft 360° expansion.

Stay with this mindful breathing for at least 5 minutes.

3. STOP breath

Adapted from an exercise by Elisha Goldstein.

Your breath is always there for you – a built-in anchor you can use anytime to come back to the present moment. This exercise is a simple way to pause when the to-do list, incoming information, or racing thoughts start to feel overwhelming. By pausing for a single mindful breath, you give yourself a little space between what's happening around you and what's happening inside. In that space, it's easier to choose how you want to respond to what's going on.

S

Stop
Pause whatever you're doing for just a moment.

T

Take a breath
Pay attention to your inhale and exhale. Take a few slow, steady breaths. You might quietly say to yourself "inhale" as you breathe in, and "exhale" as you breathe out.

O

Observe
Notice what's happening right now – in your mind, your emotions, and your body. Are there any feelings present? Any thoughts looping in your head? Is there tension, pain, or maybe a sense of ease somewhere in your body? Accept whatever you notice without judgement.

P

Proceed
Return to what you were doing, or move on to something else, now with greater awareness of how you're feeling and what you need. Ask yourself: "Is there something I can do, right now, to support myself?"

Diaphragmatic Breathing (360°)

keep your exhale slightly longer than your inhale

breathe slowly and calmly

as you inhale, let the lower part of your ribcage gently expand outward

relax your shoulders

your ribcage should expand evenly in all directions (360°)

STOP Breath

STOP

Stop

Take a breath

Observe

Proceed

You can cut out these graphics and place them somewhere you'll often see – on the fridge door or by the mirror – as a reminder of the value of one deep breath and a short pause in the middle of a busy day.

Staying connected with the world

In a crisis, it’s common to feel overwhelmed by intense emotions and racing thoughts that make it hard to rest or think clearly. You may get caught up worrying about the future, imagining worst-case scenarios, and running through an ever-growing to-do list for today, tomorrow, and the week ahead.

Grounding is a technique that helps bring you back to the present moment, giving you a sense of safety and stability. This practice can be useful no matter how you’re feeling right now. Simply move through each step slowly. It can help you handle what’s happening now as well as challenges that may come later.

If you can, do this exercise in a quiet space.

1. Sit up straight. Close your eyes to focus more deeply, or rest your gaze on one fixed point.
2. Take a moment to notice how you’re feeling.
3. Let your breathing ease. Breathe in and out through your nose.
4. Slowly stretch your arms out to the sides or above your head, or press your palms together. Notice your body settling.
5. Become aware of where you are. Look around with curiosity.

6. Name five things you can see.
7. Name three things you can hear.
8. Take a breath and notice the air you're breathing. Is it cool or warm? Fresh, dry, or damp?
9. What scents can you pick up in the air?
10. Notice where you are and what you're doing right now.
11. Reach out and touch something nearby. Feel its texture with your fingers.
12. Stretch your body: your arms, legs, or back.
13. Notice that even when difficult feelings or thoughts come up, you're still surrounded by a world you can see, hear, smell, and touch.
14. Notice that everything you do, say, and how you do it has an impact on the world around you.
15. Now, take a moment to check in with how you're feeling.

Based on the "Grounding" exercise from the publication "Important Habits in Times of Stress: Illustrated Guide", published by the World Health Organization.
The guide is available online at: **https://iris.who.int/handle/10665/331901**

Mindfulness

One way to manage stress is to fully focus on whatever you're doing at the moment – no matter what it is. Even a tedious or uninteresting task can become satisfying when you give it your full attention. By practising mindfulness, you can make your everyday life feel richer and more rewarding.

If possible, try this exercise in silence. You can ask someone to read the instructions aloud to you, or read them yourself.

1. Prepare a bottle or glass of water, coffee, or tea.
2. Sit upright.
3. Pick up your cup or glass and look at it with the curiosity you might have if you were seeing it for the very first time.
4. Notice its shape and colour, and the texture of its surface. Observe how the light passes through it or reflects off it.
5. Touch the surface with your fingers and pay attention to how it feels. Notice its weight in your hand.
6. Gently move the cup or glass and watch how the liquid inside shifts. Notice the patterns that form on the surface.

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7. Bring it close to your nose and take in the scent of the drink.

8. Lift it to your lips and pause for a moment without drinking. Notice what happens in your mouth – you might feel saliva forming or your tongue moving back to make space for the liquid.

9. Take the slowest sip you can, but don't swallow right away.

10. Let the drink swirl gently in your mouth, feeling it on your tongue and against your cheeks.

11. Notice its flavour once more.

12. When you're ready, swallow as slowly as possible. Pay attention to the sound of swallowing and the sensations that follow. Can you feel the drink moving down your throat and into your stomach?

13. Now, take a moment to notice the scent of the air you're breathing.

14. Look around you.

15. Open your hand and touch the surface you're sitting on with your fingertips, paying attention to its texture and feel.

Next time you feel overwhelmed by your thoughts or emotions, try giving your full attention to whatever you're doing at that moment – whether it's eating a meal, looking at your phone, or talking with someone close to you. See what happens when you do.

Based on the exercise "Awareness While Drinking" from the publication "Doing What Matters in Times of Stress: An Illustrated Guide" by the World Health Organization.

Your inner guests

When difficult feelings or unwanted thoughts arise, our instinct is often to fight them or to pretend nothing is happening. This is a normal reaction that stems from the fact that what we are experiencing feels hard to accept.

The problem is, even if we take on an uneven fight with our emotions, we rarely win – and the struggle only drains our mind and body. Instead of fighting or running away, try opening the door to what you're feeling. Imagine you're in a room and there's a knock at the door – you open the door and greet the guest who's there. This exercise helps you make space for your emotions.

1. **Notice your emotions**

   Take a moment to observe what you're feeling right now. You might notice joy, hope, or a burst of energy. Perhaps you believe the challenges you're facing will soon pass. Or maybe you're feeling anger, hatred, or despair, thinking the world is unfair.

You might feel betrayed and disappointed. You might have no energy at all, wishing you could drop everything and run far away. Whatever you're feeling right now, it's okay. You have a right to it.

2

Allow your feelings

See if you can simply let your feelings be, just as they are. You might quietly say to yourself, "Right now, I feel joy… or anger… or disappointment."

Accepting emotions isn't about dwelling on them – it's about acknowledging that what you're feeling is real. When you stop trying to push your emotions away and instead meet them, they often lose some of their grip on you. Think of them like guests knocking at your door. They've come to tell you something. Hear them out, and they'll leave when they're ready. Take a slow breath in, then out. Notice your "guests" with curiosity. With each breath, feel a little more room open up inside you – space for everything you're feeling right now.

3

Find them in your body

Pay attention to where you feel these emotions in your body. Maybe it's a knot in your neck, a heaviness in your chest, or a twist in your stomach. Whatever you notice is okay – there's nothing to fix. Meet these sensations with kindness. Acknowledge the pain, excitement, pleasure, or anything else that's there, and gently breathe into that spot.

(pause to breathe)

4

Recognise your thoughts

Take a moment to notice what's underneath your emotions, especially the difficult ones. If you're feeling sad, what's hiding beneath that sadness? Maybe disappointment, helplessness, or a sense of loneliness. Gently make room for each of these experiences as you notice them.

Now, turn your attention to the thoughts circling around your emotions. Are you constantly looking for ways to change your situation? Thinking about everything that still needs to be done? Or maybe your inner critic has stepped in, making you feel guilty and dwell on what you haven't managed to do. Whatever is on your mind, just notice it. Notice, too, how you're relating to these thoughts – even the uncomfortable ones. Can you offer yourself a little compassion at this moment?

5

Step back

Now take a slow, easy breath again… and imagine zooming out on your life, like a camera pulling back. Are these challenges the only thing in view? Or is there space for other feelings and experiences too?

All emotions – every fear, every worry – eventually pass. Instead of forcing change, picture yourself as an open sky, with your thoughts and feelings as clouds drifting through. Let them move in their own time. Watch them shift and fade, making room for whatever comes next.

Let it all be here. You don't need to fight or fix anything. And if your mind jumps ahead to the future, gently bring it back to your breath –
– feeling your body rise and fall like waves with each inhale and exhale.

Remember, everything you're feeling is okay. Take a slow breath in and out through your nose.

You've welcomed your emotions into your heart. Thank yourself for doing that.

Being a friend to yourself

We all feel better when we have a supportive friend by our side. Ideally, the people around us would always treat us with kindness. But life doesn't always work that way. In difficult moments, it can feel as if we are completely on our own. That's when it's important to be able to find a friend within yourself.

This isn't always easy. Each of us has an inner critic – a voice that judges us harshly, allowing no weakness, no mistakes. Yet imperfection is part of being human. Try to notice the unkind words you may be directing towards yourself. Are you blaming yourself for something? Telling yourself you should have done it better, sooner, or differently? Speaking to yourself in a sharp, irritated tone?

Would you speak this way to a close friend who was going through a hard time?

In this exercise, I invite you to treat yourself as a valued friend – someone who deserves care, kindness, and understanding.

1 **Notice what you're feeling**

Begin this exercise by taking a moment to recognise and name what you're feeling. You might say, "I'm really angry," "I'm frightened," or "I'm going through a very hard time." Use any words that fit your situation right now. Speak to yourself slowly, in a gentler tone than you usually would. Take a few steady breaths and listen for that kind, caring voice within you.

2 **Remember you're not alone**

Now, take a moment to think about others who are also going through something difficult. Some of them you know, others you don't. Even if it feels like you're the only one experiencing fear, sadness, or anxiety right now, you're not alone. Others feel this way too.

Gently remind yourself: "Everyone faces challenges sometimes. Everyone has moments when they feel worn out or hopeless. It's okay to feel this way." Take a few slow breaths, letting these words sink in and fill you.

3 **Be your own friend**

You could place a hand over your heart or gently wrap your arms around yourself. Feel the warmth and comfort in that touch. Then, offer yourself – silently – the same kind, caring words you would give to someone you love: "May I give myself the support I need right now.", "May I show myself the compassion I deserve.", "May I forgive myself., "I'm here, and I can count on myself."

Take a slow breath in and out. Feel the warmth and kindness flowing through your body. Notice the sense of friendship you've made with yourself. Remember: when you treat yourself with care, you're better able to care for others, too.

Allow yourself a few more moments of quiet and steady breathing.

Relaxation for a peaceful sleep

This exercise helps your body release tension, ease excessive stress, and prepare for sleep. It involves paying attention to your breathing, scanning through your body, and gently relaxing each part in turn.

1. Lie down in a comfortable position. Take a slow breath in through your nose, and as you exhale, gently close your eyes. This time is just for you. Be kind and gentle with yourself. Notice your breathing.
2. Feel the cool air coming in through your nose, and the warmer air flowing out. Follow the path of your breath as it travels in through the tip of your nose, down your throat, into your chest and belly… and then back out the same way.
3. Breathe in slowly through your nose, and breathe out slowly through your nose. With each breath, feel your body rise and fall as if carried by gentle waves.
4. With every such wave, let yourself sink a little deeper into the surface beneath you. Notice that you are in a place where you can feel safe and at ease. Feel your body fully supported by the surface.
5. As you keep breathing, take a moment to notice your emotions. What do you feel right now? Whatever it is, there is no need to fight it or try to change it. It's okay to feel exactly what you're feeling. If you find your mind wandering to the future, gently bring it back to your breath.
6. Take another slow breath in through your nose, and a slow breath out. Now, imagine letting go – just for a while – of all the weight you've been carrying on your shoulders. Picture yourself placing all your tasks and challenges on the ground beside where you're lying. And now, rest. Give yourself permission to use this time to recharge, so you can take it all up again tomorrow.
7. Bring your attention to your right foot. Notice how it touches the surface, and let it relax. Move your attention up to your right calf – let it soften. Then to your right thigh – release any tension there. Feel your whole right leg resting comfortably and at ease.
8. Now shift your focus to your left foot. Notice its contact with the surface, and let it relax. Feel the ease spreading through your left calf… and your left thigh… until your whole left leg is resting, heavy and comfortable.
9. When both legs are fully relaxed, notice your hips. See if you can let them soften a little more, letting them sink deeper into the surface beneath you.
10. Bring your attention to your back. Notice, one area at a time, what sensations are present in your neck, your upper back, your lower back, and your sacrum. If you feel any tension or discomfort, breathe into that spot, imagining the tension softening and flowing away with each exhale, like a receding wave. Allow your back to

grow pleasantly heavy and rest fully on the surface beneath you.

11 Now, bring awareness to your shoulders. Take a slow breath in through your nose, and as you breathe out, let your shoulders drop and relax. Let that relaxation flow gently down through your arms, forearms, hands, all the way to the tips of your fingers. There's no need to rush – simply follow the rhythm of your breath.

12 Notice your neck. If there's any tightness, allow it to release.

13 Soften your face, letting go of the emotions and expressions you've been carrying through the day. Feel your eyes resting, your forehead smoothing, your head letting go of control and giving in to its own weight. Your body may now be completely relaxed – but it doesn't have to be. Just notice what has shifted.

14 Take a gentle breath in through your nose, feeling your body lift slightly, like a wave. As you exhale, imagine that wave of air flowing from the top of your head, across your face, neck, shoulders, and arms. With the next exhale, feel the air moving through both arms, along the full length of your back and your hips. Then, sense it flowing down through both legs, all the way to the tips of your toes.

15 With each inhale, feel yourself filling with more and more of exactly what your body most needs. And with each exhale, let go of tension, worry, and any memories that are weighing you down. Another quiet, gentle breath fills you with calm, energy, and acceptance. Another slow breath out releases all that no longer serves you.

16 Inhale… and exhale. There's nothing else you need to do now.

17 Thank yourself for giving your body this much-needed rest. Slow, steady breath in… and a slow, steady breath out.

Loving-kindness meditation

Meditation is a way of freeing the mind from the overload of thoughts and emotions, and bringing it into a state of quiet awareness. It's not only a practice – it's a way of living, where being mindful of yourself and others is at the heart of things.

1 Sit comfortably. If you can, let your back be straight and gently draw your shoulder blades together to open your chest. Let your shoulders drop and rest naturally. You may close your eyes.

2 Bring your attention to your breath. Where do you feel it most easily – in your belly, your chest, or your nose?

3 Notice the quality of your breathing – is it calm and deep, or a little tense? See if you can gently slow it down. You might count to three as you inhale and to four as you exhale, or simply think of the words "breathing in" and "breathing out." Give yourself a moment to breathe in this steady way.

4 If your mind starts to wander – perhaps towards worries or things you "should" be doing – that's okay. Thoughts are like waves; they come and go. Let them drift away and return gently to the feeling of your in-breath and out-breath.

5 As your breath steadies, your body may start to relax and your mind to settle.

6 Now, turn your attention to your body. How does it feel? You might notice something clearly, or only as a subtle sensation. Some of these sensations may be pleasant, others less so. Whatever you notice is fine.

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7 Now, bring to mind a memory of someone showing you kindness. It doesn't have to be a big thing – maybe someone offered to help you or supported you in some way. Recall the details – who it was, when and where it happened. How did you feel at the time? Notice what emotions or sensations arise in your body now. Whatever is there, allow it to be.

8 Let that memory fade, and bring to mind a time when you showed kindness to someone else. Perhaps you let someone go ahead in a queue, or made time to listen when they needed it. Recall the details – who it was, when and where it happened.

9 Notice how it feels in your body to remember this. There's no need to judge or change what you find.

10 If your mind drifts to other thoughts, fears, or plans for the future, gently return to your breath.

11 Now think of a time you were kind to yourself – when you gave yourself rest, ease, or understanding. Maybe you let yourself lie down for a moment, or enjoyed a quiet cup of tea or coffee. How did you feel? What was going through your mind? What do you notice in your body now? Whatever it is, let it be. If you like, place a hand on your chest or wrap your arms around yourself in a gentle embrace, offering warmth and care to your body.

In everyday life, try to notice moments when you receive kindness, and when you show kindness to others and to yourself. Even if it's something small, acknowledge it and thank yourself for it.

What's next?

Mindfulness is a well-researched and effective method for reducing stress. It is also a valuable way to cultivate acceptance, kindness, and compassion for yourself and for others. If you find that the exercises presented here help you, you may wish to deepen your knowledge and skills through dedicated mindfulness courses or by exploring the books recommended below.

Mindfulness courses usually last around eight weeks and are led by qualified and experienced teachers. There are different types of courses, the most common being:

- **MBSR (Mindfulness-Based Stress Reduction)**,
- **MBLC (Mindfulness Based Living Course)**,
- **MBCT (Mindfulness Based Cognitive Therapy)**,
- **The Eline Snel Method –** mindfulness for children and adolescents

These courses are designed to be secular. However, there are also meditation approaches linked to various religious traditions. One of the most well-known centres of Christian meditation in Poland is the Benedictine Abbey in Lubiń. There are also several Buddhist meditation centres representing different schools of Tibetan Buddhism, as well as other centres grounded in diverse philosophical and spiritual traditions.

Recommended books:

- Padraig O'Morain – *Mindfulness on the Go: Inner Peace in Your Pocket*
- Jon Kabat-Zinn – *Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness*
- Jon Kabat-Zinn – *Mindfulness for Beginners: Reclaiming the Present Moment – and Your Life*
- Mark Williams, Danny Penman – *Mindfulness: An Eight-Week Plan for Finding Peace in a Frantic World*
- Thích Nhất Hạnh – *The Miracle of Mindfulness: An Introduction to the Practice of Meditation*

Olga Pastuch
Certified Mindfulness Teacher, "Szkoła Świętego Spokoju"

Prenatal diagnosis

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Foreword

Pregnancy can bring a whole spectrum of intense, sometimes unexpected emotions. Hormonal changes, uncertainty, medical appointments, and the long list of practical things to take care of can easily feel overwhelming. Well-meaning advice to “stay calm because stress affects the baby” often has the opposite effect, adding to the pressure and guilt.

When medical tests raise concerns, or new complications arise, these emotions can become even more intense. This chapter is for people who, during pregnancy, have learned that:

- their baby may face health challenges,
- doctors expect the baby will be born with a disability,
- the pregnancy involves a life-limiting condition,
- they have a high-risk pregnancy or serious complications,
- they have experienced a miscarriage,
- the baby has died in utero,
- due to the danger, as confirmed by a doctor, posed by the pregnancy on their life or health (including their mental health), they are facing, or have made, the decision to end the pregnancy.

A mix of emotions

Just as each situation is different, so are the feelings that come with it.

For many, the first reaction to a prenatal diagnosis is shock. Often it is followed by disbelief – wondering whether the result could be wrong, or hearing others say that “things might still change before the birth.” Another question that may surface is simply: “Why us?”

There is no satisfying answer to that. **What can be said is that it is not your fault**. An unexpected diagnosis can happen to anyone, no matter their age, health, financial circumstances, or background. Every pregnancy carries a small risk – around 2-3% – of a child being born with a developmental condition. The World Health Organization estimates that congenital disorders affect about 1 in 33 newborns globally, cause roughly 3.2 million disabilities each year, and contribute significantly to newborn deaths[1].

Some parents, despite all the difficult emotions they experienced when receiving the diagnosis, appreciate having learned about their child’s disability before birth. They pointed out that it gives the option of terminating the pregnancy if a doctor determined that continuing it would endanger the woman’s life or health (including her mental health) or alternatively, the option and value of having “time to prepare”. This time can be crucial – – allowing parents to process the diagnosis, come to terms with it and their own thoughts, and, as much as possible, get ready for their child’s arrival.

1 “Congenital disorders”, WHO, 27.02.2023, [online:] https://www.who.int/news-room/fact-sheets/detail/birth-defects, date of access: 20.12.2024.

The best gift you can give yourself during this time is permission to feel whatever comes up – without judgement – and to surround yourself with people who are supportive and accepting.

Here are some of the stories women shared with me while I was working on this chapter:

"What hurts most is the indifference – being treated like I don't have feelings. And comments like, 'You're young, you can have another healthy baby.' When you try to stand up for yourself, they excuse it by saying the staff are tired. As if that means you shouldn't remind them you're here, you're human, and you have feelings. You're not just a body on the operating table."

"I kept going in circles, looking for reasons to blame myself. Maybe I had waited too long to have a baby, maybe I shouldn't have eaten certain things. And I threw myself into reading everything about encephalopathy, determined to prepare, even if it meant ignoring my own health and my other child."

"There's a high chance Maja will be ill, but the more detailed tests carry a big risk of losing her. On the other hand, I'm almost certain I wouldn't be able to raise a sick child. We tried so hard to have this pregnancy, and now I don't want it – I feel guilty. I don't know whether to risk having a child with a disability and skip the tests, or to risk her life by going ahead with them. I can't sleep or eat."

"Hearing our son had Down syndrome wasn't as hard as dealing with people's reactions when we chose to continue the pregnancy. I felt like I had to justify one of the most personal decisions of my life. And it broke my heart that no one else seemed happy for Staś, that no one but us was waiting for him."

"I'm carrying a pregnancy with a lethal defect, and it's strange to admit, but I don't feel upset about it at all. I don't know why – maybe it's because I'm young, and the pregnancy wasn't planned? I think if I told my friends, they'd think I was some sort of robot or psychopath. Paradoxically, it's brought me closer to my husband, who has been very supportive and understands my emotions – or rather, the absence of them."

Getting support

Whatever your situation looks like, and whatever emotions or decisions come with it, you deserve respect, compassion, and a sense of safety.

The way a doctor delivers difficult news can have a profound effect on the parents' emotional and mental state. Unfortunately, you can't control how the news will be given, or the kind of support you'll get from your family, friends, doctors, or other professionals.

If you think the people around you – whether family or healthcare providers – might be open to it, you could share this short "cheat sheet" created by women I spoke to. You can always add your own ideas for what might feel supportive:

- "We're here for you, if you need anything."
- "Would you like to speak to a psychologist or a doula? I can help you find someone."
- "I'm so sorry. I'm happy to listen if you'd like to talk – or we can just sit quietly."
- "What you're going through matters to us. If you need anything at all, let us know."
- "No matter what happens, I'm with you."
- "You won't have to face this alone. I'll help you find someone who can guide you through the next steps."

Sometimes, the smallest human gestures mean the most – a gentle touch, holding someone's hand, a hug, or simply sitting together in silence.

Sharing difficult news

Telling others about a difficult diagnosis can feel overwhelming. **Whether it's your partner, parents, older children, or people at work, there's no single "right" way or time to do it.**

- Some parents prefer to send a short message to family and close friends. Such a message can briefly explain what's happening and, importantly, let people know what you need from them right now. Do you want company and support? Would you rather have some space? Or maybe you just need time, without pressure to respond straight away.
- If you have older children waiting for a baby brother or sister, it's usually best to explain in simple, calm language, leaving as little room as possible for confusion. Reassure them that they are safe, deeply loved, and can always count on you. Sometimes, stories, fairy tales, or films that touch on similar themes can help children process what is happening.
- With acquaintances or distant relatives who might ask about the pregnancy, but with whom you don't want to go into detail, you might prepare a few gentle responses ahead of time, such as:
  - "Thanks for asking, but it's not the best time to talk about it."
  - "We're going through some extra challenges right now, so it's a bit hard to discuss."
- In hard times, finding a circle of support can also help. This could be close friends or relatives, a women's group, a peer support group, or a faith community. Talking with people who have faced something similar can be especially comforting. But above all, remember: it's okay to choose what feels right for you and to put your own wellbeing first.

Fathers' feelings

Most formal support systems are designed with mothers in mind, yet fathers also often experience intense stress when unexpected results come up in prenatal screening. Cultural expectations – that men should stay strong, hide emotions, and focus on "fixing things" – can make it harder for them to find emotional balance.

- Many men in this situation describe a "frustrating helplessness," a sense of being "left out and alone," and a drop in self-confidence.

- Some cope by looking for someone to blame – often the doctor who delivered the news. While understandable, this rarely helps in the long run and can lead to exhaustion, anger, or anxiety.

- Others try to reassure themselves and their partner by saying "everything will be fine" or "the doctors might be wrong." But many women hear this as minimising the problem or failing to engage with what's really happening.

What tends to be more constructive is open communication: sharing thoughts and fears honestly, allowing space for vulnerability, maintaining physical closeness, and taking responsibility for certain practical aspects of care. These actions can ease stress and strengthen the relationship, no matter what the prognosis turns out to be.

Some fathers say they felt better once they identified specific ways to support their partner. The hardest part for them was the sense of having no role to play and of burdening their partner with their own sadness or fear. Writing down concrete tasks can make a difference – for example, taking notes during medical appointments, holding their partner's hand during scans, or finding a support group of other parents in similar circumstances.

It's important, though, that "doing tasks" doesn't take over what matters most – being present with each other. Sometimes just listening to your partner or sitting quietly together is harder – and more meaningful – than anything else.

If...

Every complicated pregnancy brings its own challenges, emotions, and difficult decisions. Whatever your situation looks like, one thing is certain: your feelings are valid. There is no “right” or “wrong” way to respond. What you need most is respect, care, and genuine support.

1. If you decide to terminate the pregnancy due to a threat to your life or health

Family stories

“Emotionally, I felt relief that it was over, but physically I was in terrible shape. My body had to adjust to the hormones. Taking some time off work turned out to be a good idea – going away with my husband into nature, sleeping as much as I needed, crying, walking in the forest, holding each other close.”

“I said a symbolic goodbye to my daughter with a close friend. We ordered good food, and I wrote her a letter. I described her as a little star who now looks after me from the sky.”

“Strangely, it brought my partner and me closer. We even each got a small tattoo of a bean on our wrists – that’s what we used to call the baby. It reminds us that we can’t control everything, but we can always stand by each other.”

Where to find help:

FEDERA Foundation
https://en.federa.org.pl

GO TO THE WEBSITE

2. If you continue the pregnancy after a diagnosis

Family stories

“One of the hardest but most important things for me was grieving the loss of a healthy child. Everyone assumes their baby will be born healthy, and letting go of that vision was painful. But allowing myself to grieve helped me avoid getting stuck in it later. It gave me space to see my child as more than just their disability. Saying out loud, ‘this is unbelievably hard’ was part of what helped me move forward.”

“What helped me most were conversations with mothers of children who had the same heart condition. Just watching those children gave me hope. At first, I joined a Facebook group and stayed quiet, just following discussions and checking parents’ profiles. Eventually I reached out and suggested meeting in person. That was a turning point. I felt welcomed, understood, supported – it was almost like joining a family. Those conversations gave me the emotional and practical preparation I needed to give Olek the best life possible.”

“It’s natural to want to learn everything you can about your baby’s condition. I went through that too. But I’d really encourage you to stick to reliable sources – websites ending in edu, org, or gov. Social media groups can be valuable, but they’re often full of dramatic, emotional stories because that’s how those platforms work. If you come across

something that scares you, remember: every situation is unique. Your story is your own."

"For me, faith was what kept me steady. It helped to know I was staying true to my values. What was harder were the comments from others – that we were somehow depriving our other children of a 'normal' family life. But in reality, getting ready together for their little brother turned into a happy and meaningful time. We looked up stories about well-known people with Down syndrome, read Magdalena Krajewska's book 'Braciszek ', and celebrated World Down Syndrome Day by wearing mismatched socks. Bringing the kids into this new reality spared us a lot of sadness and disappointment."

"My mum always told me: 'If you're worrying about the future, come back to the present. Focus on here and now.' That advice kept me grounded. And a friend of mine, father to many children, reminded me: 'Parenthood always requires us to face the unknown – whether our children are born healthy or not.' That perspective stayed with me."

"Making a plan can help you feel a sense of control over the things you actually can influence. For me, my doula was the one who helped me put everything in order and connect with the resources my family and I needed."

Where to find help:

Mudita Association
https://stowarzyszeniemudita.pl/

GO TO THE WEBSITE

3. If you are struggling with the decision

It's extremely important to remember that terminating a pregnancy is currently possible when continuing the pregenancy poses a risk to the woman's life or health. This risk may also include mental health – which is why talking with a doctor is so crucial.

You can ask for a second opinion.
You have the right to ask questions.
You have the right not to have all the answers.
You have the right to take your time.

4. If you regret the decision you made (whatever it was)

Give yourself time to come to accept your choice. Be gentle with yourself. None of us can know what life would have looked like had we chosen differently. Talking with a psychologist can help you process your decision and weave it into the story of your life.

Regret often comes with frustration or anger, especially if you feel that others influenced your choice. These feelings are normal and important to acknowledge rather than push away. However, when we hold on to regret for too long, it can block us from seeing any of the good that comes from the path we've chosen.

Family stories

"I decided to have the procedure and had to hide it from my family and some friends. It makes me so sad that they might reject or judge me."

"What really helped was being surrounded by women – honest conversations, their closeness, and the absence of judgement."

5. If you are facing a life-limiting diagnosis for your baby

Perinatal palliative care was created with families like yours in mind. It goes beyond standard medical treatment and focuses on the needs of the whole family – not only the mother, but also the father, siblings, and close relatives.

Family stories

"It mattered to me that Tadzio, even though he lived such a short life, left something good behind. Every year on his birthday I donate to a foundation – the amount matches the age he would have been, with an extra zero at the end."

"Try not to blame yourself for something that is not your fault. The most meaningful thing you can do for yourself and your baby is to take care of your own wellbeing through the rest of the pregnancy. Make sure you get enough rest, stay hydrated, and nourish yourself with good food each day."

Where to find support:

On the website **www.powitalnik.pl**, you'll find the Knowledge Base – a complete list of organizations across the country that offer free, comprehensive perinatal support, that is assistance provided during pregnancy and in the first weeks of a child's life.

GO TO THE WEBSITE

6. If you've experienced a miscarriage

Feelings of sadness, emptiness, and loss are common after a miscarriage. The intensity of these feelings can depend on many factors – the stage of the pregnancy, the bond you had already formed, the hopes and plans you carried, your path to conception, any previous losses, and your life experiences as a whole. **Remember: you have every right to grieve, even if the loss happened very early.**

Family stories

"What helped me was reminding myself that the miscarriage wasn't my fault. My psychologist encouraged me to repeat – as if speaking to my best friend – that I hadn't done anything to cause it, and there was nothing I could have done to prevent it."

"For a while, I felt less of a woman after my miscarriage. What started to shift was joining women's workshops with my doula and regularly attending a women's circle."

“It helps to give yourself space and time to grieve. Don’t rush yourself – – let yourself notice what you’re feeling. For me, journaling and joining a support group for women in my situation were vital. It gave me a way to record my experiences after saying goodbye to Tosia, but also to honour the time of pregnancy and the bond I had had with her.”

Where to find support:

“Poroniłam.pl” portal
https://www.poronilam.pl/

GO TO THE WEBSITE

“Ronić po Ludzku” Foundation
https://ronicpoludzku.com/

GO TO THE WEBSITE

“Nagle Sami” Foundation – support line for those in grief and after loss
https://naglesami.org.pl/
tel. 800 108 108

GO TO THE WEBSITE

Olga Ślepowrońska
psychologist

Practical guide to law and finances

Families raising a child with special needs can access different forms of support. This section highlights the key options and explains how to make use of them.

Sections

This guide walks you through the main types of financial and therapeutic support that the Polish state provides for children with health challenges and their families. These benefits are separate from standard health care covered by the **Narodowy Fundusz Zdrowia (NFZ, National Health Fund)**, such as doctor's visits or specialist rehabilitation, which your child's doctor should explain to you.

We have done our best to capture the regulations currently in place, but law can change quickly. For the latest information, check the online version of this "Welcome Guide" at www.powitalnik.pl.

Keep in mind that the local offices responsible for supporting you and your child may have different names depending on your gmina or powiat (local municipalities or districts). The institutions providing assistance can include:

- **MOPS – Miejski Ośrodek Pomocy Społecznej (Municipal Social Assistance Centre)**
- **GOPS / OPS – Gminny Ośrodek Pomocy Społecznej / Ośrodek Pomocy Społecznej (Community Social Assistance Centre / Social Assistance Centre)**
- **PCPR – Powiatowe Centrum Pomocy Rodzinie (District Family Support Centre)**
- **MOPR – Miejski Ośrodek Pomocy Rodzinie (Municipal Family Support Centre)**

Most forms of support require filling out applications. Some templates are available at **www.powitalnik.pl**, but many depend on local regulations. Always check your local office's website, whether it is a social assistance centre or a family support centre. If you can't find what you need, call the office, explain what kind of support you are applying for, and ask for clear instructions.

A practical tip: start a folder or binder for important paperwork

You will need to keep track of documents such as medical reports, test results, hospital discharge notes, and referrals. These are often required at doctor's appointments or when applying for benefits or certifications. Having everything organised in one folder or binder will make your life easier and help you avoid unnecessary stress.

Four steps to accessing state support

Below are four steps you should take to secure the main forms of financial and therapeutic assistance available to your family.

1

Make use of the Ustawa "Za życiem" (the "For Life" Act)

2

Obtain a disability certificate (PL: *orzeczenie o niepełnosprawności*)

3

Enrol your child in Early Developmental Support (PL: *wczesne wspomaganie rozwoju*)

4

Access funds for your child through the 1.5% tax allocation and donations

1

Make use of the Ustawa "Za życiem" (the "For Life" Act)

If your newborn has been diagnosed with a serious illness or disability, you are entitled to a range of state-guaranteed support under the Ustawa "Za życiem". To access this support, you will first need a medical certificate.

How to get the medical certificate:

1. Collect any medical records confirming your child's health condition. If you are still in the hospital, these documents are already with your doctor – you only need to refer to them.

2. Ask your doctor to complete the official certificate (Annex 1), which confirms your eligibility for support under the Ustawa "Za życiem".

   The certificate can be issued by:
   - a gynaecologist-obstetrician
   - a perinatologist or neonatologist
   - a paediatrician
   - or your primary care doctor

The medical certificate may include phrases that you may not agree with, such as "severe impairment" or "incurable illness." Remember, this document is not a verdict on your child's future. On the contrary, it is what opens the door to faster and more effective medical care for your child, and to a wide range of support for you and your family. Do not be afraid to make use of it.

What support is available and how to access it?

Priority access to specialists

When scheduling a specialist appointment for your child, let them know you have a medical certificate under the Ustawa “Za życiem”. This entitles you to an appointment within a maximum of seven working days.

One-time financial support

With the certificate, you are entitled to a one-time payment of PLN 4,000. You can use these funds in any way that best supports your family’s needs.

How to apply:

1. Complete the application form for the benefit (Annex 2) and submit it either at your local MOPS (PL: *Miejski Ośrodek Pomocy Społecznej* – Municipal Social Assistance Centre) or online at this government website.: **https://empatia.gov.pl**.
   Applications must be filed within 12 months of your child’s birth.
2. Attach the medical certificate (“Za życiem”, Annex 1).

Support from a Coordination-Rehabilitation-Care Centre (PL: *OKRO – Ośrodek Koordynacyjno-Rehabilitacyjno-Opiekuńczy*)

Check if an OKRO operates in your district and contact them to learn what support is available – depending on whether you already have an Early Developmental Support (PL: *WWR – wczesne wspomaganie rozwoju*) opinion. If no OKRO exists in your area, approach your local Psychological and Pedagogical Counselling Centre (PL: *Poradnia Psychologiczno-Pedagogiczna*), which often fulfils the role. More details are provided in Step 3 (p. 109).

Support from a family assistant

A family assistant can help your household adjust to the new reality and provide everyday support. Their role includes psychological support, assistance with official procedures (including benefits), advice on child care, and help with organising family time and household budgeting.

How to apply:

1. Download the “Application for appointment of a family assistant” (PL: *Wniosek o przydzielenie asystenta rodziny*) from your local MOPS website and complete it.
2. Attach:
   - The medical certificate under the Ustawa “Za życiem” (Annex 1).
   - An authorisation allowing the assistant to act on behalf of your family in applying for support (Annex 3).
3. Submit the completed application with attachments to your local MOPS.

To learn more about the support available under the Ustawa “Za życiem”, you can consult the online guide “Za życiem” at **https://zazyciem.gov.pl/** or read the full text of the Act itself (full name: **Ustawa z dnia 4 listopada 2016 r. o wsparciu kobiet w ciąży i rodzin "Za życiem"** – Act of 4 November 2016 on Support for Pregnant Women and Families “For Life”.

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2 Obtain a disability certificate (PL: *orzeczenie o niepełnosprawności*)

Applying for a disability certificate can feel like a heavy step, but it isn't a label that defines your child. Instead, it's a way to unlock access to services and support that may make life easier for both your child and your family.

The certificate itself is confidential – only you and the certifying commission will know about it. You decide if, when, and with whom you want to share this information.

Children may be eligible for a certificate if they have physical or developmental challenges, backed by medical documentation. The commission's role is to assess whether your child needs more care than their peers of the same age, and whether those needs are likely to continue for at least a year.

How to obtain a disability certificate for your child?

1. **Complete the application form**
   Each city or district has its own template. You can usually find it by searching online for "wniosek o wydanie orzeczenia o niepełnosprawności dziecka" (application for a child's disability certificate) along with the name of your city or district.

2. **Get a medical certificate** (Annex 4)
   Ask a doctor who knows your child's health history well to complete it. This certificate is valid for 30 days.

3. **Gather supporting medical documents**
   Collect any paperwork that confirms your child's health challenges, such as:
   - hospital discharge notes
   - specialist consultation records
   - diagnostic test results (e.g. ECG/EKG, X-ray, ultrasound, CT, MRI)

   Please note! Make copies of all documents, but also bring the originals for verification.

4. **Submit the documents**

   Hand in your application, medical certificate, and supporting documents to the disability adjudication commission (PL: *powiatowy zespół ds. orzekania o niepełnosprawności*) for your place of residence.

   Please note! Once your file is submitted, the commission will review all the documentation.

   - If something is missing, they will send you a written request to provide it by a set deadline. If you don't complete the file, the case will be closed without a decision.

   - If the documents contain conflicting information, the commission may refer your child for an additional specialist assessment at the regional or voivodeship (PL: *wojewódzki*) level. These additional assessments are free of charge. However, sometimes you may need to provide extra test results yourself.

5 **After your application has been reviewed, you'll be invited to attend a meeting with the commission**. Usually, you will need to bring your child with you. If your child is too unwell to come, you can attend alone, but you will need a doctor's note explaining why your child could not be present.

! Be well-prepared for this meeting. Bring along any medical records, psychological reports, or school evaluations that show your child's needs. Be ready to describe what daily life looks like for you – the challenges your child faces, and the extra care or support they require. This is especially important if your child's disability isn't obvious at first sight. If you need a parking card because of mobility or vision issues, make sure to mention that as well.

6 Once a decision has been made, you will receive a letter to your home address, telling you whether your child has been granted a disability certificate.

7 If you disagree with the decision, you have the right to appeal. First, you can appeal to the regional or voivodeship commission (PL: *wojewódzki zespół ds. orzekania o niepełnosprawności*), and later, if needed, to the court.

! Why might you want to appeal? There are many possible reasons. For example, you may have been denied the right to a carer's allowance (PL: *świadczenie pielęgnacyjne*, see points 7 and 8 of the certificate), or your child may not have been granted a parking card. In your appeal, you must specify which part of the decision you disagree with and why. You can also attach additional medical or psychological certificates to support your case.

What support is available and how to access it?

Having a disability certificate is the key requirement for almost all financial benefits and other forms of assistance available under Polish law. The most important type of support is:

→ Care allowance (PL: *świadczenie pielęgnacyjne*)

This is a monthly financial benefit for the parent or legal guardian of a child with a disability.

! **Please note!** To qualify, your child's disability certificate must state "the need for constant or long-term care or assistance from another person due to significantly limited ability to live independently," and "the need for the daily involvement of a parent or guardian in the child's treatment, rehabilitation, and education," or a decision indicating a "severe degree of disability." These circumstances are listed in points 7 and 8 of the certificate. If these points were not granted and you believe your child can't live independently, you should consider appealing the decision.

How to apply:

1. Fill out the application for the care allowance (Annex 5). You can also submit it online through the Emp@tia system: **https://empatia.gov.pl**.

2. Attach the following documents:
   - your child's disability certificate showing points 7 and 8 granted;
   - a declaration stating that your child does not use full-time care in an institution for more than 5 days a year (Annex 6).

3. If you are applying for the care allowance and you are not employed, you may also need to arrange social and health insurance coverage.

To be covered by social insurance, submit the following in addition to your application:

- ZUS-ERP-6 form;
- US-7 form (application to establish the period of social insurance contributions);
- documents confirming your insurance history (for example: original employment certificates, diplomas from completed schools or universities, a certificate from ZUS confirming contributions if you ran a business, original birth certificates of children together with a statement confirming you personally cared for them until the age of four, etc.).

4. **To be additionally covered by health insurance (for yourself or a family member)** submit:
   - ZUS-ZUA form – to insure yourself;
   - ZUS-ZCNA form – to insure a family member.

Important: Steps 3 and 4 apply only to people applying for the care allowance who are not employed anywhere. If you work, you do not need to complete ZUS forms or provide employment certificates. You only need to submit a statement confirming your current place of employment. However, if your employment status changes while receiving the care allowance, you must immediately notify your local MOPS.

5. Submit your documents. Hand in your application and required documents at your local MOPS, or submit them online via the Emp@tia system: **https://empatia.gov.pl**.

Your local office may request additional documents depending on your individual case.

Please note! Keep in mind that you can't receive both the parental benefit (PL: *świadczenie rodzicielskie*) and the care allowance (PL: *świadczenie pielęgnacyjne*) at the same time. Even if you are unemployed, you are entitled to the carer's allowance from the moment your child is born – whether or not you are registered with the employment office. Since the care allowance is higher than the parental benefit, it is usually better to apply for it straight away.

Care benefit (PL: *zasiłek pielęgnacyjny*)

The care benefit is a small monthly benefit designed to help cover costs connected with your child's care. It is not means-tested, which means your household income does not affect your eligibility.

How to apply:

1. Fill out the care benefit application form (Annex 7) or submit it online through the Emp@tia system: **https://empatia.gov.pl**.
2. Attach your child's disability certificate (PL: *orzeczenie o niepełnosprawności*).
3. Submit your application to your local MOPS or online through the link above.

In some cases, the office may request additional documents to confirm your eligibility.

Please note! If you are already entitled to a pension or retirement benefit, you may receive a care supplement (PL: d*odatek pielęgnacyjny*) instead of the care benefit.

Family benefit (PL: *zasiłek rodzinny*) + Supplement for the education and rehabilitation of a child with a disability (PL: *dodatek z tytułu kształcenia i rehabilitacji dziecka niepełnosprawnego*)

Note: To qualify for the family benefit and its supplements, you must meet the income criteria.

How to apply:

1. Complete the family benefit application form (Annex 8) or submit it online through the Emp@tia system: **https://empatia.gov.pl**.
2. On the form, indicate that you are applying for the Supplement for the education and rehabilitation of a child with a disability (PL: *dodatek z tytułu kształcenia i rehabilitacji dziecka niepełnosprawnego*) by ticking the appropriate box next to your child's details.
3. Attach your child's disability certificate.
4. Submit the documents to your local MOPS or online via the link above.

In some cases, the office may request additional documents to confirm your eligibility for the family benefit.

Funding from PFRON

The mission of PFRON (State Fund for the Rehabilitation of Persons with Disabilities, PL: *Państwowy Fundusz Rehabilitacji Osób Niepełnosprawnych*) is to support people with disabilities in fully participating in social and professional life. To achieve this, it provides funding for a variety of expenses incurred by people with disabilities and their families.

Through PFRON, you can apply for financial support towards, for example:

- rehabilitation stays for your child,
- orthopaedic equipment,
- adapting your home to the needs of a child with a disability,
- electronic equipment that facilitates communication, etc.

In some cases, part of the cost may already be covered by the National Health Fund (NFZ). If so, PFRON can cover the remaining amount (in full or in part).

PFRON funding is administered through local PCPR or, in some cases, through MOPS/GOPS. The available forms of support vary from county to county.

How to apply:

1. Check the PFRON website for eligible expenses: **https://www.pfron.org.pl/osoby-niepelnosprawne**
2. Contact your local PCPR (or MOPS/GOPS) to ask whether you can obtain funding for the item or service you need.
3. Submit the application either at your local office or online via the PFRON Support Service System (PL: *System Obsługi Wsparcia, SOW*): **https://sow.pfron.org.pl**. Select your district (PL: *powiat*) and the type of planned purchase.

Rehabilitation tax deduction (PL: *ulga rehabilitacyjna od podatku PIT*)

If, during the year, you cover expenses for your child's rehabilitation, you may deduct them from your personal income tax (PIT).
To qualify, your child must have a valid disability certificate.

Detailed guidance on how to claim this deduction is available on the official tax portal: **https://www.podatki.gov.pl/ulgi-i-odliczenia/ulga-rehabilitacyjna-pit/**.

Specialist care services (PL: *specjalistyczne usługi opiekuńcze, SUO*)

There are two types of specialist care services:

- general specialist care services,
- specialist care services for people with mental health conditions.

These services are tailored to the specific needs that arise from a given disability or health condition. They may be provided in cooperation with therapeutic institutions, either at home or in day support centres.

SUO is not entirely free of charge. The law specifies whether, and in what amount, you will need to pay an hourly fee for the assistance granted.

How to apply:

1. Visit your local MOPS and request support.
2. Collect the application form and the medical certificate template, which should be filled out by a specialist doctor (psychiatrist or neurologist).
3. Wait for a home visit (social worker assessment).
4. Provide MOPS with any additional documents requested by the social worker.
5. Await the decision (if the decision is negative, you can appeal).

Respite care and personal assistance (PL: *opieka wytchnieniowa i asystencja osobista*)

Respite care is designed to relieve parents of children with disabilities by providing temporary support from a caregiver. While the caregiver looks after your child, you can rest, meet friends, or attend to important matters.

The "Personal assistant for a person with disability" programme supports children with disabilities in becoming more independent and active in their daily lives.

To find out what support is available in your area and under what conditions, contact your local MOPS (Municipal Social Assistance Centre).

3 Enrol your child in early development support (PL: *WWR – wczesne wspomaganie rozwoju*)

WWR is a programme for children aged 0-7, or until the end of preschool.

Please note! Parents of children with disabilities may request a post--ponement of compulsory schooling through the Psychological and Pedagogical Counselling Centre (PL: P*oradnia Psychologiczno-Peda-gogiczna*), which in some cases allows the child to remain in preschool until the age of nine.

WWR is intended for children who, due to illness or disability, face greater challenges in acquiring skills than their peers. Within the programme, your child may access 4-8 hours per month of sessions with specialists such as a physical therapist, psychologist, speech therapist, or sensory integration therapist. Parents are also supported, with experts advising on how best to spend time with the child and encourage their development at home.

The earlier a child begins to receive comprehensive support, the greater the likelihood of developing their full potential. All WWR services are free of charge. To access them, you must first obtain an official opinion confirming the need for WWR, and then enrol your child in a WWR team.

How to apply:

1. Visit the website of your local Psychological and Pedagogical Counselling Centre (PL: P*oradnia Psychologiczno-Pedagogiczna*) and **download the medical certificate template confirming the need for WWR**. Each centre uses its own form. If you can't find it, call the Centre for guidance. If necessary, you may also use the template provided in Annex 9.

   ! Register with the Centre responsible for your area of residence. In smaller towns, there is usually only one centre, while in larger cities, catchment areas can be checked on the municipal website or by calling the Centre. You can also locate your nearest centre easily by searching "*poradnia psychologiczno-pedagogiczna*" in Google Maps.

2. **Ask the doctor most familiar with your child's condition to complete the certificate.** This may be a paediatrician or a specialist such as a neurologist, orthopaedist, ophthalmologist, or psychiatrist.

3. **If you already have a medical certificate, fill in the application for an opinion confirming the need for WWR and submit it to your local Psychological and Pedagogical Counselling Centre.** If you have trouble locating the application form, call the Centre and ask how to obtain it. Attach the medical certificate together with any medical documentation that demonstrates your child's health challenges.

   ! If you have a certificate issued under the Ustawa "Za życiem" or a formal disability ruling, it is advisable to include these as well, although they are not required in order to access WWR.

4. Once your application has been submitted, the Centre team will review it. You will then receive an invitation to a diagnostic meeting, where a panel of specialists will assess the difficulties your child is experiencing and decide whether support should be provided and in what form. If your child qualifies, the Centre will issue an official opinion confirming the need for WWR within 30 days.

5. You may enrol in free WWR sessions at any facility authorised to deliver the programme. This may be your Psychological and Pedagogical Counselling Centre or one of the many private counselling centres. It is often helpful to consult other parents in your area to find out which WWR facilities they recommend.

6. At the facility you choose, the WWR team will develop an individual support plan for your child and register you for sessions.

Special education needs statement (PL: *orzeczenie o potrzebie kształcenia specjalnego*)

A special education needs statement allows your child to access therapeutic support in preschool or school. The procedure for obtaining it is similar to that for an early development support opinion (WWR) and is carried out through your local Psychological and Pedagogical Counselling Centre. A team of experts will talk to your child to identify any challenges they may be facing and will issue a medical certificate. The centre's multidisciplinary team will then review your child's case, drawing on assessments and medical documentation, before deciding whether to grant the statement.

The statement is valid for either one school year or a full stage of education. Once presented, the school has 30 days to prepare an Individualised Education and Therapy Plan (PL: *Indywidualny Program Edukacyjno-Terapeutyczny, IPET*), which adapts teaching methods and classroom organisation to your child's individual needs and capacities.

4 Accessing Additional Resources: 1.5% Tax Allocation and Donations

While many forms of support are available to children with special needs and their families, the costs of diagnosis, treatment, and rehabilitation often exceed what is covered by the state. For this reason, parents frequently turn to additional funding sources. The most straightforward approach is to open a dedicated sub-account with a foundation that supports families raising children with disabilities or chronic illnesses.

Through such an account, you can:

- collect funds from the 1.5% of personal income tax that every taxpayer in Poland may designate for a chosen cause in their annual tax return, and
- receive private donations.

You do not need to organise large campaigns in order to benefit from the 1.5% allocation, though some parents choose to raise awareness through social media and other channels, often with very positive results. In practice, it is often sufficient to ask relatives, friends, colleagues, or neighbours to assign their 1.5% to your child's account when completing their tax return. On average, each individual contribution amounts to around PLN 80.

How to apply:

1 **Choose a foundation you trust**

Seek advice from other parents whose children have received a similar diagnosis. Each foundation has its own conditions for cooperation, different rules for reporting, and varying types of support on offer. Review these carefully before making your choice.

2 **Submit an application to the foundation**

Foundations differ in their admission requirements. Detailed information is usually available on their websites or by calling the contact numbers provided. Some foundations may require a disability certificate. Even when it is not formally required, you will need to provide medical documentation confirming your child's health condition.

3 **Use your subaccount**

Once everything is set up, you'll be given access to a personal subaccount where others can make donations or transfer their 1.5% tax contribution. Money from this subaccount is usually released after you submit invoices showing expenses related to your child's care – – such as therapy, medication, or medical equipment. The foundation will then reimburse the approved costs directly to your private bank account.

All annexes, up-to-date information on available forms of support, and other relevant templates can be found on our website: www.powitalnik.pl.

GO TO THE WEBSITE

Milena Kwiecień
mum of Błażej

Anna Sularz
mum of Hania and Kuba

Agnieszka Jóźwicka
mum of Olinek

"Paperwork matters. After every appointment, make sure there is a record. Keeping things in order helps later when applying for a disability certificate or a special educational needs certificate. Something that seems minor at the time may turn out to be important. It's worth collecting notes from every rehabilitation centre."

"Medical and therapeutic recommendations, professional opinions, test results – keep everything on paper, arranged in chronological order. That way, during appointments, you can clearly set out the dates of hospital stays, surgeries, or infections. Make use of the Ustawa "Za życiem" (the "For Life" Act) and of point 7 of the disability certificate when registering with specialists. Even if clinics are reluctant, the law is on your side."

"Whenever someone tries to turn you away, show your certificate and ask for a written refusal of an early appointment or of handling your request. That usually works."

"In my view, the most important first steps are to secure the Ustawa "Za życiem" (the "For Life" Act) certificate and a disability certificate, and arrange the best possible rehabilitation as quickly as you can. After that, set up a sub-account with a foundation and share the account number with as many people as possible – family, friends, acquaintances."

"The most important thing is not to go through this alone – don't withdraw, don't hide the illness."

"Don't assume from the start that you have to 'fight' the system or that everyone will be against you. The system is far from perfect, but there are many good, kind, and competent people within it."

A few words from a physiotherapist

Many children facing serious illness, disability, or other health challenges will need physiotherapy (also known as physical therapy) support in order to reach their full cognitive and motor potential. The earlier you recognise your child's needs and secure appropriate support, the greater the likelihood that they will achieve all that is possible for them.

Sections

Helping your child through physiotherapy

Not every child will need long-term therapy. Sometimes what makes the biggest difference is simply showing parents the right ways of caring for and playing with their child. In some cases, however, rehabilitation may be recommended. This means gently supporting and stimulating the child's body in ways that help their development follow a path as close as possible to typical growth. **The aim is for your child to gain the greatest level of independence they can, and to experience the world fully – through their body and all the senses available to them.**

Even a single physiotherapy consultation can give you a clearer picture of both your child's abilities and the challenges they may face. Longer therapy can help your child build healthy muscle tone and develop more supportive movement patterns. Therapists guide children in exploring movement and their senses, nurturing their curiosity and encouraging them to discover their surroundings in a way that matches their own pace and abilities.

Through conversations with the physiotherapist, you will also learn simple exercises you can continue at home, helping your child strengthen and use their new skills in everyday life. A good therapist will also point out other areas where your child might need support and, if needed, guide you towards the right specialists.

Supporting your child's vision

A child's visual system continues to develop well after birth. Many children who are born prematurely, or who face other developmental challenges, may have weaker vision. If this is the case, it is important to support their visual development through the right kinds of stimulation.

The first step should be an appointment with a paediatric ophthalmologist, who will check your child's eyesight. If support is needed, a vision therapist can help you choose suitable toys, show you simple vision-based play activities, and give you practical advice on how to adapt your home environment to strengthen your child's visual development.

Speech and language therapy

Another challenge your child may face is communication – both with the world around them and with you. A skilled speech and language therapist (neurologopaedist) can help you understand whether your child's communication abilities are developing as expected for their age. If any difficulties are identified, the therapist will support your child in building their speech and language skills.

Speech and language therapists also address certain feeding-related difficulties. These may include oral sensitivity, which is sometimes present in children who have been tube-fed, as well as problems with suckling, or unusually low or high muscle tone in the mouth area. With the right guidance and stimulation exercises, the therapist can help your child strengthen their feeding functions and make the transition to solid foods easier when you are ready to expand their diet.

Aleksandra Izydorczyk
Physiotherapist

How to choose the right therapist?

Finding the right therapist is not always simple. It may be a good idea to ask experienced parents of children with a similar diagnosis for recommendations.

Through our partnership with the **Functional Therapy Institute "Dzielny Miś"** in Warsaw, we are also able to offer you a free physiotherapy consultation with specialists who are already supporting many children we know. To take advantage of this opportunity, simply book an appointment using the link provided below.

DZIELNY MIŚ
Instytut Terapii Funkcjonalnej

WITH THIS LEAFLET, YOU CAN BOOK A **FREE CONSULTATION FOR YOUR CHILD** WITH A PROFESSIONAL PHYSIOTHERAPIST AT THE FUNCTIONAL THERAPY INSTITUTE "DZIELNY MIŚ".

Ul. Świętojerska 5/7
00-236 Warszawa

You can book an appointment online:
www.dzielnymis.pl (see the "zapisy on-line" tab)

or by phone: **+48 698 545 450**

Worksheet 1.
Taking care of yourself

Learning that your child may be facing serious health problems can bring up a wide range of emotions. In the “Psychological First Aid” chapter, you’ll find out more about the different stages of adjusting to this new reality.

Now, we encourage you to take a moment for yourself. The exercises and questions that follow are designed to help you gather your thoughts, make sense of what you’re feeling, and approach the future with greater calm.

You might feel that focusing on your own needs is selfish or out of place at such a difficult time for your family. Or you may want to try but find it hard to concentrate, or to put your feelings into words. That’s completely normal.

Even so, taking steps to care for yourself and your wellbeing can make it easier to face new challenges – and can also bring comfort to your relationships with those closest to you.

Sections

1. Understanding your emotions

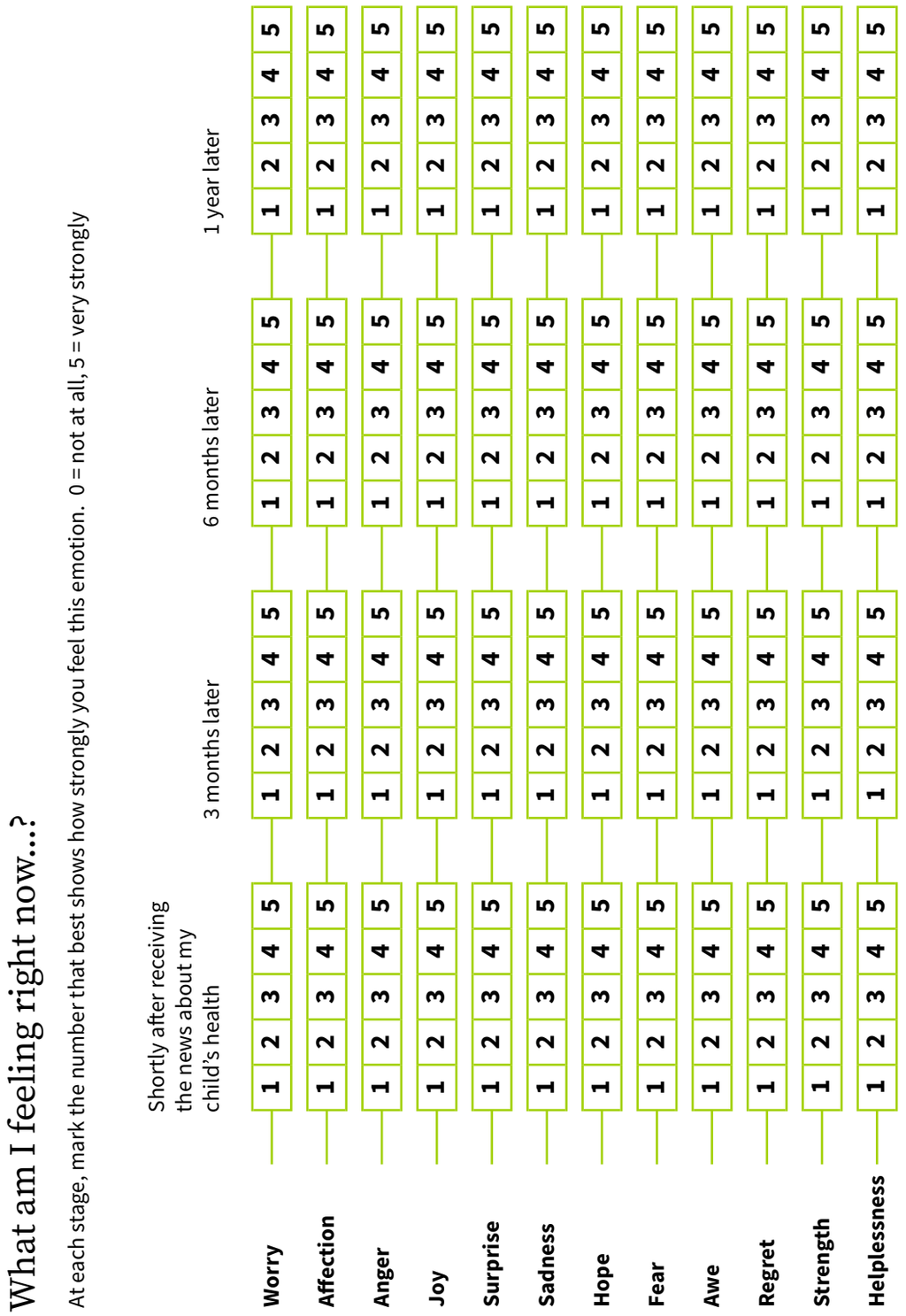
Both the birth of a child and the news that your child may have health challenges can bring about a whole range of feelings and emotions. Below you'll find a list of some common ones. Try marking on the scale which emotions you're experiencing right now. Then come back to it after a month, three months, six months, and a year. This way, you'll be able to see how your mood and your experience of parenthood change over time.

There are no right or wrong answers here. The purpose of this exercise is simply to help you connect more closely with yourself. Emotions are valuable signals from our bodies – they tell us what we might need at a given moment.

For example:

- **Sadness** may be a sign that you need rest or closeness with someone you trust.
- **Anger** can be an impulse to push for change in your situation – even if you don't yet know what that change should look like.
- **Anxiety** often shows that the challenges ahead feel overwhelming, and that you may need more time, information, or support from others to cope.

By repeating this exercise every few weeks or months, you'll also notice that emotions shift. Even if it feels right now as if joy will never return, or as if your fear will stay with you forever, over time you may discover that things have changed.



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2. Building your support network

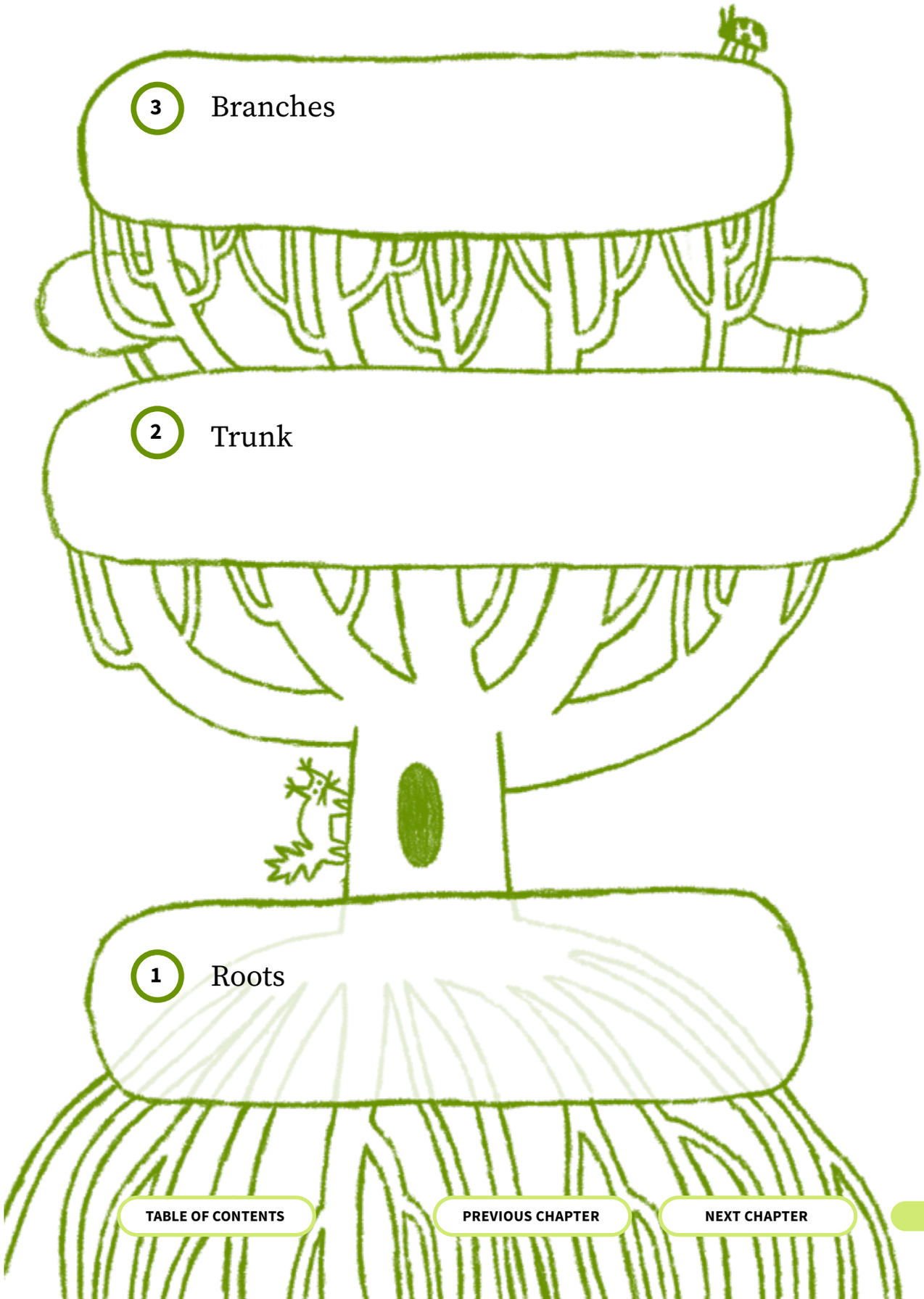
All of us need the presence and care of others in order to thrive. During difficult times, that support becomes even more important.

On the next page you'll find a drawing of a Tree of Life. It is a way of mapping out the people and resources you can rely on. The exercise may also help you notice where new connections, friendships or sources of support could be found.

1. **Roots:** Write the names of the people who give you a strong sense of safety and stability, no matter what happens.

2. **Trunk:** Add those who can offer you support – big or small – as you navigate this new situation.

3. **Branches:** Note down people you can turn to for advice or practical help, whether for yourself or your child. This may include professionals, organisations, or even people you do not know personally but who have been recommended to you.



3. Recognising your strengths

The birth of a child changes life almost overnight. It also changes us. Some parents feel a rush of energy, strength, or a new kind of wisdom. They may sense they have a mission to fulfil and will do whatever it takes. Others, in the same situation, may feel sadness, helplessness, or grief for the part of themselves and their old life that they have lost. Most often, we move between many different states – at times overwhelmed, at other times uplifted.

In many ways, it's true that facing new challenges transforms you, and you may feel like you are becoming someone different. But that doesn't mean you lose the knowledge, strengths, and skills you already had. Even in the hardest moments – when it feels as if your world is collapsing, when you feel terrified or powerless – you still carry within you the abilities and resources you had before your child was born.

The questions below are an invitation to notice those resources and to recognise the inner strength you can draw on now, and in the weeks and months ahead on your parenting journey.

Sometimes it helps to look at yourself from another perspective. We encourage you to invite a trusted friend or relative to answer these questions about you; their reflections may show you qualities you overlook in yourself.

Three qualities I value most in myself are:

Three qualities others value in me are:

Three qualities that helped me get through a difficult situation in the past are:

Three qualities I have that will benefit my child are:

The quality of my body I appreciate most is:

I am most proud that I have managed to:

4. Finding hope

In difficult times, it can help to return to words or thoughts that bring comfort and hope. Create your own collection of reflections that feel supportive to you. These might be your own thoughts, words you hear from a doctor or a loved one, or even something you come across in a book or article.

Below are a few reflections from parents who have once been in a situation similar to yours. You may find strength in their words – or you may discover that the words that truly support you are very different, and uniquely your own.

"What helped me was hearing that a diagnosis is simply a description of how a child functions in certain tests or situations. It's a way of giving other professionals the information they need when trying to support us. But the child is still the same child. Nothing about who they are has changed." — Ania, age 29

"I remind myself to stay in the here and now. Often it's not the present moment that feels frightening, but the ideas of what might come. And the truth is, I don't know what will happen – no one does." — Maciej, age 40

"For me, a diagnosis is just information, a guide for what to work on and how. It doesn't have to be a life sentence. My child's special needs are part of our life, but they are not the whole of it." — Monika, age 38

Thoughts and words that bring you comfort:

5. Calming your senses

Our senses are always at work, taking in signals from the world and shaping how we experience it. During stressful times, those signals can become overwhelming.

Nowhere is this felt more sharply than in a hospital. Harsh lights strain the eyes. A constant background of unfamiliar voices exhausts the ears. Food and drink are easily forgotten – sometimes even finishing a cup of cold tea feels impossible. The air is filled with the smell of disinfectants and medicines. Our hands are occupied with strange medical devices we have never touched before.

Together, these impressions place the body on high alert, creating tension and unease. Offering your senses moments of comfort – gentle sights, sounds, tastes, smells, or touch – can soften those feelings, ease anxiety, and give you space to breathe.

This exercise suggests a few ways to care for your senses. You can use our ideas or choose any activity that brings you pleasure and helps you feel more at ease.

How can I take care of my sense of touch?

Examples:
- slip into a soft, comfortable sweater
- kiss your child on the cheek
- hold someone you love in a hug
- stroke your pet slowly and gently

How can I take care of my sense of hearing?

Examples:
- listen to music that brings you comfort
- notice the sounds of nature
- pay attention to the familiar voice of someone you love

How can I take care of my sense of taste?

Examples:
- eat something you enjoy, slowly and with attention
- take time to savour a favourite drink
- prepare a meal the way you like it

How can I take care of my sense of smell?

Examples:
- notice the fragrance of a favourite fruit
- breathe in the scent of your child's hair
- light a candle with a fragrance you enjoy
- dab a drop of essential oil on your wrists
- wear your favourite perfume

How can I take care of my sense of sight?

Examples:
- give your eyes some rest by closing them for a short while
- spend a few minutes taking in the greenery outside your window
- look slowly through favourite photographs or an art book
- pay attention to the textures, shapes, and details of the objects around you

Try to include a few simple moments like these each day. Small gestures that soothe your senses can bring calm and ease to your body and mind.

6. Soothing activities

There are many activities that can bring joy and comfort during difficult times. Making space for them in your daily routine is important. They will not make the challenges disappear, but they can give you the strength and motivation to face them.

From the list below, highlight the ones that feel most supportive for you. There are no “better” or “worse” options here – anything that helps you feel well is really valuable. You can also add your own ideas at the end.

- Talking with a psychologist
- Joining a support group for people with similar experiences
- Walking or spending time in nature
- Physical closeness with loved ones
- Writing down thoughts, feelings, or events; keeping a journal
- Cooking
- Running, swimming, practising yoga, climbing
- Meditation
- Prayer
- Mindful breathing
- Experiencing art, creative activities
- Relaxation exercises
- Talking with family or friends
- Watching a good film or series
- Taking a trip
- Caring for plants or gardening
- Social or political involvement
- Singing or dancing
- Playing with a pet
- Going out to a restaurant, cinema, or concert
- Reading
- Visiting a massage therapist, beautician, or hairdresser
- Playing board games, card games, or chess
- Learning, developing new skills, studying
- Volunteering for others
- _____
- _____
- _____
- _____

Try to find a regular moment each week that you can devote to something that truly brings you joy and satisfaction. Don’t hesitate to ask those close to you for help with childcare during that time. If there is no one available, look into respite care options (see the chapter “Practical guide to law and finances” for more information).

When you care for yourself, you are also caring for your whole family. You are their foundation. Be kind to yourself.

Worksheet 2.
For older brothers and sisters

Sections

Every child responds differently to the arrival of a new sibling – and to the news that their brother or sister may face health challenges. In the chapter "Psychological First Aid" we described some of the emotions that often accompany the birth of a baby, and ways parents can help children work through them.

This section offers a set of activities and games designed to make conversations with older siblings easier and more natural.

- Each activity includes a suggested age range, but you know your child best and will recognise what is most suitable.
- There is no need to try everything. Choose the ideas that appeal to you, and adapt them in ways that feel right for your family.
- Think of these suggestions as starting points for open conversation, moments of closeness, and time spent together. What matters most to your child is your attention and your accepting presence.

At the end of this section you will also find a list of recommended books about emotions, sibling relationships, difference, and disability. We hope you will come across titles that you and your child will enjoy reading together.

1. Draw your perfect day together

(ages 4–12)

The arrival of a younger brother or sister often brings big changes to family life. Daily routines shift quickly, and parents' time and attention have to stretch to include more people. For an older child – who may have been at the centre of your attention – this change can sometimes feel like rejection or as if their needs are being overlooked.

This activity is a way for your child to feel heard and to know that their wishes and needs still matter to you.

Take a sheet of paper and draw a perfect day together. One part of the drawing is made by your child, the next by you, and so on, taking turns. Let the only limit be the edges of the page!

As you do this, avoid criticising your child's ideas or pointing out why they "can't" happen. Instead, treat it as a magical day when anything is possible and everything can happen.

2. Colour in your family members

(ages 3–10)

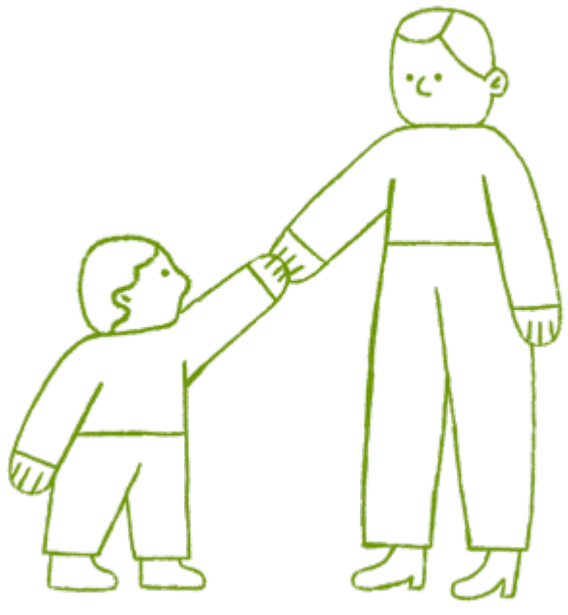
You may not talk openly with your child about the emotions you are experiencing after the arrival of a newborn. Yet even very young children sense the changes within their parents, and these feelings can leave them surprised – – or even frightened – if they don't understand where they come from.

This exercise invites you to explore and share those emotions together as a family.

The smaller figure represents the older child; the larger one represents a parent. If there are other important people in your family or close circle of friends, draw their outlines, too. Think about what feelings live inside each person, and then colour the figures according to the emotions they feel right now.

You might also reflect on where different feelings or sensations live in your bodies. Does laughter sit in your stomach, or perhaps worry, sadness, pain, or hunger? Are your feet tired or cold, or are they ready for tickles or for jumping on the bed? Colour those parts in ways that match what you're experiencing.

To support children in expressing emotions through colours, you may have a look at the book "The Colour Monster" by Anna Llenas.



3. Fill in the flower of change

(ages 5–14)

The birth of a new baby can feel like a revolution in family life. For older children, it may seem as if their world has been turned upside down. Daily routines change. Mum or Dad may be away from home more often, or absorbed by new tasks and concerns. Parents' moods may shift, their behaviour toward older children may be different, and even the way they relate to each other can change.

This flood of changes can feel overwhelming and may shake a child's sense of security. That is why it helps to talk together about what has changed – and also about all the things that have stayed the same.

To do this, draw a simple flower: a circle in the centre, with long petals around it. The number of petals should match the number of people in your family (you can also add other people who are important to you). Write the name of each person on one petal. Then, in that petal, note down what has recently changed for that person:

- "I now have three children."
- "I wake up at night to feed Maria."
- "I have less free time."
- "I spend more time at the hospital."
- "I dyed my hair red."

Even the youngest child can have a petal. You might write something like: "I came out of my mum's tummy, and everything changed."

In the centre of the flower, write down everything that has stayed the same for the whole family (except for the youngest child, for whom everything is new!). You might include things like:

- “We still live on Old Street.”
- “We still love each other very much.”
- “We still enjoy eating pizza.”
- “We still have a messy shoe rack.”

The petals can be filled in by the people they belong to, or you and your child can imagine together what each family member might write.

4. Make a little book about your child

(ages 2–10)

When a newborn arrives, it is natural to focus so much attention on them to meet all their needs. But it is just as important not to forget about older children. Show them that you still see them, that you remember about them, and that you still delight in who they are.

Create a small book about your older child. This could be as simple as a notebook where you paste photos with playful captions. Include a picture of them with their new sibling – or, if that isn’t possible, photos of each child separately.

The aim is to let your older child know that you notice them, value their new role in the family, and most of all, love them with all your heart.

When leaving home – for example, to go to the hospital – you can also show your child that you are taking the book with you, as a reminder of them throughout the day.

5. Talk about the things that matter

(ages 4–10)

Encourage your child to share their thoughts and feelings with you. One way to do this is by asking them to finish the sentences below. Don't judge their answers – just listen with attention and acceptance.

- "My favourite thing is when Mum/Dad…"
- "My superpower is…"
- "It annoys me when…"
- "If I were king/queen of the world, I would…"
- "Since my brother or sister was born, I…"
- "I feel scared when…"
- "I feel happy when…"
- "When I feel afraid, I want you to…"
- "Lately, what makes me angry is…"
- "I wish I could…"
- "When I feel sad, I like it when Mum or Dad…"

To make it easier for your child to join in, try finishing a few sentences yourself first. You might say: "My favourite thing is when you hug me tightly after I come back from the hospital" or "My favourite thing is watching you have fun on the playground. What do you like most about what I do?"

You can keep inventing new questions and answers together, as many as you like.

6. Play a family game

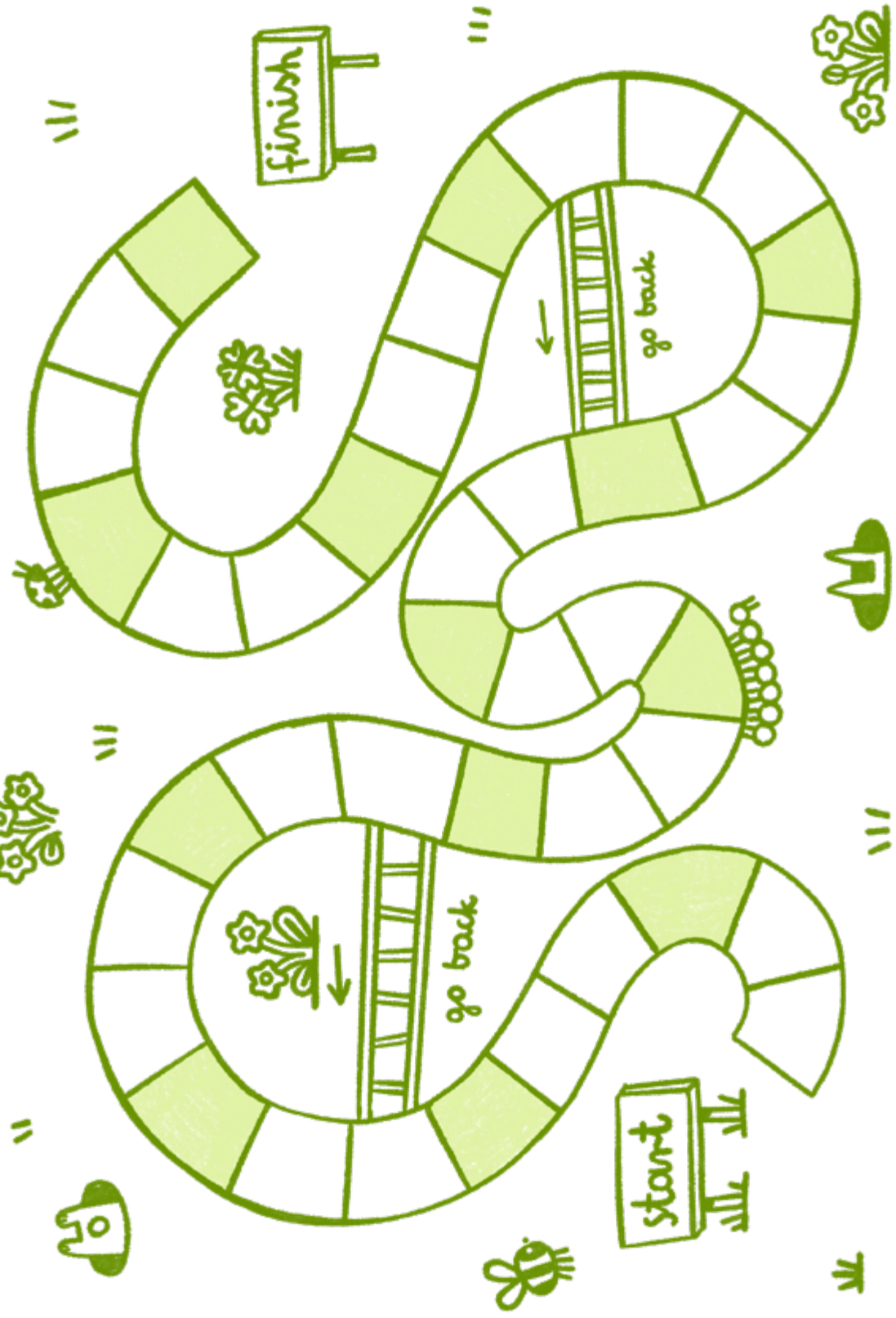
(ages 5–12)

Talking is important, but so is play. Spontaneous play helps families spend time together and strengthens bonds. The game below is designed to help you get to know one another better. Set aside a little time to prepare it together.

You will need: a die, some counters (or pieces of modelling clay), a sheet of paper, and a pen.

1. Cut the paper into 20 small slips and number them from 1 to 20.
2. Make counters out of modelling clay (or use anything small that can be moved around the board).
3. Take turns rolling the die and moving your counter across the board.
4. The first player is the one who had the most interesting dream last night. If no one remembers their dreams, the youngest player goes first.
5. Whenever a player lands on a green square, they draw one of the numbered slips and complete the task from the list below.

Feel free to change the tasks or add your own so that the game suits your child(ren)'s ages and interests.



Suggestions for tasks

- Draw a tiny picture of “fear” as you imagine it – maybe a little funny, like with huge teeth. Tell the others what sometimes makes you afraid and what helps you cope with that fear. Then erase the drawing with a rubber.
- Tell each player something you like about them.
- If you’d like, give the other player a gentle, friendly hug in a way that feels nice for you.
- If each family member were an animal, which animal would they be?
- Think about what “superpower” each person in your family has.
- Share a happy memory of something your family did together.
- Draw “anger” as a character. Tell the others what made you angry recently. Then, with the other players, crumple the paper and tear it into tiny pieces.
- Gently hug the person sitting to your left.
- Do something kind for the person sitting to your right.
- Draw a portrait of the person sitting to your left.
- Tell your family about the most beautiful thing you’ve seen recently.
- Say something nice to the player sitting to your right.
- Share something interesting about yourself that others may not know – for example, a dream you had recently or something that made you happy.
- The oldest player tells a story from their childhood.
- Tell the others about something that surprised you recently.
- Share with your family the best place you’ve ever visited.
- Imagine each family member as a character from their favourite story or cartoon. Who would they be?
- Pretend you are a “magic goldfish.” Tell the others what you would give them to make their wishes come true.
- Draw “sadness” as you picture it. Say what made you feel sad recently. Then fold the paper into a tiny square. Let each player hold it in their hands and say something supportive, like “I’m here” or “I love you very much.”
- Say where you would most like to go with the person sitting to your left.

You can also use the slips of paper on their own – draw one and do the task. This version works especially well in waiting rooms, like at the doctor’s office.

7. Create small rituals to share with your child

(ages 3–15)

For children to grow and develop well, it is important that they have some constants around them – familiar people, safe places, and predictable parts of the day that act as anchors in a changing world.

Try building simple, enjoyable rituals into your daily routine. These can help your child feel your love and create a sense of safety.

Here are a few ideas:

- Before bedtime, each of you shares three good things that happened during the day.
- As your child falls asleep, tell them the things you love about them or love doing together.
- Hide little notes around the house for your child to discover when you are away for longer periods.
- Once a week, prepare breakfast with your child's favourite foods and bring it to them in bed.
- Create your own secret "language" of gestures to share in everyday situations – for example: a hand on your heart to say "I love you", two fingers on your forehead to say "I'm proud of you", a hand on your cheek to say "You are important to me".
- Before bedtime, talk together about the emotions of the day. Ask: "Who felt happy today? Who felt sad? Who felt angry? Who felt afraid? Who felt calm?"

Recommended books, films, and series that help children understand disability and difference

- *Wonder* by R.J. Palacio – The story of Auggie, a boy with a facial difference, and how he navigates school, friendship, and acceptance.
- *We're All Wonders* by R.J. Palacio – A picture-book adaptation of Wonder, aimed at younger children.
- *El Deafo* by Cece Bell – A graphic novel memoir about growing up with hearing loss and using a hearing aid.
- *My Three Best Friends and Me, Zulay* by Cari Best – About a girl who is blind and how she and her friends support one another at school.
- *A Friend for Henry* by Jenn Bailey – A gentle story told from the perspective of a boy on the autism spectrum, about seeking connection.
- *Susan Laughs* by Jeanne Willis – Shows a young girl doing everyday activities; only at the end do we see she uses a wheelchair.
- *Views from Our Shoes: Growing Up with a Brother or Sister with Special Needs* edited by Donald J. Meyer – A collection of short stories written by siblings themselves.
- *My Sister, Alicia May* by Nancy Tupper Ling – A story about two sisters, one of whom has Down syndrome.
- *It's Okay to Be Different* by Todd Parr – – A bright, simple picture book celebrating differences of all kinds.
- *Being the Other One: Growing Up with a Brother or Sister Who Has Special Needs* by Kate Strohm – Written for slightly older children/teens, reflecting on sibling experiences.
- *All My Stripes: A Story for Children with Autism* by Shaina Rudolph and Danielle Royer – Helps children understand autism as an important part of a child's identity.
- *The Invisible Boy* by Trudy Ludwig – About inclusion, kindness, and noticing children who might feel left out.
- *Maple* by Lori Nichols – A little girl prepares to welcome her baby sister, full of warmth and nature imagery.
- *Peter's Chair* by Ezra Jack Keats – A classic about an older brother learning to share his space with the new baby.
- *You Were the First* by Patricia MacLachlan – Celebrates the unique role of the firstborn child when a new sibling is on the way.
- *Sometimes* by Rebecca Elliott – From the *Owl Diaries* author; a picture book about a child visiting a sibling in hospital.
- *Waiting for Baby* by Rachel Fuller – – A simple board book that can be helpful for families preparing siblings when there may be extra concerns around the baby's health.

Worksheet 3.
Your relationship

Sections

1. The five love languages

Every relationship goes through changes, challenges, and moments of crisis. **To keep your partnership steady and growing through those times, it is important to speak openly about your feelings and needs**.

This worksheet introduces the concept of "five love languages." Developing the ability to listen with care and to speak with gentleness can support you not only in the first weeks after your baby's arrival, but throughout your life together.

Each of us has our own way of giving and receiving love. These can be described as "love languages." Just as shared words are needed for conversation, a shared "language of love" is essential for emotional connection.

To feel deeply loved, we need the people closest to us to show their love in ways we can understand and that meet our needs. We may still recognise that we are loved even if it is expressed differently, but it is when we find a common language of love that a relationship can bring its fullest joy and fulfilment.

The idea of the "love languages" was developed by psychologist Gary Chapman. He observed that love can be expressed in five different ways:

Words

Acts of service

Quality time

Gifts

Physical touch

Words
For people whose love language is words, hearing affection spoken aloud is essential.

- They want to hear "I love you" often, expressed with warmth and sincerity.
- They feel valued when their partner tells them they are important, attractive, or appreciated.
- Romantic words, honest compliments, and affirmations of their strengths and contributions all matter deeply.

Acts of service
For others, actions mean more than words.

- They feel loved when their partner helps with everyday tasks: cooking a favourite meal, folding laundry, or finding a specialist for the child.
- What makes the difference is the effort invested to make life easier, lighten the load, or take care of something important for the family.
- Support with tasks that the person dislikes or has no time for can be especially meaningful.

Quality time
Some people feel most loved when their partner gives them undivided attention and shares experiences with them.

- They value time set aside for regular, enjoyable activities together.
- It doesn't have to be extraordinary: a film at home, reading aloud, a short bike ride, or simply sharing a morning coffee.
- These moments reassure them that the relationship matters and that they are a priority.

Gifts
For some, receiving gifts is the clearest expression of love.

- It is not about expensive presents. What matters most is the gesture itself: the thought, effort, and time put into choosing or making something.
- A gift communicates: "I know you, I see you, and I remembered what matters to you."
- Remembering special occasions is important, but small, unexpected gifts can be even more powerful, expressing gratitude simply for the other person's presence.

Physical touch
For others, love is most strongly felt through touch.

- Hugs, holding hands, a gentle stroke, a kiss, sex, or even a massage all carry deep meaning.
- Touch has a special power: it triggers oxytocin, often called the "bonding hormone," helping us feel safe and connected.
- Especially in times when there is little space for intimacy, even small gestures of closeness – an embrace, a kiss, a squeeze of the hand – can sustain a sense of love and security.

For a relationship to grow and remain a source of joy and fulfilment for both partners, it helps to understand not only your own love language, but also your partner's. Take a moment to reflect. As you answer the questions below, keep in mind that a person may speak and respond to more than one love language.

Which love language do I appreciate the most?

What is the love language my partner speaks to me?

Which love language is most important to my partner?

What is the love language I speak to my partner?

When you understand which expressions of love matter most to each of you, you can make conscious choices in daily life – and you can ask for them directly. Saying gently but clearly that, for you, tidying the house or caring for the child feels like a deeper act of love than affectionate words (or the other way around!) can open up new paths to genuine communication. It is important to remember that no single love language is more valuable or more “right” than another.

In difficult times, these differences can become especially visible. Perhaps after receiving your child’s diagnosis your partner has moved into “task mode” – spending days arranging appointments, searching for therapies, or running errands to make sure nothing is missing at home. If your love language is touch and physical closeness rather than acts of service, you may feel overlooked, lonely, or forgotten. If your love language is time spent together, you may feel rejected when your partner can’t pause for a calm conversation or a short walk – no matter how many text messages saying “I love you” they send.

Take care to find a shared language of love.
It will allow your relationship to grow and give you both a deeper sense of joy and fulfilment.

2. Nonviolent communication

Nonviolent communication (NVC) is a way of speaking and listening developed by psychologist Marshall Rosenberg. It places strong emphasis on recognising and respecting the needs of both people in a relationship. (It is also a powerful tool for communicating with children, friends, colleagues, or anyone else in your life.)

At the heart of NVC is the idea that behind every action and every message we send lies a need. Depending on whether those needs are met, we experience particular feelings – which then shape how we speak to others.

The challenge (and the skill) is to express our own needs in ways that can be understood by the other person, while at the same time respecting their needs.

A supportive conversation always has two interwoven parts: **listening with empathy** and **speaking honestly about yourself**.

- ***Empathic listening*** means giving the other person your full attention, showing care and compassion, and listening without judgment or criticism.

- ***Honest self-expression*** means sharing your own feelings and needs directly, in a way that invites understanding rather than aims to blame.

To see what this looks like in practice, imagine a familiar situation. Your child is waiting for an appointment with a neurologist, but the wait for the best specialist is several months. In this situation, you may feel anger or discouragement. These emotions reflect an important unmet need: ensuring proper care for your child. In such a situation, one person might react with anger and frustration: “That makes no sense! We’re never going to get that appointment. You can’t rely on anyone!” Another might respond in resignation or sadness: “I’m useless. I can’t even manage to find the right doctor. It’s all my fault”.

Sometimes the feelings come out as blame: “If you had remembered earlier, we would have found a better appointment. I have to do everything on my own!”

We all say such words at times. But it is easy to see that they do not make understanding any easier. So how can you listen to your partner with empathy in moments like these?

1. **Begin by reflecting back what your partner has said, so they feel heard.** Example: “So the wait for the specialist will be very long” or “It’s hard to find a neurologist who can help us right away.”

2. **Ask about the feelings behind their words.** Example: “How do you feel about having to wait?” or “Are you very upset that we can’t see the doctor this week?”

3. **Ask about the needs or wishes hidden behind those feelings.** Example: “You want to make sure Maria gets the best possible care, don’t you?” or “I can imagine you would like our son to be diagnosed as quickly as possible…”

4. **Think about how you might help meet that need.** Don’t insist on a solution, just gently suggest possibilities. Example: “Maybe we could try looking for a specialist in another city?” or “I could ask in the parents’ group if anyone can recommend someone else. Do you think that might help?”

5. **Remember that sometimes the need can’t be met.** In such moments, offer understanding and presence. Example: “It’s hard for me too, when all we can do is wait” or “I know you feel powerless right now. I’m here with you.”

Being able to **express yourself openly** is another important part of communication. Imagine this situation: since your baby was born, the new responsibilities have left you and your partner with very little time for one another. This feels very difficult for you.

How can you talk about it openly?

1. **Begin with your observations** – without criticism or judgment. Speak about your own perspective, not about your partner's behaviour. Example: "I feel like we haven't had much time together lately" or "Since Ola was born, I haven't been able to talk with you as often as I'd like."

2. **Name the feelings this brings up for you.** Example: "I'm afraid we're drifting apart" or "I feel very lonely."

3. **Share the need or wish behind those feelings.** Example: "I'd love for us to spend at least five minutes each day in a calm conversation" or "I'd like us to have lunch together next weekend, just the two of us."

4. **Make a gentle request for a concrete action** that could help meet your need, or suggest something yourself – without demanding. Example: "Could you ask your dad to stay with Jan for a little while so we can have coffee together?" or "Maybe we could watch a short episode of a series while the baby naps? I need a moment to switch off from everything."

Sometimes you may simply want to share your worries with your partner, without asking for anything in return. In such moments you can say: "I just want you to listen" or "I just want you to sit with me for a while."

Below, you will find a list of human needs, compiled by the author of Nonviolent Communication. Using this list can help you recognise the needs behind your emotions and actions, and allow you to express them more clearly.

If you are not able to understand your own needs and find ways to respond to them, sooner or later you may feel sadness, irritation, or even anger.

What do we need?

Physical needs:

- safety and protection,
- touch,
- rest,
- air, food, and water,
- shelter,
- movement and exercise,
- sleep,
- expression of sexuality.

Connection with ourselves:

- authenticity,
- self-expression,
- a sense of wholeness and integration,
- purpose,
- integrity,
- clarity,
- competence,
- creativity,
- achievement,
- self-worth,
- privacy,
- agency and influence over one's life,
- growth and personal development,
- self-acceptance,
- meaning,
- coherence and inner consistency,
- stimulation and vitality,
- self-respect,

- celebration of fulfilled needs and dreams, as well as mourning unmet needs,
- awareness,
- learning,
- challenge.

Enjoyment of life:

- physical and emotional wellbeing,
- humour,
- inspiration,
- comfort and ease,
- hope,
- simplicity,
- adventure,
- joy,
- variety and diversity,
- play.

Autonomy:

- independence,
- space,
- freedom to choose one's own plans, goals, dreams, and values,
- spontaneity,
- freedom to choose one's own path toward fulfilling them.

Connection with others:

- emotional safety,
- closeness,
- being seen,
- warmth,
- empathy,
- intimacy,
- contact with others,
- love,
- encouragement,
- belonging,
- equal opportunities,
- strength from being part of a group,
- respect,
- honesty,
- companionship,
- attention; being taken into account,
- bonds,
- support,
- community,
- cooperation,
- interdependence,
- reciprocity,
- trust,
- harmony,
- contact with nature,
- beauty,
- peace,
- order,
- understanding and being understood,
- connection with the world,
- coherence,
- sharing joys and sorrows; talents and skills.

Reflect for a moment:

Which needs feel most important to you right now? Circle them on the previous pages or write them here.

What steps could you take to meet those needs?

Which needs feel most important to your partner at the moment?
Mark them in a different colour or write them below.

What could you do to help your partner meet those needs?

The guidance in this section is only an introduction to Nonviolent Communication and the five love languages, both of which can be practised and refined throughout life. At the end of this chapter, you will find a list of recommended books if you would like to read further.

And if it feels hard to put these ideas into practice right now, that is perfectly natural. A gentle place to start is by thinking about how you can show love to your partner in ways that matter most to them, while also learning to express your own needs clearly and to receive theirs openly.

3. A special day together

Now we invite you to dream a little – and to let those dreams turn into plans. Imagine a day that is just for the two of you, when you can spend time exactly as you wish. Plan that day together.

If your ideas are different, you can compromise or take turns deciding how to spend each hour or part of the day.

Our perfect day

8:00

9:00

10:00

11:00

12:00

13:00

14:00

15:00

16:00

17:00

18:00

19:00

20:00

21:00

22:00

23:00

24:00

Now comes the harder part:

- Circle two hours from the plan above that you would most like to experience. In the coming month, set aside time to make them happen.
- Think about what support you might need to put your plan into action. Who could you ask for help? Is there anything practical to arrange in advance – buying cinema tickets, ordering candles for a bath, or organising childcare? If so, make those arrangements ahead of time.
- Treat this time as something important, a real priority. It is essential for your growth as a couple and for your strength as a family.
- Finally, choose a date about a year from now and book it for a full day together. Protect it carefully. You will have time to prepare – use it well. If you plan to be away from home, decide on the place and make any necessary bookings. Arrange childcare or time off work well in advance.
- As the chosen date approaches, you may feel tempted to use the time "more productively" – to catch up on work or house tasks, to take your child to extra activities – or, on the other hand, to do nothing at all, avoiding the effort of planning something special. Practical obstacles

may also arise: bad weather, a child's illness, an unexpected work duty. Try to prepare for such possibilities in advance, and don't let them discourage you. This day is your celebration.

4. Everyday moments of love

Special occasions matter, but most of life together is made up of ordinary days, filled with routine joys, challenges, and responsibilities. This is why it is equally important to care for your daily life as a couple.

Look for small ways to carve out moments just for the two of you, gestures of affection, or reminders of how much you mean to each other. The best way to do this is to create your own habits or rituals. They don't need to be elaborate or expensive; even the simplest things can bring you closer.

Here are a few ideas to get you started, and some space to add your own as well:

- A cup of tea together each evening after the children are asleep.
- A kiss every morning at eight o'clock.
- A kind note tucked into a coat pocket.
- A shared bath on the last day of each month.
- A daily text with a playful compliment for your partner.
- Each evening, sharing three meaningful things that happened during the day.
- Your own ideas:

We wish you a relationship full of care and joy.

Suggested reading:

- Gary Chapman, *The Five Love Languages: How to Express Heartfelt Commitment to Your Mate*
- Marshall B. Rosenberg, *Nonviolent Communication: A Language of Life*
- Melanie Dimmitt, *Special: Antidotes to the Obsessions That Come with a Child's Disability*

"I pulled away from my family because I thought no one would really understand what was happening with my child or know how to help. My husband threw himself into work to earn money for treatment and rehabilitation. And although we were together, in reality we each lived in our own world."

"In the hardest moment, what gave me hope was God, and my husband – he held my hand when I heard words like 'intellectual disability, no speech...'. He cried with me, and afterwards he was the one who spoke with our family."

"My husband – because at that time he was the only one I had the strength to talk to – was always at the other end of the line. Even though it was harvest season and he was overwhelmed with work, I could call him anytime for advice, and he carried that burden with me. Only later did I learn that he himself had struggled to cope with the diagnosis."

Our Support:
Mudita Association

Mudita supports parents whose children are living with disabilities, serious illness, or other special developmental needs.

We cannot take away your challenges, but we will do our best to make your life a little easier.

At Mudita, you can access the following types of support:

Psychological Support

1. Support Line

Call and talk with one of our specialists.

"I carry so many emotions inside and have no one to share them with."

It is completely normal to feel that the daily challenges are too heavy to handle alone. You have the right to have a bad day. You have the right to feel lonely.

At this difficult moment – such as receiving your child's diagnosis – we are here for you. Whatever your situation, your views, or the problems you bring, you will receive free, anonymous, and non-judgmental support.

"After this conversation, I feel so much lighter. I have more clarity and I better understand what's going on with me."

Mudita Association Support Line
(support available in Polish only)

GO TO THE WEBSITE

+48 123 786 798
https://stowarzyszeniemudita.pl/telefon-wsparcia/

2. Support Groups

Join a network of parents facing similar challenges.

Every person's situation is unique, and every family is one of a kind. Yet many of the difficulties parents of children with special needs face are shared. Being part of a support network strengthens your sense of self-worth and gives you the resilience needed to cope better with everyday challenges.

"Among other mums raising children with atypical development, I stopped feeling alone."

Meetings are held weekly on Zoom and are led by psychologists or other specialists.

To join, write to us at:
kontakt@stowarzyszeniemudita.pl.

Respite support

1. Flying Spa

Take time to recharge and care for yourself.

Mothers and fathers, like everyone else, need rest, relaxation, and a chance to look after their own wellbeing. That's why we created the Flying Spa. We bring massages, breathing sessions, or even a hairdresser directly to parents who find it difficult to leave home while caring for their child. We can also invite you to a salon for a massage or a treatment of your choice.

"I was surprised that after just one hour to myself I could feel so much better. That little bit of relaxation was exactly what I needed."

To book a session, write to:
latajacespa@stowarzyszeniemudita.pl.

2. Respite events

Give yourself a break and spend time among friends.

Our respite events are gatherings where parents of children with disabilities can enjoy massages, creative workshops, and different ways to relax. They are also a chance to connect with others, chat over coffee, and simply take a breath.

We usually welcome parents with their children. For younger participants, we do our best to provide volunteer care and fun activities.

You can find the calendar of events we organise in different cities across Poland at:
https://stowarzyszeniemudita.pl/kalendarz-wydarzen/.

GO TO THE WEBSITE

3. Respite retreats

Catch your breath on holiday.

Each summer we organise respite retreats for families of children with disabilities.

These retreats give parents – who devote so much of their energy to caring for their loved ones – the chance to truly rest. During the stay, children are cared for by volunteers for several hours each day and can take part in activities adapted to their abilities. Parents gain time to read, relax in a hammock, or share conversations with others. It's a moment to restore strength and build warm, supportive connections with fellow parents.

As one mother said:
"This retreat gives us the strength and energy to keep going. When you're caught in the daily grind, sooner or later you burn out. Here I realised that I have the right to live like any other mum. All it takes is the right place and the right people."

You can find up-to-date information about our respite retreats here: **https://stowarzyszeniemudita.pl/wsparcie/turnusy-wytchnieniowe/**.

GO TO THE WEBSITE

Information and Logistical Support

Hotline

The special needs of our children can sometimes feel as complex as an unplanned journey to another planet. Suddenly, there are countless issues, questions, and challenges you never imagined facing. How do I find a babysitter for my daughter with drug-resistant epilepsy? Which car seat will work for my son who has limited mobility?

We receive dozens of such questions, and our curious team works hard to track down the answers.

If you have any questions – whether legal or simply about daily life with a child with special needs – write to us at: **kontakt@stowarzyszeniemudita.pl**.

You'll also find updated information about available forms of support here: **https://stowarzyszeniemudita.pl/**.

GO TO THE WEBSITE

If you'd like to learn what support we currently offer in English – – or in another language you speak – please email us at: **kontakt@stowarzyszeniemudita.pl**.

"What gave me hope were my husband's words – that he is still the same boy – and the conversations we had with professionals who knew what they were talking about. Psychologists and teachers explained what steps we could take and reassured us that there was a good future ahead for our son and our family."

"After the diagnosis, the hardest part was the silence. There was no one to explain, no one to offer a kind word, no one to give us direction. The family wanted to help, but they didn't know how. They struggled to understand or accept the situation. What I missed most on this journey was psychological support."

"If I could give one piece of heartfelt advice, it would be this: don't face your doubts and emotions alone. Reach out for support – see a psychologist, join a support group, or find another parent who has lived through something similar."

"Today I would tell myself: seek support, so that you don't carry this by yourself."

"At the beginning it's normal to feel completely lost. None of us knew what to do. Don't be ashamed to ask for help. Say how you feel. Take time to know yourself and listen to what's inside you."

"What gives me the most hope is seeing my son make progress. Despite the challenges, he still has the chance to live a fulfilling life – different from the one I imagined during pregnancy, but still a happy one."

"Now I would remind myself that I have the right to all these emotions, that what I am going through is a kind of grief, and that I need time – lots of time – to make sense of it. I would tell myself: let go, stay in the present, deal with what's here and now, don't get lost in the future. Hold on to hope, believe in small miracles, and keep going step by step."

Until we meet again!

This is where our “Gentle Welcome Guide” comes to an end, but your journey through this extraordinary path of parenthood will continue. We hope we can accompany you along the way.

If you would like to contact us for any reason – even just to let us know you are there reading this publication and to share a little of your experience – please write to: **kontakt@powitalnik.pl**.

The “Gentle Welcome Guide” is a social innovation created to provide emotional, practical, and informational support for parents who have received, or are awaiting, a diagnosis for their child.

All the quotations included here come from conversations with parents and professionals who generously shared their stories, emotions, and experiences with us.

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“Until we meet again!”
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